A proposed framework for the legal protection of premature and critically-ill neonates in the context of South African child law

by

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In memoriam matris meae

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LIST OF ABBREVIATIONS

BDP:	Bronchopulmonary Dysplasia
ceg:	centre for ethics and health
CNS:	Central Nervous System
CPAP:	Continuous Positive Airway Pressure
CRC:	United Nations Convention on the Rights of the Child
ECHR:	European Convention on the Protection of Human Rights
ELBW:	Extremely Low Birth Weight
EoL:	End-of-Life Decisions
FAS:	Fetal Alcohol Syndrome
HFEAct:	Human Fertilization and Embryology Act
HLA system:	Human Leukocyte Antigen system
HIV/aids:	Human Immunodeficiency Virus/acquired immunodeficiency syndrome
HPCSA:	Health Professions Council of South Africa
ICESC:	International Covenant on Economic Social and Cultural Rights
ICESCR:	International Covenant on the Economic, Social and Cultural Rights.
ICU:	Intensive Care Unit
LBW:	Low Birth Weight
MDG:	Millennium Development Goals
NAS:	Neonatal Abstinence Syndrome
NCOB:	Nuffield Council on Bioethics
NHI:	National Health Insurance
NICU:	Neonatal Intensive Care Unit

NEC:	Necrotising Enterocolitis
NVK:	Nederlandse Vereniging voor Kinder-geneeskunde
RCPCH:	Royal College of Paediatrics and Child Health
ROP:	Retinopathy of Prematurity
SACJH:	South African Journal of Child Health
SANC:	South African Nursing Council
SANITSA:	South African Neonatal and Infant and Toddler Support Association
SIDS:	Sudden Infant Death Syndrome
SMA:	Spinal Muscular Atrophy
TAC:	Treatment Action Campaign
VLBW:	Very Low Birth Weight
WHO:	World Health Organisation

CHAPTER 1

INTRODUCTION

1.1 Background and problem statement

The joy parents feel when looking forward to the birth of their baby is replaced by fear and anxiety when the baby is premature or is very ill at birth.[1] Parents' concern is not only for the future of their baby, but also for the future of the family, since having a premature or critically-ill neonate will inevitably influence the family as a whole, not only emotionally, but also financially.[2] Until relatively recently, it would not have been possible to do much for the baby and most extremely premature babies would have died at birth or soon afterwards.[3] Many critically-ill babies would also not have been able to survive for more than a few weeks or months after birth.[4] "Doubtless it was simpler when babies with severe disability had no prospect of remaining alive. No ethical code was needed to reach conclusions—ultimately, nature decided for us."[5] Advances in medical science have been accompanied by an increase in the survival rate of premature and critically-ill

1 Lubbe 2008:1.
2 Brazier and Cave 2007:376.
3 Brazier and Cave 2007:376.
4 Brazier and Cave 2007:376.
5 McClean 1999:121.

neonates. However, the risk of morbidity increases as the gestation period decreases.[6] The morbidity experienced includes both mental handicaps and physical handicaps.[7] However, the law has not kept up with the advances in neonatal medicine, and this has consequently given rise to uncertainty about the legal position, both for health care professionals and for parents.[8]

Premature birth can roughly be defined as childbirth occurring before 37 weeks of gestation, but after approximately 28 weeks of gestation, where 40 weeks is the normal duration of pregnancy.[9] Normally it is not only the gestational period that is taken into consideration in determining whether a baby is premature or not, but also the birth weight.[10] There has been a steady increase in the survival rate of low birth weight babies from the 1940s, when it was considered that a baby weighing less than 1500 g could not survive, to the 1970s, when a baby weighing 1000 g at 28 weeks' gestation is able to survive.[11] Nowadays even preterm infants weighing less than 750 g at 25 weeks' gestation can survive.[12] In terms of public hospital policy in South Africa, a baby who weighs less than

6 Miller 2007:25.
7 Lubbe 2008:27; Miller 2007:25.
8 McHaffie ea 1999:444.
9 Furdon 2006:2 http://www.emedicine.com/ped/topic1889.htm
10 Johnston 1998:2; Millller 2007:11.
11 Miller 2007:24.
12 Miller 2007:24.

1000 g is not regarded as capable of maintaining life in a public hospital or ambulance and is therefore not given advanced care, but is often left to die.[13] Private hospitals are not bound by the same rules of practice as public hospitals and they may use discretion regarding treatment such as resuscitation.[14]

Nowadays a combination of factors determine whether a premature baby should be treated or not, including gestational age and estimated weight. The policy that is currently employed in the private hospital sector is that such babies are given the opportunity to prove that they can survive on their own, by giving basic care only. If a baby is given primary health care only and made comfortable, yet proves that he or she can survive on his or her own, such a baby would be given advanced care.[15]

Miller[16] also draws a distinction between extreme prematurity (i.e. an infant born before 28 weeks of gestational age) and prematurity on the

13 Mentioned by Dr Carin Maree, Senior Lecturer, Department of Nursing Science, University of Pretoria, during a personal interview.
14 According to Dr Carin Maree, senior lecturer, Department of Nursing Science, University of Pretoria, during a personal interview.
15 According to Dr Carin Maree, Senior lecturer, Department of Nursing Science, University of Pretoria, during a personal interview.
16 Miller 2007:7.

one hand, and extremely low birth weight (an infant who weighs less than 1000 g at birth) and low birth weight on the other.

The shorter the term of pregnancy the greater the risk of complications.[17] Infants born prematurely have an increased risk of mortality in the first year of life.[18] These fragile babies are very vulnerable as they are also at greater risk of developing serious health problems, such as cerebral palsy and chronic lung disease, gastrointestinal problems, mental retardation and vision or hearing loss.[19]

Babies who are also in danger of being denied treatment or who face possible rejection are critically-ill neonates with visible congenital defects such as myelomeningocele, gastroschisis,[20] or cleft lip or palate. Conjoined twins or babies with serious but invisible defects, such as congenital cardiac defects or those with acquired conditions like HIV/aids, are also at risk of rejection.[21] The fact that they might be denied treatment and consequently denied the right to life raises legal and ethical issues. Although some of these conditions (like gastroschisis and cleft lip or palate) can be corrected surgically, there is a possibility

17 Miller 2007:24-25.
18 Miller 2007:24.
19 Miller 2007:25.
20 See chapter 3 par 3.3.3.3 for an explanation of this term.
21 Dr Carin Maree, Senior lecturer, Department of Nursing Science, University of Pretoria, during a personal interview.

that babies who suffer from these conditions may be rejected or even left to die, since these conditions are seen as carrying a social stigma.[22]

Apart from medical challenges and ethical controversies over the aggressiveness of the care rendered to such infants, there are other issues that should be addressed, such as whether treatment should be withheld and these neonatal patients allowed to die. Decisions in these issues have given rise to several legal, religious and ethical disputes:[23] Some people are of the opinion that sanctity of life is an overriding factor and life should be protected at all costs, but others contend that quality of life is the most important factor and that severely handicapped babies should be allowed to die with dignity.[24]

The question of the medical treatment of neonates is not addressed in South African legislation—in either the National Health Act 61 of 2003 or the Children's Act 38 of 2005. It was this aspect which motivated the researcher to investigate the current legal and medical position of neonates in South Africa. The ultimate purpose of this research is to frame recommendations on how the legal protection of neonates in

22 According to Dr Carin Maree, Senior lecturer, Department of Nursing Science, University of Pretoria, during a personal interview.
23 See also Miller 2007:8.
24 This aspect is highlighted in chapter 4 par 4.4 where ethical aspects are discussed. See also Weir 1984:87,147-159.

South Africa can be improved. One of the questions that will be investigated is how far health care professionals will have to go to preserve life "at the inevitable expense to some babies, families, and society of disability, emotional trauma, and financial cost".[25]

1.2 Research methodology

This dissertation is mainly based on a literature study, which relied on guidelines, legislation, academic books, journals, reports and case law. Experts working in the field were also consulted. A literature study of national and international articles in legal and medical journals, legal and medical books and unpublished theses was undertaken. Relevant literature was identified by means of a computer-aided search of articles, books, reports and guidelines available in the library of the University of South Africa. Where these sources were not readily available in the Unisa library, they were ordered. Relevant articles and books were identified from footnote references and these were also followed up. Different websites which provided further information and articles were visited.

Legal comparative research played an important role in this study, especially since South Africa has hitherto lagged behind in critical care

25 Miller 2007: 7.

decisions and legal comparative research can therefore provide valuable insight[26] regarding legal reform.[27] A legal comparative study which drew on the law of England and Wales was undertaken, and relevant aspects of the law of Scotland and Northern Ireland were also considered.

The English common law tradition influenced South African law because the Cape was formerly a British colony, which brought South Africa into contact with the common law. Great Britain annexed the Cape in 1795 and 1806 and the Cape became a British colony and consequently, of necessity, English law penetrated South African law.[28] Although Great Britain had occupied the Cape, it declared that Roman-Dutch law would still be the law used at the Cape.[29] The consequence is that both English and Roman-Dutch law have influenced South African law. Certain aspects of English law are still to be seen in the South African legal system: “It is clear that reception of English rules of law (for example, the ‘time of the essence’-rule and the rules relating to agreements in restraint of trade in the field of contract law) and of English legal terminology (for example, ‘malice’ and ‘duty of care’ in the field of delict), took place in no small measure.”[30]

26 Venter ea 1990:71.
27 Venter ea 1990:207.
28 Hosten ea 1998:353,356.
29 Venter ea 1990:29.
30 Hosten ea 1998:356.

Precedents for judgments in critical care decisions are to be found in cases that reached the courts in England and Wales. These judgments provide valuable insights into the route that should be followed if similar cases reach South African courts. Of particular importance are the different reports that were compiled to provide guidelines regarding critical care decisions, especially the comprehensive report compiled by the Nuffield Council on Bioethics.

The Netherlands was chosen as the second country for legal comparative research. Roman-Dutch law was received into the law of the Netherlands and although the law of the Netherlands was codified, Roman-Dutch law was not discarded upon codification.[31] In the words of Hosten:[32] "In fact the background of the modern Netherlands code is the same as the background of our South African law; the jurisprudence of the Netherlands, and for that matter the whole of Western Europe's is of value to us. The study of classical Roman-Dutch law did not die out in the Netherlands despite the codification of its law." Of particular importance for this study is the Groningen Protocol which regulates end-of-life decisions regarding neonates, which was drafted by paediatricians assisted by the public prosecutor.

31 Hosten ea 1998:337.
32 Hosten ea 1998:337.

In order to justify a legal comparative research study, it is important to note that South Africa, the United Kingdom and the Netherlands ratified the United Nations Convention on the Rights of the Child, 1998 (hereinafter the CRC). The best interests of the child is an important aspect that was introduced by the CRC and it should be employed in all cases relating to children by all the countries that ratified the CRC.

1.3 Analysis of research

In Antiquity premature and critically-ill neonates would either have died as a result of a lack of medical expertise and technology or they would simply have been killed if they were deformed. This dissertation therefore begins with an overview of infanticide in chapter 2. Legal historical research was done in preparation for the writing of this chapter and primary sources were relied on as far as possible. The practice of infanticide was scrutinised from the point of view of sources that influenced South African law, namely Roman law, Roman-Dutch law, canon law, English law and the law as applied by certain indigenous South African tribes.

In chapter 3 an overview is given of certain diseases and congenital malformations that often occur in neonates, both premature and critically-ill neonates.

In chapter 4 the ethical theories that are to be employed in the medical treatment of patients, including neonates, as well as the principles of biomedical ethics, are discussed. Court cases are cited in which the “quality of life” and “sanctity of life” principles were considered.

In chapter 5 South African legislation is scrutinised in order to determine to what extent it protects neonates. The conclusion drawn includes a discussion of the weak points and the strong points of South African legislation pertaining to medical care and critical care decisions relating to neonates.

In chapter 6 legislation and case law from England and Wales relevant to the care of neonates are discussed, in addition to reports and studies, in an attempt to obtain guidance so that guidelines can be formulated for the protection of premature and critically-ill neonates in South Africa. A further purpose of this investigation is to provide guidelines to the legislator so that present legislation can be amended to provide better protection to neonates in South Africa. It was suggested by the Nuffield Council on Bioethics that protection of neonates should be embodied in guidelines rather than legislation. In chapter 7 the law as it is applied in the Netherlands is analysed to ascertain whether it contains any valuable lessons for South Africa. In addition to the discussion of

legislation, guidelines and case law pertaining to critical care decisions were analysed.

In chapter 8 recommendations were made for changes in the current position to afford premature and critically-ill neonates more legal protection.

1.4 Limitations

Every effort was made to obtain recent court cases and relevant legislation from England and Wales. The same effort was made with regard to legislation and cases from the Netherlands. It was more difficult, however, to obtain judgments in court cases from the Netherlands than from England and Wales. Despite the best efforts of the author, assisted by staff from the Unisa library, it is uncertain whether the cases from the Netherlands that were discussed are indeed the most recent decisions.

CHAPTER 2

THE HISTORICAL DEVELOPMENT OF INFANTICIDE[1]

2.1 Introduction

In Antiquity, and also among primitive cultures, a premature neonate, severely malformed baby or critically-ill neonate would not have survived for even a short while owing to a lack of medical expertise and technology. In modern times, the practice of infanticide is unacceptable in the light of the focus on human rights, especially the right to life that is guaranteed in all international human rights documents and is also contained in section 11 of the Bill of Rights of the Constitution of the Republic of South Africa, 1996. In South Africa a person who deliberately kills a neonate will be criminally prosecuted, but this was not the case in Antiquity, specifically in the Roman and Greek cultures.

The history of the practice of infanticide from Antiquity until the Rise of Christianity was therefore investigated in this chapter. From time immemorial it has been a recognised practice in various cultures to dispose of malformed, weak, sickly and unwanted infants. The sources that were perused are historical sources and legal sources that have

1 A version of this chapter was published as an article under the title, "An historical overview of infanticide in South Africa" in *Fundamina* vol 15(2), 2009:174-192.

either been received into South African law or have influenced South African law, namely Roman law, Roman-Dutch law, canon law, English law and South African customary law.

Infanticide is the practice of intentionally killing a newborn infant of a given species[2] —by the parents themselves or with their consent.[3] This practice used to be committed for various reasons, such as that the baby had been born out of wedlock, for economic reasons (for example population control),[4] sex selection or ridding society of potentially burdensome deformed members.[5] Silverman[6] remarks that infanticide is the oldest method of family planning. Infanticide was a more popular method of population control than abortion—it was safer for the mother and, moreover, the sex of the baby was known.[7]

It is important to note that two types of infanticide are found in the literature: on the one hand infanticide could refer to the killing of a healthy but unwanted child, and on the other hand to the murder of ill, malformed, weak or sickly babies.[8] Certain ancient cultures, like the

2 Burchell and Milton 2006:673. See also Faber 1976:253 and Langer 1974:353. The definitions for neonaticide, feticide and filicide are provided in par 2.1.1.
3 Williams 1958:26.
4 Faber 1976:253; Voirol 2002:117; Wilkinson 1978:442; Williams 1958:26.
5 Craig 2004:57; Voirol 2002:117.
6 Silverman 1981:12. See also Langer 1974:354.
7 Wilkinson 1978:451.
8 Moseley 1986:345. See also Voirol 2002:117.

Roman culture, regarded the birth of a deformed baby as a bad omen and therefore babies who were born with a minor defect, such as a cleft palate, harelip or missing finger, were put to death.[9]

Various methods were used to commit infanticide: sometimes a family member killed the baby by strangling it;[10] the baby was often drowned as the water would muffle its cries[11] or it was abandoned.[12] The rationale behind exposure or abandonment was to afford the baby the opportunity to be found and raised by a good Samaritan.[13] Such a baby was therefore left outside shortly before dawn to give him or her maximum number of daylight hours in which to be found and rescued.[14]

Since infanticide is as old as mankind itself, this practice will be discussed with reference to examples from Greek and Roman mythology, as well as extracts from Greek and Roman literature. This will be followed by a discussion of the way in which infanticide was regarded by the original sources of South African law, namely Roman law, Roman-Dutch law, English law and finally the law of infanticide as

9 Aish HaTorah http://www.aish.com/seminars/worldperfect/wp03n11.htm See also Williams 1958:30.
10 Wilkinson 1978:450.
11 Price http://www.christiancadre.org/member_contrib/cp_infanticide.php
12 Bennett 1923:344-347; Voirol 2002:117.
13 Rawson in Rawson (ed) 1986:172; Wilkinson 1978:450.
14 Wilkinson 1978:450.

applied by certain indigenous South African cultures. The way infanticide was seen in the Middle Ages and under canon law will be briefly examined.

2.1.1 Terminology

The distinction between the terms neonaticide, infanticide and filicide is based on the age of the victim.[15] Neonaticide is also defined as "parental murder of infants within 24 hours of their birth".[16] Resnick (1970) was the first person to define neonaticide in these terms.[17] According to Weir,[18] filicide is the murder of children who are more than a day old by their parents. Bonnet distinguishes between active and passive neonaticide.[19] Active neonaticide is the violent killing of an infant, while passive neonaticide would be negligence or abandonment after birth, for example leaving a baby outside where it would eventually die of exposure or dehydration.[20] Infanticide is the murder of a child up to the age of one year and filicide the murder of a son or daughter older than one year.[21]

15 Schwartz and Izzer 2007:1.
16 Weir 1984:4.
17 Drescher-Burke ea 2004:2.
18 Weir 1984:4.
19 Drescher-Burke ea 2004:1.
20 Drescher-Burke ea 2004:1.
21 Schwartz and Izzer 2007:2. Burchell and Milton 2006:673.

"Infanticide is the killing of a new-born child committed by the parents or with their consent."[22] If one killed another person's child, however, that would be regarded as murder.[23]

There is also a less frequently used term, namely feticide, which would imply the deliberate killing of a fetus so that the mother gives birth to a dead baby.[24] In medical terms in a South African context, a fetus exists up to 25 weeks into pregnancy; after this period it would be termed a baby because all its vital organs are fully developed.[25] However, in South African law a fetus is only called a baby once it is completely separated from the mother and can breathe on its own.[26]

2.2 Greek and Roman mythology and literature

2.2.1 Greek mythology

According to Wilkinson,[27] "[i]nfanticide in the form of exposure of infants was deeply rooted in Greek mythology even in legends of infant gods, from Zeus downwards, being exposed but rescued, as well as heroes

22 Williams 1958:26.
23 Williams 1958:26.
24 Moodley in Moodley (ed) 2011:259.
25 Dr Carin Maree, Department of Nursing Science, University of Pretoria.
26 For a case of feticide committed in South Africa, see the note on the Best case as discussed in the following note: Kruuse 2009:126-136.
27 Wilkinson 1978:448.

and heroines". One of the best known examples is that of Zeus, who was left by his mother Rhea on the island Crete, but survived because he was cared for by Gaia and some nymphs.[28]

Another well-known case of infanticide from Greek mythology is that of Oedipus.[29] His father, Laius, King of Thebes, learnt from an oracle that a son of his, borne by Queen Jocasta, would eventually kill him (that is, the king,) and marry his mother (that is, the king's wife). In order to prevent this prophecy from being fulfilled, Laius gave the child, Oedipus, to a herdsman, whom he ordered to kill the child. The herdsman, however, felt sorry for the baby Oedipus and did not kill him, but pierced his feet and left him to die on a distant mountainside— a common practice used in ancient Greece to dispose of unwanted babies.[30] However, the baby was found by a shepherd who took him to the childless King Polybus of Corinth, who adopted the baby. Eventually Oedipus unwittingly fulfilled the prophecy when he killed his father and married his mother.[31]

The above mythological tales are all about healthy, yet unwanted babies. There is, however, also the story of Hephaestus, the son of Zeus

28 Bellingham 1989:15-16; Cotterell 2000:42.
29 Bellingham 1989:94-95; Bulfinch 1981:143-144; Cotterell 2000:66-67.
30 Cotterell 2000:66.
31 Cotterell 2000:66-67.

and Hera:[32] Since Hephaestus was born lame his mother Hera tried to drown her imperfect child, but she was thwarted by the sea nymphs, who rescued him and took him to the beach.[33] This is an example of the second type of infanticide, namely the killing of a deformed infant.

Medea,[34] "a witch, a feminist and a powerful woman",[35] was married to Jason (who is famous for his efforts to obtain the Golden Fleece), but when he spurned Medea in order to marry Glauce, a Theben princess, she took revenge by murdering the two sons she had by Jason.[36]

Other Greek gods or demi-gods who were left to die of exposure at birth were Poseidon, Asclepius, Amphion, Zethus, Ion and Perseus.[37] From this we can deduce that in Greek mythology it was a common practice among the Greek gods to dispose of their unwelcome children.[38]

32 Bulfinch 1981:22; Cotterell 2000:46.
33 There is also another version of this story, according to which Hephaestos' father, Zeus, flung him from Mount Olympus to the volcanic island of Lemnos because he had interfered in a quarrel between Zeus and Hera. According to this version of the legend, this act of Zeus resulted in Hephaestos being lame. See Bulfinch 1981:22 and Cotterell 2000:46.
34 Bellingham 1989:74; Cotterell 2000:60.
35 Schwartz and Izzer 2007:6.
36 As a result of the well-known myth about Medea, infanticide and filicide are nowadays called the Medea-syndrome. See Schwartz and Izzer 2007:7; Weir 1984:7; Wen Chen Wu 2003:978.
37 Bennett 1923:344; La Rue van Hook 1920:137.
38 Bennett 1923:344.

2.2.2 Roman mythology

The most famous example from Roman mythology of healthy babies who were abandoned in the hope that they would die is probably that of Romulus, the mythical founder of Rome, and his twin brother, Remus.[39] They were the sons of Rhea Silvia, the only child of Numitor, king of Alba Longa, and Mars, the Roman god of war. Amulius, the brother of King Numitor of Alba Longa, had dethroned his brother and ordered his servants to kill the twins. Instead of murdering the twins the servants cast them into the Tiber. According to legend they were then found by a she-wolf who raised the twins—hence the famous statue of Romulus and Remus suckling the she-wolf.[40]

2.2.3 Greek literature

From Greek literary sources we gather that the Greeks did not raise all their offspring; they killed "weak, deformed, or unwanted children."[41] Plato[42] explains the rite of *amphidromia* that had to be performed before an infant was accepted into the family circle by the father of the household: If the baby was not accepted it was exposed and left to die.[43] Proof that the Greeks did not raise more than one or two of their children

39 Livy 1 4 3-8. See also Langer 1974:354.
40 Cotterell 2000:78-79.
41 Barton 1998:594.
42 Plato *Theaetetus* 160e-161a. See also Williams 1958:26.
43 Williams 1958:26.

can also be found in Polybius,[44] who wrote that married people often raised only one or two of the children born to them. The Greek author Plato[45] also advocated infanticide, not only of imperfect infants, but also for purposes of population control.[46] The famous Greek author Aristotle[47] strongly favoured the enactment of a law that deformed infants should not be reared, but should be left to die of exposure. He also advocated infanticide as a means of birth control.[48]

Exposure was probably the most popular means of discarding unwanted babies among ancient peoples.[49] However, according to Euripides,[50] babies were not only exposed to the elements, but could also be cast out.

La Rue van Hook[51] mentions that in Greek culture a girl was not as welcome as a boy since a son could perpetuate the family and could help to protect the state in times of war. Girls were less favourably

44 Polybius *Histories* 36 17 7. See also Williams 1958:27.
45 Plato *The Republic* 5 8 459 and 5 8 460.
46 Williams 1958:27.
47 Aristotle *Politics* 7 14 10. See also La Rue van Hook 1920:142.
48 Aristotle *Politics* 7 14 12. See also Langer 1974:354.
49 Herodotus 1 112 and 1 116.
50 Euripides *Ion* 933, 951, 956 and *The Phoenician Maidens* 25.
51 La Rue Van Hook 1920:136.

looked on, since a dowry had to be provided for them and they could not help to defend the state.[52]

2.2.4 Roman literature

In Roman culture there was a rite similar to that of the Greeks, during which a baby was either accepted into the family circle by the *paterfamilias* (the head of the family) or rejected: "After eight days a baby was formally accepted into the family clan by a solemn ceremony at the domestic hearth."[53]

According to Seneca,[54] the Romans drowned infants who were weak and abnormal at birth: *"liberos quoque, si debiles monstrosique editi sunt, mergimus".* This is confirmed by Livy,[55] who writes that it was regarded as a bad omen when a baby was born with abnormalities. Such a baby had to be removed from the earth and was consequently

52 Golden 1981:316; La Rue van Hook 1920:136.

53 Durant 1944:56.

54 Seneca *De Ira* 1 15 2: *"We also drown children who are born weak and deformed."* (Own translation.)

55 Livy 27 37 5-6: *"Liberatas religione mentes turbavit rursus nuntiatum Frusinone natum infantem esse quadrimo parem, nec magnitudine tam mirandum quam quod is quoque, ut Sinuessae biennio ante, incertus mas an femina esset natus erat. Id vero haruspices ex Etruria adciti foedum ac turpe prodigium dicere; extorrem agro Romano, procul terrae contactu, alto mergendum. Vivum in arcam condidere provectum in mare proiecerunt."* ["*After their minds had been set free from religious scruples, people were once more upset, since it had been reported that in Frusino a baby was born as big as a four year old infant; and it was not so much a wonder on account of size as at Sinuessa two years ago, it was uncertain whether this baby was male or female. Soothsayers from Etruria were called in and they said it was a terrible and loathsome portent: and that the child had to be removed from the face of the earth and drowned in the sea. They put it alive in a chest, carried it to the sea and cast it into the sea."*] (Own translation.)

drowned. He wrote about a specific incident where a baby who was abnormally large at birth was placed in a chest while still alive and thrown into the sea to drown.[56]

Tacitus,[57] a Roman historian, related that babies were also killed as a form of birth control and in a passage he criticised the Germans for the absence of a similar practice in their culture. He also made a scathing attack on the Jews, who chose not to control their numbers, but preferred to increase them instead and regarded it as a crime to murder an *agnatus* (a relation descended from a common ancestor): *"nam et necare quemquam ex agnatis nefas".*[58]

In both Roman and Greek times, according to their literature, girls were less highly regarded than boys. According to Lucius Apuleius,[59] a girl was thought to belong to an "inferior sex" (*sexus sequioris*) and he describes how a certain husband ordered his wife to kill the baby she was expecting if it turned out to be a girl.

56 Livy 27 37 5-6.
57 Tacitus *Germania* 19 5: *"(The Germans) did not control the number of their children and regarded it as a crime to kill any later children."*
58 Tacitus *Historiae* 5 5: "*For it is a crime against the gods to kill any of our relatives."*
59 *Metamorphoses* 10 23.

Maritum habuit, cuius pater peregre proficiscens mandavit uxori suae, matri eiusdem iuvenis (quod enim sarcina praenationis oneratam eam relinquebat) ut si sexus sequioris edidisset fetum, protinus quod esset editum necaretur. At illa, per absentiam mariti nata puella, insita matribus pietate praeventa, descivit ab obsequio mariti, eamque prodidit vicinis alumnandam, regressoque iam marito natam necatamque nuntiavit. [60]

Although Dionysius of Halicarnassus[61] was a Greek historian, he wrote Roman history. In his work he praised the methods used by Romulus to control the Roman population effectively. According to him, Romulus set an example that should be followed by the Greeks. Romulus obliged Roman citizens to bring up all their male children and the first born of the females; only deformed children under the age of three years could be disposed of by means of exposure.[62]

The literary sources discussed above clearly reveal that both the Greeks and the Romans were unwilling to raise deformed children. Infanticide

60 Lucius Apuleius *Metamorphoses* 10 23: *"She had a husband, whose father when he was leaving abroad, ordered his wife, the same young man's mother (for he left her burdened with pregnancy) that if she gave birth to a baby of inferior sex, it should immediately be killed when it is born. But while her husband was still abroad, she gave birth to a girl whom she wanted to prevent from killing, because of the natural affection which she had for the child, she diverted from her husband's command and secretly gave the baby to the neighbours to nurse."* (Own translation.)

61 Dionysius of Halicarnassus 2 15 1-2.

62 Dionysius of Halicarnassus 2 15 1-2.

was also a form of birth control. Girls were not as highly regarded as boys and were more likely to be left to die of exposure.[63] The literature seems to indicate that only infants from birth to the age of three years were exposed and left to die.[64]

2.3 Roman law

It is important to take cognisance of the way the Roman *familia* (family) operated before the practice of infanticide in Roman law is considered. Ulpian[65] gives a definition of the *familia*: According to him the *familia* included things (for example assets) and persons (that is, a wife, sons, daughters, adopted children and slaves). The *paterfamilias* was the head of the family.[66] According to Roman law he had the power of life and death (*ius vitae necisque*)[67] over the members of his household and could therefore decide whether a child should be reared or not.[68]

63 Langer 1974:354; Wen Chen Wu 2003:978-979.
64 Dionysius of Halicarnassus 2 15 1-2.
65 *Digesta* 50 16 195. See also Buckland 1963:101-102; Kaser (translated by Dannenbring) 1984:37,74-76.
66 Moseley 1986:349; Van Zyl 1983:87-88; Voirol 2002:118. See also Kaser (translated by Dannenbring) 1984:74-76, 304-306.
67 Dionysius of Halicarnassus 2 26 4; Moorman 2 6 1. See also Buckland 1963:102-103; Kaser (translated by Dannenbring) 1984:74-76,305-306; Robinson 2002:309; Voirol 2002:118; Wen Chun Wu 2003:979.
68 The Law of the Twelve Tables 4 2: *"Endo liberis iustis ius vitae necis…"*; in Cicero *De Legibus* 3 8 19. Cicero *De Domo Sua* 29 77: *"vitae necisque potestatem"*. See also Wilkinson 1978:449.

Gaius[69] writes about the unusual powers that the *paterfamilias* had under Roman law:

> *Item in potestate nostra sunt liberi nostri quos iustis nuptis procreavimus. Quod ius proprium civium Romanorum est. Fere enim nulli alii sunt homines qui talem in filios suos habent potestatem qualem nos habemus.*

The following sentence from Justinian[70] echoes Gaius regarding the power of the *paterfamilias*:

> *Ius autem potestatis quod in liberos habemus proprium est civium Romanorum: nulli enim alii sunt homines qui talem in liberos habeant potestatem qualem nos habemus.*

Later on the powers of the head of the family were limited to some extent, since the *paterfamilias* was not allowed to kill his son without listening to him and accusing him before the prefect or provincial governor.[71] At the time of the Roman Empire the patriapotestas *of the*

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69 Gaius 1 55: *"Likewise our children, whom we begot from a legal marriage are under our authority. That law is peculiar to the Roman people for there are no other people who have such power over their children as we have."* (Own translation.) See also Buckland 1963:102.

70 *Institutiones* 1 9 2: *"However the right of authority we have over our children is peculiar to Roman citizens: for there are no other people who have such authority over their children as we have."* (Own translation.)

71 *Digesta* 48 8 2: *"Inauditum filium pater occidere non potest, sed accusare eum apud praefectum praesidemue proviniae debet".*

paterfamilias was restricted.[72] Durant[73] remarks that these powers of the *paterfamilias* were checked "by custom, public opinion, the clan council, and praetorian law; otherwise they lasted to his death, and could not be ended by his insanity or even by his own choice."

As mentioned earlier, a child became a member of the household of the *paterfamilias* if he or she was accepted into the family and the clan at a solemn ceremony at the domestic hearth which resembled the ceremony of the Greeks.[74] After he or she was born, the baby was laid at the father's feet and only after the *paterfamilias* had taken him or her in his arms (*ius tollendi, suscipiendi*), thereby indicating the legitimacy of the baby and his willingness to raise the child, did the baby become a member of the household.[75] During the Empire this ceremony became obsolete and was ended by a praetorian procedure "which required fathers to recognise their children".[76]

As early as the time of the Twelve Tables,[77] it was laid down that a baby who was terribly deformed at birth (*monstrum*) should be quickly put to

72 Hadley 1904:123.
73 Durant 1944:57.
74 Durant 1944:56.
75 Bennett 1923:346.
76 Buckland 1963:102.
77 Cicero *De Legibus* 3 18 19: *"deinde cum esset cito necatus tamquam ex duodecim tabulis insignis ad deformitatem puer, brevi tempore..."* [*"Then after the child had been*

death. Ulpian[78] was of the opinion that if a woman gave birth to a malformed baby (*non humanae figurae*) this should not be held against her, and that the parents should not be penalised if they had observed the statutes.

Since the *paterfamilias* had absolute power over his family members, infanticide was not regarded as murder or another type of crime.[79] One of the immediate family members, such as the father or mother, killed the infant soon after birth—often by abandoning the baby and leaving it to die of exposure, by smothering the child or by drowning the newborn.[80] Even at the end of the Republican era (509 BC to 31 BC)[81] the *lex Pompeia de parricidio,* a comprehensive statute on the killing of relatives by relatives, did not mention the random killing of a child by his father.[82] According to Justinian,[83] it was permissible for a father to kill his son (*quod et occidere licebat*), but if another relative (such as the mother or grandfather) killed a child, it was regarded as *parricidium* (the murder of any near relative).[84] The law became increasingly intolerant of

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quickly put to death according to the law of the Twelve Tables (namely) that terribly deformed children must immediately be killed…"] (Own translation.)

78 *Digesta* 50 16 135.

79 Boswell 1988:58-59; Buckland 1963:103; Durant 1944:57; Hadley 1904:105; Kaser (translated by Dannenbring) 1984:304-307; Thomas 1976:414.

80 Price: http://www.christiancadre.org/member_contrib/cp_infanticide.php

81 Evans 1991:4.

82 *Digesta* 48 8 2. See also Hadley 1904:120.

83 *Digesta* 28 2 11.

84 Silverman 1981:12.

infanticide, specifically exposure as a means of getting rid of unwanted babies.[85] According to Justinian, such children were to be regarded as freemen.[86]

With the rise of Christianity, attitudes towards infanticide hardened further, and from then onwards it was regarded as a serious crime, namely murder, since all human life was seen as inviolable.[87] In AD 318 the Roman Emperor Constantine decreed that the killing of a child constituted the crime of *parricidium*,[88] and by AD 374 infanticide became an offence in Roman law for which a citizen could be punished by death.[89]

According to the *Codex Theodosianus*,[90] *parricidium* (the murder of a relative) was not to be punished in the usual way; unusual and even more extreme means had to be employed to punish the guilty party: such a person was to be sewn into a bag filled with snakes and thrown into the nearest sea or river.

85 Rawson (ed) 1986:172.
86 Boswell 1988:189-191; Rawson (ed) 1986:172.
87 Langer 1974:355; Voirol 2002:118; Wen Chen Wu 2003:979.
88 Du Plessis 2010:29,112; Langer 1974:355; Moseley 1986:352; Voirol 2002:118.
89 Du Plessis: 2010:111-112; Thomas 1976:415.
90 *Codex Theodosianus* 9 17 1.

In conclusion, it seems that even the Roman law authorities distinguished between the killing of a healthy baby (*parricidium*) and that of a deformed baby or *monstrum*. As the law developed it became unsympathetic towards a person who committed *parricidium*, whereas the law was more lenient towards those who killed a malformed infant.

2.4 The Middle Ages

The Middle Ages (*circa* AD 410 to 1500)[91] saw a further change in attitudes and the stigma of having an unwanted child came to fall solely on the mother, with an even a higher degree of stigmatisation being cast upon unwed mothers.[92] During the Middle Ages, superstition was rife and it was believed that deformities "or behavioural abnormalities"[93] were the result of evil or supernatural forces.[94] Fathers believed that mothers were to blame for the deformity of a child. As a result of this perception, mothers often killed their unwanted or deformed babies.[95]

Infanticide was regarded as a crime by the state and the church from the early Middle Ages and it was "the most common crime in Western

91 Dupré (ed) 1999:69.
92 Voirol 2002:118.
93 Moran: http://www.deathreference.com/Ho-Ka/Infanticide.html
94 Moran: http://www.deathreference.com/Ho-Ka/Infanticide.html
95 Voirol 2002:118.

Europe from the Middle Ages to the end of the eighteenth century".[96] Girls who were guilty of committing infanticide during the Middle Ages were punished in the most horrific ways, such as being tied into a sack with a dog or a cock and thrown into a river to drown.[97]

Silverman[98] remarks that infanticide by direct killing was a crime during this time, and as such punishable by law, but exposure was not punishable by law. This resulted in infanticide by means of abandonment being practised with impunity on a gigantic scale.[99]

2.5 Canon law

Canon law was created by the Roman Catholic Church for use in its ecclesiastical courts.[100] Canon law took Roman law as its point of departure, but it developed and simplified Roman law, abolishing unnecessary formalism in the process.[101] Roman law together with canon law eventually evolved into Roman-Dutch law.[102]

96 Moran: http://www.deathreference.com/Ho-Ka/Infanticide.html
97 Silverman 1981:13.
98 Silverman 1981:12.
99 Silverman 1981:12.
100 De Vos 1992:76; Du Plessis 2010:364; Wessels 1908:130.
101 De Vos 1992:77; Wessels 1908:132.
102 De Vos 1992:83-84; Wessels 1908:132.

A study of canon law soon reveals that life was held sacred by the church, whether it was the life of an adult or a child, and infanticide was regarded as a crime. The Decretals of Pope Gregory IX contain texts that describe the proper punishment of infanticide, namely that a person who is guilty of infanticide should be punished for three years, during one of which he may only have bread and water.[103] Both negligent and intentional infanticide were punishable under canon law:[104]

> *De infantibus autem qui mortui reperiuntur cum patre et matre et non apparet, utrum a patre vel a matre oppressus sit ipse vel suffocatus, vel propria morte defunctus, non debent inde securi esse parentes, nec etiam sine poena.*

The attitude of the Roman-Dutch authors was less rigid than that of the canonists regarding infanticide.

2.6 Roman-Dutch authorities

The crime, *crimen expositionis infantis*, existed in Roman-Dutch law.[105] The crime could be subdivided into two categories. The first category

103 *Corpus Iuris Canonici* Decret. Greg. Lib V. Tit. X Cap III.

104 *Corpus Iuris Canonici* Decret. Greg. Lib V. Tit. X Cap III. "However, regarding infants who are found dead with the father and mother and it is not certain whether he was smothered or suffocated by the mother or father or died a natural death, hence not even careless parents must go unpunished."

105 Matthaeus *De Criminibus* 47 2. See also Burchell and Milton 2006:673; Hunt and Milton 1990:366; Snyman 2008:454.

included abandoning a young child without the intention of killing it, namely by leaving it in a place where it was likely to be found and raised by other people.[106] The second category of this crime consisted of abandonment of a child with the intention of killing it.[107] The former was punished more leniently than the latter, which was punishable by death.[108] The opinions of a few Roman-Dutch authors on this aspect will be discussed below.

One of the most important and famous Roman-Dutch writers, Grotius (1583-1645),[109] wrote about the law of Holland. He was of the opinion that a body must have a soul or a spirit in order to be regarded as a human being and that deformed babies (that is *monstra*) should immediately be killed by means of suffocation:

> *Voor gheboren menschen houdmen alleen zodanighen, die't lichaem hebben bequaem om een redelicke ziele te vaten. Andere wanschapene gheboorten houdmen voor geen menschen, maer veel eer is men in deze landen ghewoon de selve terstond te smooren.*[110]

106 Van Leeuwen *Roomsch Hollandsch Recht* 4 34 3. See also Burchell and Milton 2006:673; Snyman 2008:454 and *Oliphant* 1950 1 SA 48 (O).
107 Van Leeuwen *Roomsch-Hollandsch Recht* 4 34 3. It seems that this form of *crimen expositionis infantis* is the only form of exposure currently recognised in South Africa law. See Burchell and Milton 2006:673; Hunt and Milton 1990:366; Snyman 2008:454.
108 Burchell and Milton 2006:673.
109 De Vos 1992:171-180.
110 Grotius *Inleidinge tot de Hollandsche Rechts-Geleerdheid* 1 3 5.

Grotius[111] implied that babies born with deformities (that is *monstra*) did not have a spirit or a soul.

Antonius Matthaeus II gives a lengthy exposition of this crime. According to him, a distinction should be drawn between the two categories mentioned above.[112] Someone who had abandoned a child with the intention of killing it should be punished according to the *Lex Cornelia a*nd the *Lex Pompeia* in the same way as someone who had committed *parricidium.*[113] However, someone who exposed an infant where it could be found by someone else had to be punished *extra ordinem* (which means "more leniently" here).[114] And such a person also lost his *patria potestas.*[115]

For Matthaeus[116] it was also important to distinguish between a human being who was merely misshapen, but had a soul, or one who lacked a soul and was a *monstrum*. The killing of a human being with a soul, as opposed to a *monstrum*, was regarded as murder:

111 Grotius 1 3 5.
112 Matthaeus *De Criminibus* 47 16 2.
113 Matthaeus *De Criminibus* 47 16 2.
114 Matthaeus *De Criminibus* 47 16 2.
115 Matthaeus *De Criminibus* 47 16 2.
116 Matthaeus *De Criminibus* 48 5 6.

Sed non inepte fortasse fecerit, qui diviserit utramque sententiam, et sine fraude monstra caedi dixerit, si non tantum figura sit monstrosa…[117]

A clear distinction between the mere killing of a child (referred to under the broad term *parricidium*) and exposure is drawn by Van Leeuwen (1626-1682).[118] The punishment for parricide was the most severe: The guilty parties were tortured on a wheel until they died.[119] Women who were guilty of killing their children were often strangled with a cord tied to a stake.[120] Those who had exposed their children were punished less severely, although they were still punished harshly: for example, they could be whipped, branded and banished.[121] Van Leeuwen[122] also draws a distinction between those who left their children in inhabited places where they could easily be found and raised by a good Samaritan, and those who left their children in uninhabited places where they would in all likelihood die.

117 Matthaeus *De Criminibus* 48 5 6: *"But it would perhaps not be inappropriate to divide the two opinions and say that monsters can be killed without punishment, if not only their form is monstrous…'*
118 Van Leeuwen *Roomsch Hollandsch Recht* 4 34 2.
119 Van Leeuwen *Roomsch Hollandsch Recht* 4 34 2.
120 Van Leeuwen *Roomsch Hollandsch Recht* 4 34 2.
121 Van Leeuwen *Roomsch Hollandsch Recht* 4 34 3.
122 Van Leeuwen *Roomsch Hollandsch Recht* 4 34 3.

This was also the law that applied in Friesland, since Huber (1636–1694)[123] also distinguishes between leaving an infant to die of exposure and putting the infant to death. If the baby was left in an uninhabited place so that the chances of the baby being found were slim, a heavier punishment was imposed than in those instances where the baby was left in inhabited places where it could more easily be found and raised by someone else.[124] Mothers who intentionally caused the death of their babies were punished in the most inhumane and cruel manner— they were sewn into a bag and drowned.[125]

Johannes Voet (1647–1713)[126], one of the most famous Roman-Dutch authors, wrote about Roman law, but also augmented the existing law of his own time.[127] He distinguished between babies who were born with a human form and those that did not have a human form, but were so-called monsters.[128] Parents did not have to rear these babies; they could be strangled or drowned with impunity.[129]

123 Huber *Heedensdaegse Rechtsgeleertheyt* 6 13 33-34.
124 Huber *Heedensdaegse Rechtsgeleertheyt* 6 13 33.
125 Huber *Heedensdaegse Rechtsgeleertheyt* 6 13 33.
126 De Vos 1992:184.
127 De Vos 1992:184-187.
128 Voet *Commentarius ad Pandectas* 1 6 13.
129 Voet *Commentarius ad Pandectas* 1 6 13.

Although Moorman (1696–1743)[130] regarded murder of a child as a terrible crime, for which the death penalty could be imposed,[131] he held a different opinion regarding *monstra*. According to him, infants born with deformities should not be regarded as children and should be suffocated:[132]

> *Hoe verre monstreuse geboortes kunnen gedood worden, en wie dat eigentlyk voor monsters te houden zyn, verdient, hier ondersogt en nagespoort te worden; wien aengaande het bekent ende uitgemaekte saek is, dat monsters en wanschapene geboortes voor geen kinderen worden gereekent, en dat men gewoon is deselve in deese handen te smoren.*

According to Van der Keessel (1738–1818),[133] a person born with a body that can contain a spirit should be regarded as a human being.[134] He relied on Grotius, who wrote that *monstra*[135] were not regarded as human beings and ought to be suffocated immediately.[136] Van der Keessel[137] was, however, of the opinion that this should not be done randomly, but only after consultation with the official (*magistratus*) and

130 Moorman *Verhandeling over de Misdaden en der selver Straffen* 2 1 1.
131 Moorman *Verhandeling over de Misdaden en der selver Straffen* 2 3 1; 2 6 14; 2 6 16 and 2 6 19.
132 Moorman *Verhandeling over de Misdaden en der selver Straffen* 2 6 19.
133 De Vos 1992:211.
134 Van der Keessel *Praelectiones* 1 3 5.
135 The word *monstra* can be translated with “grossly deformed beings”.
136 Van der Keessel *Praelectiones* 1 3 5.
137 Van der Keessel *Praelectiones* 1 3 5.

skilled doctors. This author felt that such infants should not immediately be killed, but that one had to wait before taking such drastic steps, until it was clear that the infant was not a human being with spirit. Van der Keessel's approach, therefore, is less extreme than that of Grotius.

Van der Linden (1756–1835)[138] was of the opinion that deformed babies (*monsters of wanschapene geboorten*) should not be allowed to live, but should be suffocated (*smooren*).[139] If such a baby was killed it did not constitute the crime of murder.[140] He mentioned that it was a prerequisite for child murder that the baby must have been carried full term and must have been born alive: *"Tot een Kindermoordt wordt vereischt, dat het gedood kind geleefd heeft, en voldragen geweest is."*[141] Exposure (*te vondeling leggen*) is also discussed by Van der Linden.[142] If it were done with the purpose of killing the child, it was regarded as murder for which the punishment was the death penalty. In those cases where it was not the purpose to kill the child, the guilty party was punished with other less severe punishments, such as *"confinement, lijfstraffe, of bannissement"*.[143]

138 De Vos 1992:213.
139 Van der Linden *Koopmans Handboek* 2 5 2.
140 Van der Linden *Koopmans Handboek* 2 5 2.
141 Van der Linden *Koopmans Handboek* 2 5 12.
142 Van der Linden *Koopmans Handboek* 2 5 12.
143 Van der Linden *Koopmans Handboek* 2 5 13.

Exposure (*te vondeling leggen*) is discussed along the same lines by Van der Linden: If it was done with the purpose of killing the child it was regarded as murder for which the punishment was the death penalty.[144] In cases where the purpose was not to kill the child (*onvoorzigtige doodslag*), the guilty party was punished with another, less severe, punishment such as *"confinement, lijfstraffe, of bannissement".*[145]

As Roman law developed, the *patriapotestas* diminished and with it the *ius vitae necisque* of the *paterfamilias.*[146] This trend continued, so that by the seventeenth century the Roman-Dutch authorities were opposed to the killing of healthy babies.[147] Those who committed *infanticidium* (also classified as *parricidium*) during this period had to receive the most severe punishment, but the Roman-Dutch authorities were of the opinion that *monstra* should be killed rather than raised.[148] If a mother exposed her baby and left it in a place where it was likely to be found and raised by a good Samaritan, this was also regarded as mitigating circumstances when it came to the question of punishment.[149] On the other hand, if a mother left her child in a solitary place where it was not

144 Van der Linden *Koopmans Handboek* 2 5 13.
145 Van der Linden *Koopmans Handboek* 2 5 12-13.
146 Labuschagne 1996:216.
147 Labuschagne 1996:216-217.
148 Labuschagne 1996:217.
149 Boswell 1988:43-45.

likely to be found and it died, this was regarded as murder and punished as such.

2.7 English law

A superficial perusal of case law regarding infanticide confirms the fact that South African courts frequently relied on English law. In view of the fact that English law significantly influenced legal development in this field, a brief exposition of its development will be given.

In 1803 the Malicious Shooting or Stabbing Act[150] was passed, according to which all charges of infanticide (or the procurement of the miscarriage of any woman) had to be tried in the same way as murder and the crime was punished by death.[151] A prerequisite for the crime was that the birth should have been completed and the baby should have been born alive.[152] This meant that infanticide could be committed with impunity where part of the baby's body was still inside the mother, since it was difficult to obtain evidence to prove otherwise.[153] The

150 43 Geo 3 c 58 (also known as Lord Ellenborough's Act). See Grey 2008:91; McDonagh 2003; Weir 1984:15.
151 43 Geo 3 c 58. See also McDonagh 2003:95.
152 See also Grey 2008:91; Langer 1974:360.
153 Langer 1974:360.

consequence was that infanticide flourished in England in the early nineteenth century.[154]

As a consequence of the economic and social conditions in mid-nineteenth century England,[155] mothers had to work in factories and fields and often had no other choice than to leave their children in the care of professional nurses.[156] These nurses were often referred to as “killer nurses” since they quickly got rid of the babies in their charge.[157] Harsh economic conditions led mothers to pay a small premium to enrol their babies at burial clubs that would pay them a benefit in the event of the death of their babies.[158] Some mothers even enrolled their babies at more than one burial club; when the babies died they were able to collect money from the different burial clubs.[159] This practice was known as "baby farming".[160] According to Langer, “[b]y 1860 this became the subject of much official agitation, which led to Parliament introducing the first Infant Life Protection Act[161] in 1872.”[162] This Act made provision for

154 Langer 1974:360; McDonagh 2003:95.
155 Law Reform Commission New South Wales: http://www.lawlink.nsw.gov.au.lrc.nsf/pages/R83CHP3
156 Langer 1974:360; Silverman 1981:13.
157 Langer 1974:360; Silverman 1981:13.
158 Langer 1974:360; Silverman 1981:13.
159 Langer 1974:360; Silverman 1981:13.
160 Silverman 1981:13; Weir 1984:15-16.
161 35 & 36 Vict c 38. See also Weir 1984:15.
162 Langer 1974:361; Silverman 1981:13. According to s 27 of the Offences Against the Person Act 1861 (24 & 25) Vict c 100, persons charged with the abandonment or exposure of a child under the age of two years, thereby jeopardizing its health or life had to be punished to penal servitude.

the compulsory registration of all households in which more than one child under the age of one were in the charge of a nurse or day care provider for more than twenty-four hours.[163] In terms of this Act all deaths, including still-births, had to be reported immediately.[164]

Although the killing of a child was regarded as murder for which the mandatory punishment was the death sentence, English courts and juries were reluctant to convict such mothers for the murder of their newborn infants.[165] In an attempt to reform the strict legislation in this regard the Infanticide Act was introduced in 1922.[166] The purpose of this Act was "to mitigate the application of the law of murder to mothers who kill their newborn babies whilst suffering from the effects of childbirth".[167] This Act applied to cases where a woman killed her new-born child because she was suffering from psychological after effects of birth, such as puerperal psychosis.[168]

163 The Infant Life Protection Act, 1872 (35 & 36 Vict c 38) s 2. See also Langer 1974:361.
164 The Infant Life Protection Act, 1872 (35 & 36 Vict c 38) s 8. See also Langer 1974:361.
165 Silverman 1981:13.
166 12 & 13 Geo 5 c 18. See also Ashworth 2006:280; Card 2006:294. This Act was preceded by the Criminal Code Bill of 1878. See Williams 1958:36.
167 Ashworth 2006:280.
168 Ashworth 2006:280; Card 2006:294-295; Langer 1974:365, note 27; Ormerod 2005:498.

Grey[169] has noted that the 1922 Infanticide Act did not resolve the issues surrounding "newborn murder" and new Acts were needed, namely the 1929 Infant Life (Preservation) Act[170] and the 1938 Infanticide Act.[171] The 1929 Act, which is still in force in England and Wales, created a criminal offence, namely child destruction, in the case of the killing of a child capable of being born alive.[172]

The 1922 Act was replaced by the Infanticide Act of 1938.[173] In the 1938 Act, there were two significant changes, namely the definition of "new-born child" was replaced by "child under the age of twelve months";[174] and furthermore the scope of the Act was extended to include mothers

169 Grey 2008:92.
170 1929 19 & 20 Geo 5 c 34.
171 1938 1 & 2 Geo 6 c 36.
172 Section 1 of the 1929 Act reads as follows:
(1) Subject as hereinafter in this subsection provided, any person who, with intent to destroy the life of a child capable of being born alive, by any wilful act causes a child to die before it has an existence independent of its mother, shall be guilty of felony, to wit, of child destruction, and shall be liable on conviction thereof on indictment to penal servitude for life:
Provided that no person shall be found guilty of an offence under this section unless it is proved that the act which caused the death of the child was not done in good faith for the purpose only of preserving the life of the mother.
(2) For the purposes of this Act, evidence that a woman had at any material time been pregnant for a period of twenty-eight weeks of more shall be prima facie proof that she was at that time pregnant of a child capable of being born alive.
See also Campbell in Goldworth ea (eds) 1995:308,329; Elliston in Norman and Greer 2005:390-391.
If a similar Act had been in force in South Africa, the father in the Best case, mentioned in par 2.1.1 fn 26 above, who arranged that his unborn child be killed, could have been convicted of the offence, child destruction.
173 1 & 2 Geo 6 c 36. See also Ashworth 2006: 280; Card 2006:294-295; Ormerod 2005:498; Weir 1984:23.
174 Infanticide Act 1938 (1 & 2 Geo 6 c 36) s 1.

who had not fully recovered from the effects of lactation.[175] This was an extension of the provisions of the 1922 Act, which included only mothers who had not fully recovered from the effects of birth as a ground for mental disturbance.[176] The 1938 Act offered the opportunity to the jury to change a verdict of guilty of murder to a verdict of guilty of infanticide if the prescribed conditions were met.[177]

A woman who had killed her baby could therefore either be charged with infanticide or she could raise infanticide as a defence.[178] It should be noted that this defence was available to the mother only and if the baby was killed by any person other than the mother, it would still constitute murder.[179] Although it has been amended, the Infanticide Act of 1938 is still in force.[180]

175 Infanticide Act 1938 (1 & 2 Geo 6 c 36). See also Ashworth 2006:280; Barton 1998:596; Card 2006:293-294; Ormerod 2005:498; Williams 1958:36-37.
176 Ashworth 2006:280-281; Barton 1998:596; Card 2006:294-295; Ormerod 2005:498; Williams 1958:36-37.
177 Infanticide Act 1938 s 1(2). See also Card 2006:294.
178 Infanticide Act 1938 (1 & 2 Geo 6 c 36). See also Ashworth 2006:280; Ormerod 2005:498.
179 Ormerod 2005:498.
180 Ashworth 2006:281; Barton 1998:596; Card 2006: 294-295.

2.8 The Cape Colony

According to De Kock,[181] infanticide was "considered throughout the history of South Africa as a sin of the first magnitude". After the abolition of slavery at the Cape Colony in 1838, a few cases of infanticide occurred in three rural districts near Cape Town.[182] At that time the law did not distinguish between child murder and other forms of murder, all of which were punishable by death.[183] One such case was that of a slave woman, Susanna van Bengale,[184] who was condemned to death and executed in a most inhumane manner on 13 December 1669.[185] Her baby was ill and, according to those who testified against her, she had strangled "her infant, a half-caste girl".[186] Her punishment was that her "breasts be ripped from her body by red-hot irons, and that she then be burnt to ashes".[187] Eventually she was sewn into a sack and drowned on 13 December 1669.[188]

During the 1830s the law did not distinguish between child murder and other forms of murder and the death sentence was the punishment for

181 De Kock 1950:185.
182 Scully 1996:88-89.
183 Van der Spuy in Jackson (ed) 2002:131.
184 Böeseken 1977:31.
185 Böeseken 1977:31. See also De Kock 1950:184; Leibbrandt 1901:308-309; Van Niekerk 2005:142-145.
186 Boëseken 1977:31; Leibbrandt 1901:308.
187 Leibbrandt 1901:308-309.
188 De Kock 1950:184; Leibbrandt 1901:308-309; Van Niekerk 2005:142-145.

both offences.[189] Several cases of infanticide were reported in the rural districts near Cape Town.[190] The facts of these cases were similar: The women were unmarried and the act of infanticide was committed out of fear of being ostracised by the community because their babies had been born out of wedlock.[191]

Eventually, in 1845, legislation[192] was enacted in the Colony in terms of which mothers who had killed their offspring should be convicted of concealment of birth rather than child murder, since the punishment for the former was not the death penalty, as was the case with the latter.[193]

South African law regarding infanticide has been influenced by both Roman-Dutch law and English law.

R v Adams[194] was the first reported case in the Supreme Court of the Cape of Good Hope in which the accused was charged with the common-law crime of *crimen expositionis infantis*. In this case Christina Adams, who had abandoned her baby boy on the day of his birth, was

189 Van der Spuy in Jackson (ed) 2002:131.
190 Scully 1996:88-89.
191 Scully 1996:88-89.
192 Ord 10 of 1845 (C).
193 Van der Spuy in Jackson (ed) 2002:131.
194 (1903) 20 SC 556. Regarding "exposure" as a crime, see also *Bengu* 1965 1 SA 298 (N):303G-H.

found guilty of *crimen expositionis infantis*.[195] The Court referred to the fact that infanticide was a specific crime which had to be treated in a particular way in terms of English law: "[T]he crime *crimen expositionis infantis* was well known to the common law of the Colony, but had been made a crime in England by Statute."[196] As far as could be ascertained there were no decided cases after the *Adams* case in which the accused was charged with the crime *crimen expositionis infantis*. After the *Adams* case the perpetrators were charged instead with concealment of birth under Cape Ordinance 10 of 1845.[197]

2.9 Infanticide in Southern Africa

2.9.1 Introduction

Certain indigenous Southern African cultures also killed some of their offspring with impunity, including deformed babies (who were considered to be monsters) and one or both twins, since they were considered dangerous.[198] Superstition was often the reason behind this practice, since it was believed that such a baby would bring ill luck to the family or the community.[199] In this section this practice will be examined,

195 *Adams*:556-557.
196 *Adams*:557.
197 *Arends* 1913 CPD:194; *Verrooi* 1913 CPD:864.
198 Labuschagne 1996:216; Myburgh 1985:69.
199 Labuschagne 1996:216; Schapera 1970:261.

commencing with the San[200] and the Khoikhoi;[201] thereafter this custom will also be examined as it manifested among certain other indigenous cultures, namely the Zulu, the Northern Ndebele and the Northern Sotho (Tswana).

2.9.2 The San[202]

The San were the earliest inhabitants of Southern Africa. It is not known exactly for how long they have lived in Southern Africa, but according to some researchers they have occupied Southern Africa for more than 5000 years.[203] At present they live mainly in the northern and north-eastern districts of the Kalahari.[204] Linguistically, three groups can be distinguished, namely the southern tribes (like the Auni and the Batwa), the central tribes (Naron, !Kô, Gwi, Tennekwe and Hiechuare) and the northern tribes (!Kung, Auen and Heikum).[205]

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200 For the use of the terminology see Boonzaaier ea 1996:2. The San (also known as Soaqua or Sonqua) was formerly known as the "Bushmen". They did not have cattle, but were hunters and lived off the veld. See also Elphick 1985:23-28. The terminology that will be used in this dissertation to denote "Bushmen" is "San".

201 The terminology used by the different authors for these people differs. Previously these people were referred to as "Hottentots", but Boonzaaier ea 1996:1-2 mention that they referred to themselves as the "Khoikhoi" to distinguish them from the San. They were not hunters, but herdsmen. See also Elphick 1985:23-28; Wells 1998:417 n 1. The terminology that will be used to denote the so-called "Hottentots" is therefore "Khoikhoi".

202 It should be noted that both Schapera and Dornan use the word "Bushmen" for the San people.

203 Stoffberg 1982:21.

204 Stoffberg 1982:18.

205 Stoffberg 1982:21-22.

According to Schapera,[206] twin births were very rare among the San, but if they did occur the customary way of dealing with this phenomenon differed from tribe to tribe. The Auen and Heikum (that is the northern tribes) killed one of the twins immediately after birth.[207] If the twins consisted of a boy and a girl, the boy was killed in this way.[208] The !Kung tribe (also a northern tribe) had a different custom: they buried both alive because they believed that the birth of twins would bring bad luck to the parents.[209] Apparently the Naron (one of the central tribes) allowed both to live.[210] It does not appear to have been a practice among these tribes to kill or expose deformed children.[211] According to Dornan,[212] the San he interviewed denied that deformed children were wilfully killed at birth, but he mentioned that he had never seen deformed grown-up people, neither had he seen twins.[213] He came to the conclusion that in the rare event that twins were born, one or both of them were killed.[214]

206 Dornan 1975:129; Schapera 1965:114.
207 Schapera 1965:114
208 Schapera 1965:114.
209 Kuhse and Singer 1985:101-103; Schapera 1965:114-115.
210 Schapera 1965:115.
211 Schapera 1965:115.
212 Dornan 1975:129.
213 Dornan 1975:129.
214 Dornan 1975:129.

2.9.3 The Khoikhoi[215]

The Khoikhoi apparently buried misshapen or deformed children (especially girls) alive in a burrow or left them to die of exposure, since it was believed that they would bring bad luck to the community.[216] The Naman[217] tribe regarded twin births as unlucky, but the children were not murdered.[218] Among some other tribes the custom was to kill one of the twins, especially if it was a girl, by either exposing her or leaving her as prey for wild animals, the reason for this being that the mother would have been unable to rear them both.[219] A boy was welcomed into the world with great joy and festivities, but a girl was not as joyfully received as a boy.[220]

The Khoikhoi also buried babies alive together with their mothers in cases where their mothers died while giving birth or while suckling the baby. Female infanticide was practised by the Khoikhoi women, who left the second member of the twins to die if this happened to be a girl.[221]

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215 It should be noted here that the terminology used by both Dornan 1975 and Schapera 1965 for the Khoikhoi is the "Hottentots". According to Stoffberg the Hottentots are also referred to as the Khoe-Khoen, see Stoffberg 1982:26.
216 Post 1887:282-283; Schapera 1965:266.
217 According to Stoffberg the Nama tribe can today be found in Namibia; see Stoffberg 1982:26.
218 Schapera 1965:266.
219 Schapera 1965:266.
220 Schapera 1965:266.
221 Deacon 1998:276.

Both the San and the Khokhoi practised infanticide as a means of population control, especially child-spacing.[222] Unwanted babies of this kind (that is babies who were born when a previous sibling was still being breastfed) were buried alive or left to be eaten by wild animals.[223]

In conclusion it can be said that most tribes belonging to the San and Khoikhoi murdered either one or both members of twins, and babies born with deformities.

2.9.4 The Zulu

The Zulu tribe mostly occupy the province of Natal (now known as KwaZulu-Natal).[224] Ngobese[225] mentions that in the Zulu culture the birth of twins was regarded as a bad omen, since it is believed that they disrupt the smooth order of life: twin-bearing is for animals, not for humans. He does not elaborate on this issue and does not explain what happened to twins,[226] but according to certain authors one twin was "immediately destroyed lest the father or family member would die".[227] Breytenbach's[228] research showed that the twin born first had the right to

222 Scully 1996:94.
223 Scully 1996:94.
224 Stoffberg 1982:38.
225 Ngobese 2003:66.
226 Ngobese 2003:66.
227 Tyler 1971:104.
228 Breytenbach 1971:232. See also Krige 1965:75.

live, while the second twin was killed by placing a lump of earth in its throat. It is doubtful, however, whether this is still done today.[229] Today a killing of this nature would be regarded as murder if it came to the attention of the authorities.[230]

2.9.5 The Northern Ndebele

The Northern Ndebele hail mainly from Polokwane (formerly known as Pietersburg) and Mokopane (formerly known as Potgietersrus) in Limpopo (previously known as Northern Transvaal).[231] In the past the Northern Ndebele regarded a twin that was born first as the junior, and drowned the baby in a clay pot filled with water.[232] Nowadays both babies are allowed to live.[233] However, the birth of a *monstrum* or deformed baby was regarded as an abnormal occurrence, and the baby was smothered by the midwives immediately after birth.[234] The midwives who had smothered the first-born twin or deformed baby were not considered to have committed a crime, being seen instead as having freed the community from the possible negative effects that could result from such a birth.[235]

229 Breytenbach 1971:232.
230 Breytenbach 1971:232.
231 Stoffberg 1982:42.
232 De Beer 1986:316; Post 1887:285.
233 De Beer 1986:317.
234 De Beer 1986:317.
235 De Beer 1986:317-318.

2.9.6 Lebowa

Lebowa (a former homeland for people belonging to the Northern Sotho tribe)[236] was situated in the old northern and north-eastern Transvaal. Among the inhabitants of this tribe it was regarded as necessity and not murder when one twin or a deformed child was killed.[237] Deformed children included a breech delivery or a baby whose upper front teeth appeared first. It was believed that such children would bring ill luck to the tribe if allowed to live.[238]

2.9.7 The Tswana

According to Schapera,[239] "[i]nfanticide was in the olden days generally practised in regard to children born feet first, or cutting their upper teeth first, and sometimes also in regard to twins." Such children were regarded as evil omens (*ditlhodi*) and had to be discarded to prevent them from bringing bad luck to their parents.[240] If parents committed infanticide in such a case, no action was taken against the parents, while in other cases of infanticide the parents could be found guilty of murder.[241]

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236 Stoffberg 1982:42.
237 Prinsloo 1983:174: Prinsloo 2007:735.
238 Myburgh 1985:69.
239 Schapera 1970:261. See also Myburgh 1985:69; Post 1887:287 and Van den Heever: 1984:243-244. See Krige and Krige 1947:218 and 321 for a description of a similar practice among the Lovedu.
240 Schapera 1970:261; Van den Heever 1984:243-244.
241 Myburgh 1985:69; Schapera 1970:261.

Schapera[242] mentions that infanticide still occurs occasionally but that the matter is not handed over to the authorities, but rather kept secret to avoid trouble, although the mother is punished within the tribe.

Sometimes mothers also committed infanticide with regard to a child born out of wedlock; if the mother was found guilty of this crime, her body was smeared with a mixture of medicines that would cause intense pain.[243]

2.10 Conclusion

Infanticide has been practised since time immemorial. In antiquity babies could be killed at the whim of the head of the household, whether the baby was healthy or deformed. Apart from infanticide as a means of population control,[244] deformed babies were also killed out of superstition. It should also be noted that girls were often not as much wanted as boys and were therefore often killed.[245]

At the time when the Roman-Dutch authorities were actively writing, a change in attitude can be noted: the killing of a healthy baby was regarded as murder, but a malformed baby was not raised, but put to

242 Schapera 1970:262.
243 Schapera 1970:261-262.
244 Wilkinson 1978:446.
245 Wilkinson 1978:449.

death. Although very scant information is available in the literature on infanticide among indigenous South African cultures, it seems that infanticide of one twin or of a deformed baby was practised—mostly out of superstition.

> *Over the centuries three Western institutions have in turn taken the lead to develop social policy aimed at limiting parental autonomy with respect to offspring: the first was religion; the second law and for the last hundred years, medicine has taken on the task*.[246]

The last two of these institutions, namely law and medicine, will be further investigated in this dissertation.

246 Silverman 1981:12.

CHAPTER 3

CLINICAL EVALUATION: OVERVIEW OF DISEASES OFTEN ENCOUNTERED IN PREMATURE AND CRITICALLY-ILL NEONATAL INFANTS

3.1 Introduction

Since this is not a medical exposition *per se*, the clinical aspects pertaining to premature and critically-ill neonatal babies will not be dealt with in depth in this chapter. Only a broad overview of some of the conditions with the highest rate of morbidity and mortality[1] will be discussed below.

3.2 Prematurity

According to the World Health Organisation (WHO) babies who are born before 37 weeks' gestation are called pre-term babies.[2] They mostly weigh less than 2500 g and are therefore also low birth weight babies.[3] With the advances in technology, medical treatment and neonatal care facilities, the gestational age at which a baby is regarded as viable has

1 According to Lubbe 2008:27, the difference between morbidity and mortality is that morbidity refers to illness rate, while mortality refers to death rate.
2 Johnston 1998:105; Kliegman ea (eds) 2007:701; Redshaw ea 1985:6. http://www.emedicine.com/ped/topic1889.htm
3 Johnston:1998:105; Kliegman ea (eds) 2007:701-702.

dropped to 25 weeks and even those between 23 and 24 weeks of gestational age and with a lower birth weight can now be saved.[4] The reason why a neonate of 25 weeks is deemed viable is as follows: During foetal development, the gas exchange portions (respiratory bronchi[5] and alveolar[6] ducts[7]) of the lungs usually develop between 20 and 24 weeks' gestational age.[8] This has to be followed by vascularisation of the gas exchange portions, which takes place rapidly between 22 and 28 weeks' gestational age.[9] Only once alveoli have been vascularised can gas exchange (and by implication, extra-uterine life) occur.[10] This is the reason why fetuses of less than 24–26 weeks' gestational age have limited to zero functionality in terms of gas exchange and are therefore not usually viable.[11] However, as it becomes possible to save more premature babies, the morbidity risk increases.[12] The morbidity that some premature infants may face are long-term problems such as cerebral palsy, neurological and motor delays,

4 Johnston 1998:105; Miller 2007:24.
5 Bronchi is the plural of bronchus. *Dorland's* 1985:192: "any of the larger air passages of the lungs, having an outer fibrous coat with irregularly placed plates of hyaline cartilage, an interlacing network of smooth muscle, and mucous membrane of columnar ciliated epithelial cells".
6 Alveolar is the adjective derived from alveolus. *Dorland's* 1985:53: "a general term used in anatomical nomenclature to designate a small saclike dilatation".
7 *Dorland's* 1985:406: "a passage with well-defined walls, especially a tube for the passage of excretions or secretions".
8 Merenstein and Gardner 2006:596.
9 Merenstein and Gardner 2006:596.
10 Merenstein and Gardner 2006:596.
11 Merenstein and Gardner 2006:596.
12 SANITSA August 2008: "Motivation for recognition of postbasic specialisation in neonatal nursing science by SANC." (Unpublished). See also Miller 2007:25.

learning, language and social problems, thermoregulatory difficulties, visual and auditory impairment, chronic lung diseases, nutritional deficits and poor growth.[13] Premature babies can be perfectly healthy and develop normally in body and mind, but they will probably need some form of specialised care immediately after birth and for a further period after birth.[14] However, the lower the gestational age when the baby is born, the higher the risk of a neurological handicap should the baby survive.[15]

A baby born before 37 weeks of gestation is considered to be premature, and a baby born between 35 and 37 weeks of gestation is considered to be moderately premature. A very premature baby is one born between 27 and 34 weeks of gestation, while an extremely premature baby is one born before 27 weeks of gestation.[16] Low birth weight (LBW) is the term used when the birth weight of a baby is between 1500 g and 2500 g.[17] Infants with a very low birth weight

13 SANITSA August 2008: "Motivation for recognition of postbasic specialisation in neonatal nursing science by SANC." (Unpublished). See also Miller 2007:25.
14 See Furdon http://www.emedicine.com/ped/topic1889.htm for details regarding the treatment of preterm infants.
15 Johnston 1998:105.
16 Lubbe 2008:26; Nuffield Council on Bioethics 2006:30.
17 Lubbe 2008:26.

(VLBW) weigh less than 1500 g at birth and those with an extremely low birth weight (ELBW) have a birth weight of less than 1000 g.[18]

The greater the prematurity and the more immature their organs are, the more these babies are at risk.[19] They have basic physiological needs that have to be met, such as nutrition, comfort, ventilation and maintenance of body temperature. The latter can be problematic, since they lose heat easily, they do not have enough subcutaneous fat and physical activity is low.[20] Preterm babies tend to bleed and bruise easily because their capillary walls are weak and clotting factors in their blood are reduced.[21] Cerebral palsy is a common long-term outcome associated with prematurity, resulting from intracranial haemorrhage in the period of 28 to 32 weeks' gestational age.[22] The neurological system of a premature baby is exceptionally vulnerable during this period because of the presence of the germinal[23] matrix.[24]

18 Lubbe 2008:26. See also Kliegman ea (eds) 2007:702; Nuffield Council on Bioethics 2006:30.
19 Johnston 1998:108-109.
20 Johnston 1998:109.
21 Johnston 1998:109.
22 Kliegman ea (eds) 2007:407-409; Verklan and Walden (eds) 2004:843-846.
23 *Dorland's* 1985:548: "pertaining to or of the nature of a germ cell or the primitive stage of development".
24 *Dorland's* 1985:781: "the intercellular substance of a tissue, as bone matrix or the tissue from which a structure develops, as hair or nail matrix". Kliegman ea (eds) 2007:407-409; Verklan and Walden (eds) 2004:843-846.

Premature babies often suffer from respiratory distress syndrome (also called hyaline membrane disease)[25] soon after birth, primarily as a result of the immaturity of their lungs.[26] It is a condition in which the air sacs cannot stay open owing to lack of surfactant in the lungs.[27] Chronic lung disease (also known as bronchopulmonary dysplasia (BDP)) is a common complication of mechanical ventilation in all preterm (and full-term) infants, but the risk tends to be higher for smaller and younger preterm infants.[28] They often suffer from breathing problems and need mechanical ventilation and supplementary oxygen.[29] BDP is characterised by progressive destruction of lung tissue and implies long-term morbidity.[30] Since their brains are immature, premature babies often suffer from apnoea,[31] which may be accompanied by hypoxia.[32] Premature infants commonly73 suffer from anaemia and may require a blood transfusion owing to the immaturity of their haematological

25 See the discussion of *In re O (a Minor) (Medical Treatment)* [1993] 2 FLR:149 in chapter 6 par 6.2.4.1. The premature baby in this case suffered from respiratory distress syndrome and her vital organs were at risk should she not receive an emergency blood transfusion. The Royal College of Paediatrics and Child Health published a document called, "Guidelines for Good Practice: *Management of Neonatal Respiratory Distress Syndrome*" (December 2000) in which they give recommendations, among others, regarding resuscitation, treatment with surfactant, and when CPAP (Continuous positive airway pressure) should be considered.

26 Kliegman ea (eds) 2007:731; Levene and Miall in Norman and Greer (eds) 2005:111-112; Lubbe 2008:193; Verklan and Walden (eds) 2004:488.

27 Lubbe 2008:193; Verklan and Walden (eds) 2004:488.

28 Kliegman ea (eds) 2007:737.

29 Kliegman ea (eds) 2007:737; Lubbe 2008:192.

30 Johnston 1998:139.

31 *Dorland's* 1985:100: "cessation of breathing".

32 *Dorland's* 1985:644: "reduction of oxygen supply to tissue below physiological levels despite adequate perfusion of the tissue by blood."

system.[33] Premature infants are very susceptible to infections as their immune systems are still immature.[34]

Neonates,[35] especially premature babies, often suffer from jaundice as a result of immaturity of the liver.[36] Neither the digestive function, nor the liver function, nor the renal function of a preterm infant is well developed.[37]

Necrotising enterocolitis (NEC) is a life-threatening intestinal disease that affects mainly premature infants.[38] It is characterised by areas of necrosis[39] of the intestines. Depending on the seriousness of the condition, surgery is often required.[40] Infants who recover from NEC often have to deal with morbidity.[41]

33 Gupta and Weindling in Norman and Greer (eds) 2005:280.
34 Johnston 1998:137; Kliegman ea (eds) 2007:755; Lubbe 2008:49. See *Re C (a Baby)* [1996] 2 FLR:43. This case is discussed in chapter 6 par 6.2.5.8. This case concerns a premature baby who was susceptible to infections and contracted meningitis.
35 *Dorland's* 1985:873: "a new-born infant".
36 Kliegman ea (eds) 2007:756-757; Lubbe 2008:44-45.
37 Johnston 1998:110.
38 Johnston 1998:136-137; Lubbe 2008:194; Gupta and Weindling in Norman and Greer (eds) 2005:278-280.
39 *Dorland's* 1985:871: "the sum of the morphological changes indicative of cell death and caused by the progressive degradative action of enzymes".
40 Johnston 1998:136-137.
41 Verklan and Walden (eds) 2004:669-673.

Retinopathy of prematurity (ROP) is an eye disease that often affects immature babies.[42] Normally maturation of the retina takes place during the last 12 weeks of full-term pregnancy, but in premature babies the retina is often not fully vascularised.[43] As a result of various extra-uterine[44] conditions abnormal new blood vessels may form that may cause scarring or detachment of the retina.[45] These children are more likely to develop nearsightedness and amblyopia[46] or blindness.[47]

Preterm babies are not always able to adapt well to extra-uterine life and this often results in morbidity or mortality, although prematurity is not the only cause of mortality and morbidity. Congenital malformations are other possible causes.

3.3 Congenital malformations

Congenital malformations will be discussed in the categories listed below:

42 Kliegman ea (eds) 2007:2598; Lubbe 2008:201-202.
43 *Dorland's* 1985:1438: "to supply with vessels".
44 *Dorland's* 1985:478: "situated or occurring outside the uterus".
45 Lubbe 2008:202.
46 *Dorland's* 1985:55: "dimness of vision without detectable organic lesion of the eye".
47 Kliegman ea (eds) 2007:2598-2600; Levene and Miall in Norman and Greer (eds) 2005:118-119,121; Lubbe 2008:202.

3.3.1 Central nervous system (CNS)

Congenital malformations of the central nervous system are often life-threatening and give rise to long-term morbidity.[48] Here the following conditions will be discussed as examples of CNS abnormalities: anencephaly,[49] spina bifida[50] with myeolomeningocele,[51] encephalocoele,[52] microcephaly[53] and spinal muscular atrophy.[54]

3.3.1.1 Anencephaly

This is a gross malformation where the forebrain is largely missing and the skull bones are partly absent, exposing the neural tissue.[55] The baby will probably be stillborn; if not, the baby will not survive beyond a few

48 According to Dr Carin Maree, Senior Lecturer, Department of Nursing Sciences, University of Pretoria, during a personal interview.

49 *Dorland's* 1985:72: "congenital absence of the cranial vault, with cerebral hemispheres completely missing or reduced to small masses attached to the base of the skull".

50 *Dorland's* 1985:1233: "a developmental anomaly characterised by defective closure of the bony encasement of the spinal cord, through which the cord and meninges may or may not protrude". In the Prins case discussed in chapter 7 paragraph 7.3.4, the baby who was euthanased by the physician, Prins, suffered from a severe form of spina bifida.

51 *Dorland's* 1985:859: "hernial protrusion of the cord and its meninges through a defect in the vertebral canal".

52 *Dorland's* 1985:437: "hernia of the brain, manifested by protrusion of brain substance through a congenital or traumatic opening of the skull".

53 *Dorland's* 1985:820: "abnormal smallness of the head, usually associated with mental retardation". Baby J suffered from microcephaly after sustaining severe head injuries when he was one month old. See *In re J (a Minor) (Child in care: Medical Treatment)* [1992] 3 WLR:507 and the discussion of this case in chapter 6 par 6.2.7.

54 *Dorland's* 1985:136: "a wasting away; a diminution in the size of a cell, tissue, organ or part".

55 Johnston 1998:213; Kliegman ea (eds) 2007:2447-2448; Verklan and Walden (eds) 2004:878.

hours or will die within a few days.[56] Comfort measures only should be provided.[57]

3.3.1.2 Microcephaly

The brain is underdeveloped and the head is small, the forehead slopes backwards—it is a neuronal[58] proliferation[59] defect which occurs between three and four months' gestational age.[60] Survival is highly likely, but with severe morbidity.[61]

3.3.1.3 Spina bifida with myelomeningocele

A myelomeningocele is the exposure of the internal surface of the spinal cord or the nerve roots where there is a midline defect in the spine.[62] The spinal cord and meninges[63] are exposed through the skin.[64] The majority of cases occur in the thoracolumbar,[65] lumbar,[66] and

56 Kliegman ea (eds) 2007:2447-2448.
57 Johnston 1998:213; Verklan and Walden (eds) 2004:828.
58 *Dorland's* 1985:888: "pertaining to a neuron or neurons".
59 *Dorland's* 1985:1074: "the reproduction or multiplication of similar forms, especially of cells and morbid cysts".
60 Johnston 1998:215-216; Kliegman ea (eds) 2007:2451-2452; Verklan and Walden (eds) 2004:828-829.
61 Johnston 1998:215; Verklan and Walden (eds) 2004:829.
62 Johnston 1998:214; Kliegman ea (eds) 2007:2444-2447; Verklan and Walden (eds) 2004:880.
63 *Dorland's* 1985:794: "the three membranes that envelop the brain and spinal cord: the dura mater, pia mater, and arachnoid".
64 Johnston 1998:214; Kliegman ea (eds) 2007:2445; Verklan and Walden (eds) 2004:880-881.
65 *Dorland's* 1985:1363: "pertaining to the thoracic and lumbar parts of the spine".
66 *Dorland's* 1985:759: The lumbus is "the part of the back between the thorax and the pelvis".

lumbosacral[67] regions.[68] There is almost always an exudation of fluid.[69] In about 80% of cases hydrocephalus[70] is associated with this condition.[71] The degree of paralysis depends on the site of the lesion: if it is below the first sacral vertebra, the infants can still learn to walk independently; if it is between the fourth and fifth lumbar vertebrae, the infant will be able to walk with crutches or braces; if the lesion is above the second lumbar vertebra, the infant may become dependent on a wheelchair.[72] It was suggested by Dr Lorber, an authority from Sheffield in England, that a distinction be drawn between neonates with a poor prognosis (that is, those where the lesion is high) and neonates likely to suffer lesser handicaps because the lesion is lower.[73] The former should not be subjected to treatment, while the latter should be receiving

67 *Dorland's* 1985:1166: The sacrum is "the triangular bone just below the lumbar vertebrae, formed usually by five fused vertebrae (sacral vertebrae that are wedged dorsally between the two hip bones." *Dorland's* 1985:759: Lumbosacral means "pertaining to the loins and the sacrum".

68 Verklan and Walden (eds) 2004:880-881.

69 Johnston 1998:214.

70 *Dorland's* 1985:622: "a condition marked by dilatation of the cerebral ventricles, most often occurring secondarily to obstruction of the cerebrospinal fluid pathways, and accompanied by an accumulation of cerebrospinal fluid within the skull; the fluid is usually under increased pressure, but occasionally may be normal or nearly so. It is typically characterized by enlargement of the head, prominence of the forehead, brain atrophy, mental deterioration, and convulsions, and may be congenital or acquired, and be of sudden onset, or be slowly progressive". See chapter 6 par 6.2.5.7 for a discussion of baby C (*In re C (a Minor) (Wardship: Medical Treatment)* [1989] 3 WLR 240) who was born with hydrocephaly and also a malformation of the brain and where the court had to decide whether treatment should be given or withheld.

71 Johnston 1998:214; Katzen in Kahn (ed) 1984:21; Kliegman ea (eds) 2007:2446.

72 Katzen in Kahn (ed) 1984:21; Kliegman ea (eds) 2007:2447; Verklan and Walden (eds) 2004:881.

73 Katzen in Kahn (ed) 1984:21;Weir 1984:43.

treatment as soon as possible.[74] It should, however, be noted that Dr Lorber's approach is controversial and not all health care professionals agree with this approach, mainly because of the associated ethical issues.[75] Morbidity is high in these cases and 80% of these patients die by eight weeks and 100% by ten months if surgery is not performed.[76] A fetus suffering from this disease may be legally aborted if the abnormality is detected during pregnancy.[77] However, the advancements in medical technological over the last two centuries also offered more hope to these infants.[78] There are now different options available: these infants can now be treated after birth, this condition can be prevented prenatally and intrauterine treatment can be given.[79] In conclusion it can be said that Dr Lorber's suggestion not to treat those in whose case surgery would be futile, has since been abandoned.[80]

3.3.1.4 Encephalocoele

Neural tissue is exposed through a skull deficit that mostly occurs at the occipital region or above the nose.[81] This condition is severely disabling

74 Katzen in Kahn (ed) 1984:21.
75 Katzen in Kahn (ed) 1984:21. For a discussion concerning this debate see Kuhse and Singer 1985:48-73; Reid 1977:16-19.
76 Verklan and Walden (eds) 2004:881.
77 Katzen in Kahn (ed) 1984:21.
78 Niazi and Walker in Özek ea (eds) 2008:67.
79 Niazi and Walker in Özek ea (eds) 2008:67,70.
80 Niazi and Walker in Özek ea (eds) 2008:70.
81 Johnston 1998:214; Kliegman ea (eds) 2007:2447; Verklan and Walden (eds) 2004:879.

and lethal; motor deficits and impaired intellectual functioning may occur.[82] Surgery is not always successful.[83]

3.3.1.5 Spinal muscular atrophy

The muscles of these patients waste away, although not always at the same rate; this condition will eventually result in paralysis.[84]

3.3.2 Cardiovascular system

Malformations of the cardiovascular system can also be life-threatening if they are not or cannot be treated early. The conditions that will be discussed as examples are: hypoplastic[85] left heart syndrome, transposition of the great arteries, pulmonary[86] atresia[87] and cardiomyopathy[88].

82 Johnston 1998:214; Kliegman ea (eds) 2007:2447; Verklan and Walden (eds) 2004:879-880.
83 Johnston 1998:214.
84 Johnston 1998:152; Kliegman ea (eds) 2007:2557-2559. See also *An NHS Trust v MB* [2006] EWHC 507 (Fam), which concerns a baby who was born with spinal muscular atrophy in its severest form. This case is discussed in chapter 6 par 6.2.5.9.
85 *Dorland's* 1985:642: "[Hypoplasia is] the incomplete development or underdevelopment of an organ or tissue".
86 *Dorland's* 1985:1094: "pertaining to the lungs".
87 *Dorland's* 1985:135: "congenital absence of or closure of a normal body orifice or tubular organ".
88 *Dorland's* 1985:222: "a general diagnostic term designating primary myocardial disease, often of obscure or unknown etiology".

3.3.2.1 Hypoplastic left heart syndrome

The development of the left ventricle and ascending aorta are incomplete.[89] This results in blood flow through the left side of the heart being obstructed.[90] Hypoplastic left heart syndrome is the most common fatal cardiac malformation during the perinatal period and can only be treated by open heart surgery.[91] Heart failure usually occurs within the first few days of the baby's life and death can occur within a week or two after birth.[92] Surgery is not always successful.[93]

3.3.2.2 Transposition of the great arteries

In this condition the placement of the pulmonary artery and the aorta are reversed.[94] This means that the aorta arises from the right ventricle and the pulmonary artery from the left ventricle.[95] The two circulations (pulmonary and systemic) are therefore completely separate as soon as the *ductus arteriosus*[96] has closed, which can be lethal.[97] The baby

89 Johnston 1998:208; Kliegman ea (eds) 2007:1926-1928; Verklan and Walden (eds) 2004:626.
90 Kliegman ea (eds) 2007:1926; Verklan and Walden (eds) 2004:626.
91 Johnston 1998:208; Kliegman ea (eds) 2007:1927-1928.
92 Johnston 1998:208.
93 Johnston 1998:208; Verklan and Walden (eds) 2004:627.
94 Johnston 1998:207; Kliegman ea (eds) 2007:1918; Verklan and Walden (eds) 2004:621.
95 Johnston 1998:207; Kliegman ea (eds) 2007:1918; Verklan and Walden (eds) 2004:621.
96 *Dorland's* 1985:407: "a fetal blood vessel connecting the pulmonary artery directly to the descending aorta".
97 Kliegman ea (eds) 2007:1918.

seems well in the first day or two, but then cyanosis[98] and respiratory difficulties become progressively worse.[99] The *ductus arteriosus* has to be kept patent until a surgical procedure can be done to create a cross-over of circulations.[100]

3.3.2.3 Pulmonary atresia

The pulmonary artery and the right ventricle are all hypoplastic[101] since the pulmonic valve is completely obstructed.[102] Often cyanosis is the only abnormality on clinical examination, and this increases within 24 hours.[103] Surgical valvotomy may be performed, but the prognosis is often poor.[104]

98 *Dorland's* 1985:333: "a bluish discoloration, applied especially to such discoloration of skin and mucous membranes due to excessive concentration of reduced hemoglobin in the blood".
99 Verklan and Walden (eds) 2004:621-623.
100 Johnston 1998:207; Kliegman ea (eds) 2007:1918; Verklan and Walden (eds) 2004:622.
101 *Dorland's* 1985:642: "incomplete development or underdevelopment of an organ or tissue".
102 Johnston 1998: 207; Kliegman ea (eds) 2007:1912; Verklan and Walden (eds) 2004:619.
103 Johnston 1998:207; Kliegman ea (eds) 2007:1912; Verklan and Walden (eds) 2004:619.
104 Johnston 1998:207; Kliegman ea (eds) 2007:1912-1913; Verklan and Walden (eds) 2004:620.

3.3.3 Gastrointestinal tract

3.3.3.1 Diaphragmatic[105] *hernia*[106]

This is a life-threatening congenital malformation where the intestines occupy the thoracic cavity through a defect in the diaphragm.[107] Emergency surgery to close the diaphragmatic defect may be life-saving.[108]

3.3.3.2 Exomphalos[109]

This condition is also known as omphalocele.[110] It is an abdominal hernia where the abdominal viscera protrude into the umbilical cord, usually covered by a peritoneal sac and with umbilical arteries and veins inserted into the apex of the defect.[111] Mortality depends on the severity of other defects associated with this condition.[112] In most cases immediate surgical repair is required to prevent infection or drying of the

105 *Dorland's* 1985:371: "the musculomembranous partition separating the abdominal and thoracic cavities". Therefore diaphramatic: "pertaining to of the nature of the diaphragm".
106 *Dorland's* 1985:601: "the protrusion of a loop or knuckle of an organ or tissue through an abnormal opening".
107 Johnston 1998:100,205; Kliegman ea (eds) 2007:746; Verklan and Walden (eds) 2004:322.
108 Johnston 1998:100,205; Kliegman ea (eds) 2007:747; Verklan and Walden (eds) 2004:118.
109 *Dorland's* 1985:475: “hernia of the abdominal viscera into the umbilical cord”.
110 Verklan and Walden (eds) 2004:650.
111 Johnston 1998:204; Kliegman ea (eds) 2007:776; Verklan and Walden (eds) 2004:651.
112 Verklan and Walden (eds) 2004:650.

tissue or rupture of the sac.[113] Morbidity is often associated with the condition.[114]

3.3.3.3 Gastroschisis[115]

Gastroschisis is the herniation of the abdominal contents through a large defect in the abdominal wall, usually to the right of the umbilicus; there is no membrane covering the intestines.[116] The protruding gut is usually inflamed from exposure to amniotic fluid and the baby is often born with peritonitis.[117] This condition is often associated with premature and small-for-dates babies.[118] Surgical repair is essential and morbidity is expected.[119]

3.3.3.4 Intestinal atresia[120]

Atresia can occur in any part of the intestines.[121] Duodenal atresia is a congenital obstruction of the duodenum.[122] Conditions associated with it

113 Kliegman ea (eds) 2007:776; Verklan and Walden (eds) 2004:652-654.
114 Verklan and Walden (eds) 2004:654.
115 *Dorland's* 1985:543: "a congenital fissure of the abdominal wall not involving the site of insertion of the umbilical cord, and usually accompanied by protrusion of the small and part of the large intestine".
116 Johnston 1998:204; Kliegman ea (eds) 2007:726; Verklan and Walden (eds) 2004:652.
117 Johnston 1998:204; Verklan and Walden (eds) 2004:651-652.
Dorland's 1985:994: "inflammation of the peritoneum".
118 Verklan and Walden (eds) 2004:652.
119 Verklan and Walden (eds) 2004:652.
120 *Dorland's* 1985:135: "a congenital absence or closure of a normal body orifice or tubular organ".
121 Kliegman ea (eds) 2007:1558.
122 Kliegman ea (eds) 2007:1559; Verklan and Walden (eds) 2004:659; Weir 1984:44.

are Down's Syndrome[123] and prematurity.[124] Initially it is not life-threatening, but unless it is surgically repaired it becomes lethal.[125]

3.3.4 Genito-urinary defects

3.3.4.1 Renal agenesis[126]

The absence of both kidneys leads to impaired fetal growth.[127] This condition is associated with Potter's Syndrome.[128] These babies are usually stillborn or die within hours or days after birth.[129]

3.3.4.2 Dysplastic[130] *or cystic kidneys*

Renal dysplasia appears in the form of cysts like grapelike clusters.[131] It commonly results in renal failure and death.[132]

123 See the discussion of Trisomy 21 par 3.3.5.3 below.
124 Kliegman ea (eds) 2007:1559; Verklan and Walden (eds) 2004:861. See also the discussion of *In re B (a Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421 in chapter 6 par 6.2.5.5, which concerns a baby girl born suffering from Down's Syndrome and who needed surgery to correct a duodenal obstruction.
125 Johnston 1998:201; Verklan and Walden (eds) 2004:659.
126 *Dorland's* 1985:39: Agenesis means "the absence of an organ". Renal agenesis, therefore, means the absence of kidneys.
127 Johnston 1998:210.
128 Johnston 1998:210; Kliegman ea (eds) 2007:2222-2223; Verklan and Walden (eds) 2004:805.
129 Verklan and Walden (eds) 2004:805.
130 *Dorland's* 1985:413: "abnormality of development".
131 Kliegman ea (eds) 2007:2222-2223; Verklan and Walden (eds) 2004:807.
132 Verklan and Walden (eds) 2004:807-808.

3.3.5 Chromosomal disorders[133]

3.3.5.1 Trisomy 13

Trisomy 13 is also known as Patau's Syndrome[134] and occurs when the thirteenth chromosome pair contains three chromosomes instead of two.[135] Most chromosomal disorders occur because of transfer of additional material, but a few disorders are the result of the loss of some material.[136] Trisomy 13 is characterised by cleft lip and palate, psychomotor defects, malformed ears, microphthalmia,[137] deformities of the scalp, hands, fingers and wrist, "rocker" feet, absent testes and renal abnormalities.[138] The mortality rate is high and 44% of cases die within the first month; 18% die within the first year and only 5% live longer than a year.[139] No treatment should be given, but only supportive care.[140]

133 Abnormalities in the chromosome number result in chromosomal disorders. See Kliegman ea (eds) 2007:506-513.
134 *Dorland's* 1985:1399: "the presence of an additional (third) chromosome of one type in an otherwise diploid cell". The baby in the Kadijk case suffered from Trisomy 13. This case is discussed in chapter 7 par 7.3.4.
135 Johnston 1998:221;Kliegman ea (eds) 2007:507; Weir 1984:45-46.
136 Kliegman ea (eds) 2007:506,510.
137 *Dorland's* 1985:822: "abnormal smallness in all dimensions of one or both eyes". Weir 1984:45-46.
138 Johnston 1998:221-222; Kliegman ea (eds) 2007:507-509; Verklan and Walden (eds) 2004:865.
139 Johnston 1998:222; Kliegman ea (eds) 2007:509; Verklan and Walden (eds) 2004:865; Weir 1984:45-46.
140 Verklan and Walden (eds) 2004:865.

3.3.5.2 Trisomy 18

This is also called Edward's Syndrome.[141] These infants are usually small for gestational age; their ears are low-set, their fingers are overlapping and ulnar[142]-deviated, and they have "rocker" feet.[143] The heart usually has a ventricular septal defect[144] with patent ductus arteriosus.[145] There is a 90% mortality rate associated with this condition and it is also accompanied by mental retardation.[146] Mortality is high and 30% die within two months, usually of heart failure.[147] Supportive care only should be given.[148]

3.3.5.3 Trisomy 21

This condition is commonly known as Down's Syndrome.[149] This is the most common chromosomal disorder that occurs in infants and it occurs in about 1 out of 600-800 births.[150] In 25% of cases the infant received an extra chromosome from the father.[151] Although younger mothers are

141 Johnston 1998:221; Kliegman ea (eds) 2007:507; Weir 1984:45.
142 *Dorland's* 1985:1418: "the inner and larger bone of the forearm, on the side opposite that of the thumb".
143 Johnston 1998:221; Kliegman ea (eds) 2007:507-510; Verklan and Walden (eds) 2004:863; Weir 1984:45.
144 *Dorland's* 1985:1449,1189: It is a defect of the dividing wall of one of the ventricles of the heart.
145 Verklan and Walden (eds) 2004:863. For an explanation of this term see also par 3.3.2.2.
146 Kliegman ea (eds) 2007:507; Verklan and Walden (eds) 2004:863; Weir 1984:45.
147 Verklan and Walden (eds) 2004:863.
148 Verklan and Walden (eds) 2004:863.
149 Kliegman ea (eds) 2007:507.
150 Kliegman ea (eds) 2007:507-508; Weir 1984:44.
151 Verklan and Walden (eds) 2004:861.

also at risk of giving birth to a baby with Down's Syndrome, the risk increases with advancing maternal age.[152] Babies born with Down's Syndrome have characteristic facial features, for example a flat face with eyes slanting upward, a short nose with a flat bridge, a protruding tongue, and square hands with short fingers.[153] This condition is associated with mental retardation.[154] They often suffer from congenital heart disease and duodenal atresia as well.[155] This syndrome is not fatal and these patients may live for up to 50 years of age.[156]

3.3.6 Metabolic and endocrine disorders

For successful transition to extrauterine life, it is essential to achieve metabolic control.[157] These disorders are usually associated with the absence of an enzyme or the abnormal secretion of a hormone.[158]

3.3.6.1 Hypothyroidism[159]

In hypothyroidism the thyroid gland fails to develop or is ectopic and does not produce enough thyroxine,[160]the chief function of which is to

152 Kliegman ea (eds) 2007:508; Verklan and Walden (eds) 2004:861; Weir 1984:44.
153 Kliegman ea (eds) 2007:507; Verklan and Walden (eds) 2004:861-863; Weir 1984:44.
154 Kliegman ea (eds) 2007:507; Verklan and Walden (eds) 2004:862; Weir 1984:45.
155 Kliegman ea (eds) 2007:507-508; Verklan and Walden (eds) 2004:862.
156 Kliegman ea (eds) 2007:508.
157 Verklan and Walden (eds) 2007:886.
158 Verklan and Walden(eds) 2007:886.
159 *Dorland's* 1985:644: "deficiency of thyroid activity […] In infants, severe hypothyroidism leads to cretinism."
160 Johnston 1998:222-223; Verklan and Walden (eds) 2004:705.

increase the rate of cell metabolism.[161] If congenital hypothyroidism is diagnosed early and treated early, mental retardation can be prevented, but lifelong treatment is necessary for normal growth and development.[162]

3.3.6.2 Galactosaemia[163]

The enzyme (galactose-1-phosphate uridyl-transferase) that converts galactose to glucose is absent; this results in infants being unable to digest lactose.[164] Galactose accumulates and this is extremely toxic to the brain, liver and kidneys.[165] Complications can be prevented by early diagnosis and lifelong treatment.[166]

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161 *Dorland's* 1985:803: "the sum of all the physical and chemical processes by which living organized substance is produced and maintained, and also the transformation by which energy is made available for the uses of the organism (catabolism)".

162 Kliegman ea (eds) 2007:2324-2325; Verklan and Walden (eds) 2004:710.

163 *Dorland's* 1985:534: "a hereditary disorder of galactose metabolism occurring in two forms. The classic form, due to deficiency of the enzyme galactose-1-phosphate uridyl transferase, is marked by accumulation of galactose 1-phosphate and galactose in the tissues and by hepatomegaly, cataracts, and mental retardation, with vomiting, diarrhoea, jaundice, poor weight gain, and malnutrition in early infancy. The second form, due to galactokinase deficiency, is marked only by cataract formation and accumulation of galactose in the blood and tissues. Both are transmitted as autosomal recessive traits".

164 Johnston 1998:223; Kliegman ea (eds) 2007:609-610; Verklan and Walden (eds) 2004:889.

165 Johnston 1998:223; Kliegman ea (eds) 2007:610; Verklan and Walden (eds) 2004:889.

166 Johnston 1998:223; Kliegman ea (eds) 2007:610; Verklan and Walden (eds) 2004:889.

3.3.7 Congenital infections

Congenital infections (infections that are acquired before birth, i.e. *in utero*) include rubella (commonly known as German measles) syndrome[167] and congenital HIV/aids.[168] If rubella is contracted in early pregnancy, it can cause serious damage to the fetus.[169] It is associated with malformation of the eyes, the brain and the heart and with sensorineural deafness.[170] If a mother has HIV/aids the baby could also be infected, either across the placenta or through contact with blood during delivery.[171] The risk for mortality is high in infants infected with HIV/aids and they often die within the first year or two of life.[172]

3.3.8 Substance abuse

3.3.8.1 Cigarette smoking

The babies of mothers who smoked during pregnancy suffer from intrauterine growth retardation: their birth weight is low, there is a decrease in head circumference and the length of the baby.[173] In addition to a small increase in congenital malformations there is also an

167 *Dorland's* 1985:1297: "a congenital syndrome due to intrauterine rubella infection".
168 Johnston 1998:169.
169 Johnston 1998:169.
170 Johnston 1998:169.
171 Johnston 1998:171.
172 Kliegman ea (eds) 2007:1427.
173 Johnston 1998:13; Verklan and Walden (eds) 2004:48.

increased risk of sudden infant death syndrome (SIDS).[174] The more the mother smokes, the higher the risk to the infant.[175] Smoking could also increase the possibility that the baby will be premature.[176]

3.3.8.2 Alcohol

The use of alcohol during pregnancy can result in fetal alcohol syndrome (FAS), which carries a high risk of mental retardation and has an effect on the growth of the baby.[177] It can also lead to congenital defects of the heart or kidneys, or the senses of hearing and sight.[178] These babies have recognisable faces, which include a short palpebral[179] fissure,[180] flat midface, smooth philtrum[181] and thin vermillion of the upper lip.[182]

3.3.8.3 Cocaine

The abuse of cocaine by pregnant mothers can lead to various disorders: congenital defects, intrauterine growth retardation and

174 Verklan and Walden (eds) 2004:48.
175 Johnston 1998:13.
176 Johnston 1998:13.
177 Verklan and Walden (eds) 2004:50.
178 Verklan and Walden (eds) 2004:50.
179 *Dorland's* 1985:956: "eyelid, either of the two movable folds that protect the anterior surface of the eyeball".
180 *Dorland's* 1985:505: "any cleft or groove, normal or otherwise".
181 *Dorland's* 1985:1006: "the vertical groove in the median portion of the upper lip".
182 Johnston 1998:13.

hypertonia.[183] The cognitive development of the baby is affected and impairment to speech and language can also occur.[184]

3.3.8.4 Marijuana (dagga)

The abuse of marijuana can lead to congenital anomalies, intrauterine growth retardation and short- and long-term neurobehavioural morbidity.[185]

3.3.8.5 Opiates[186]

The babies of mothers who abuse opiates may suffer from conditions that include hypoxia, intrauterine growth retardation, congenital infections, increased risk of SIDS and neonatal abstinence syndrome (NAS).[187]

3.4 Conclusion

In conclusion, it should be said that the mortality and the morbidity of preterm infants and critically-ill neonates have a tremendous effect, not only on the family, but also on the community and the health sector.[188]

183 *Dorland's* 1985:636: "a condition of excessive tone of the skeletal muscles; increased resistance of muscle to passive stretching".
184 Verklan and Walden (eds) 2004:53.
185 Verklan and Walden (eds) 2004:96.
186 *Dorland's* 1985:930: "a remedy containing or derived from opium; also any drug that induces sleep".
187 Verklan and Walden (eds) 2004:58.
188 Miller 2007:25.

There are long-term as well as short-term financial implications for the family, the community (albeit indirectly) and the government coffers when a baby is born preterm or is critically-ill, since medical fees, especially ICU (Intensive Care Unit) fees, are exorbitant and moreover such an infant is likely to need specialised care for the rest of his or her life.[189] Since the treatment and hospitalisation of these infants are expensive, this also has a negative effect on the health sector.[190] Furthermore, it is traumatic for a family if a baby cannot be saved and dies. The individual, social and economic aspects of dealing with a preterm infant or critically-ill neonate will be further investigated in this study and possible solutions will be suggested.

189 Miller 2007:25.
190 This will be dealt with more detail in chapter 5.

CHAPTER 4

ETHICAL QUESTIONS SURROUNDING THE TREATMENT OF PRETERM INFANTS AND CRITICALLY-ILL NEONATES

4.1 Introduction

In this study so far, the historical aspects pertaining to infanticide received attention. Special attention was also given to the views of Roman scholars, as well as those of later scholars, such as the Roman-Dutch authors. Clinical aspects were also discussed and a range of illnesses that occur frequently in preterm and critically-ill neonates were dealt with. Next it is appropriate to scrutinise the ethical considerations that guide health care professionals regarding this group of infants. These principles are generally applied in decision making, but not always with due regard for the principles or the appropriateness of the selected principles.

Before considering the biomedical ethics pertaining to preterm babies and critically-ill neonates, it is necessary to discuss ethics in general. There are various definitions of ethics. According to Strauss,[1] "ethics can be defined as the science of the rules of moral conduct which should be followed because they are good in themselves. Ethics involves the

1 Strauss 1987:21.

rational study of preferences; therefore it provides a basis for the making of value judgments." The standard definition of ethics is the following: "the philosophical study of morality".[2] Ethics guides our decision-making and leads us to make the best decision in a particular circumstance.[3]

Medical technology, skills and expertise have advanced to such an extent that more babies, including extremely preterm infants and critically-ill neonates, survive, albeit with long-term morbidity.[4] These medical advances have, however, made it increasingly necessary to consider and develop the biomedical ethics pertaining to this vulnerable group. Biomedical ethics provides a theoretical framework within which health care professionals should make decisions and act.[5] Although biomedical ethics cannot provide all the answers in terms of what is right and what is wrong in each case, it nevertheless lays down the principles on which decision making should be based.[6] Nowadays decisions regarding the treatment or non-treatment of critically-ill neonates are more complicated than they were in most ancient cultures,

2 Audi (ed) 1999:284.
3 Bryant ea 2005:18.
4 See also Nel 1996:1.
5 Campbell ea 2005:14.
6 Bryant ea 2005:18.

when a deformed or unwanted child was simply killed. Even during the time when the Roman-Dutch authors[7] were active, it was an acceptable practice to kill a deformed baby. There is no question that the chances of survival of preterm infants, especially extremely preterm infants and critically-ill infants, would have been very slim in ancient times in view of the lack of medical expertise.

The ethical theories that can help us to draw the line between what is good and what is not, between which actions are morally appropriate and which are not, will be dealt with below.

The principal ethical theories, namely deontology, utilitarianism and virtue ethics, will be discussed. This discussion will be followed by an exposition of the four principles of biomedical ethics, namely beneficence, non-maleficence, autonomy and justice. The chapter will conclude with a discussion of the "sanctity of life" *versus* "quality of life" principles from an ethical perspective.

7 See chapter 2 par 2.6.

4.2 Ethical theories

4.2.1 Deontology

Deontology as an ethical theory stands in complete contrast to consequentialism.[8] Deontology is a duty-based approach to ethics.[9] The followers of this philosophical approach hold that fundamental duties and obligations in medical care should not be breached, irrespective of the consequences.[10]

Kant[11] (1724-1804) is the leading exponent of deontology.[12] According to Kant, everyone should be treated as an end—no one should be treated merely as a means to an end.[13] In other words, a person should not be used merely to help others.[14] In Kantian philosophy human dignity is considered to be that which gives a person intrinsic value.[15] The notion of personhood is a keynote in Kant's philosophy, which means that one

8 Fletcher ea 1995:11.
9 See also Bryant ea 2005:23.
10 Miller 2007:54; NCOB: 2006:9.
11 Bryant ea 2005:22. Kant's works include *Fundamental Principles of the Metaphysics of Morals*. Liberal Arts Press, New York, 1949; *Analytic of the Beautiful: From the Critique of Judgment, with Excerpts from Anthropology from a Pragmatic Viewpoint*. Bobbs-Merrill, New York; *Groundwork of the metaphysics of morals*. 1953, Hutchinson, London.
12 Dhai ea in Dhai and McQuoid-Mason 2011:9; Herring 2006:14; Van Niekerk in Moodley (ed) 2011:25. See also Slabbert 2010:85-87.
13 Bryant ea 22; Herring 2006:14. See also Currie and De Waal 2005:273 fn 5.
14 Herring 2006:14.
15 Currie and De Waal 2005:273.

should not treat people in a way that is contrary to their wishes and that more emphasis should be placed on obligations than on rights.[16]

While Kant places more emphasis on obligations than on rights, this way of thinking is in line with many "current concepts of human rights".[17] "A special obligation is created by a specific relationship, and the obligation is limited to people in this relationship. Parents have special obligations to their children, and physicians to their patients, such as sick preterm infants."[18] In the case of preterm infants and critically-ill neonates, their parents have to make decisions on their behalf and health care professionals have to provide medical treatment that is both effective and available, but at the same time respect the decisions of the surrogate decision makers.[19] The autonomy of the decision makers is restricted, because they also have a duty not to harm the child.[20] Miller notes that the "strengths of deontology are that it is consistent and takes account of special obligations and individual justices".[21] He also notes that the "weaknesses are that there are no real rational justifications for the rules; there may be conflicting duties and obligations; it is not

16 Herring 2006:15.
17 Herring 2006:15.
18 Miller 2007:54.
19 Miller 2007:54.
20 Miller 2007:54.
21 Miller 2007:54. See also Van Niekerk in Moodley (ed) 2011:27-28.

situational; and it is not necessarily benevolent as it is indifferent to the consequences of an action."[22]

4.2.2 Utilitarianism

The classical origins of utilitarianism[23] are found in the works of David Hume (1711–1776), Jeremy Bentham (1748–1832) and John Stuart Mill (1806–1873).[24] Broadly speaking, utilitarianism determines whether an action is good or bad by its outcomes or consequences.[25] A course of action is regarded as morally right if its outcomes or consequences lead to overall benefit, human happiness and usefulness.[26] The extent to which the consequences are good or bad can be determined by weighing up all the consequences of each alternative course of action.[27] The scales will tip in favour of the course of action that produces "the greatest good for the greatest number".[28] The problem with this approach is that the idea of what exactly "maximum happiness" is will differ from person to person.[29] Utilitarianism is open to the criticism that

22 Miller 2007:55. See also Van Niekerk in Moodley (ed) 2011:28-29.
23 Utilitarianism is also known as a consequentialist or teleological approach/theory. See Beauchamp and Childress 1979:20.
24 Beauchamp and Childress 1979:20; Miller 2007:55.
25 Beauchamp and Childress 1979:20-21; Herring 2006:12; NCOB 2006:9; Slabbert 2010:87-88; Steinbock (ed) 2007:17.
26 Bryant ea 2005:23; Childress in Steinbock 2007:17-18.
27 Herring 2006:12; Holland 2003:205; Miller 2007:55.
28 Beauchamp and Childress 1979:21; Campbell, Gillett and Jones 2005:5; Herring 2006:12,17; Holland 2003:205; Miller 2007:55; NCOB 2006:9; Childress in Steinbock (ed) 2007:17-18.
29 Beauchamp and Childress 1979:23-24.

there are other things, besides happiness, that should be taken into consideration, namely virtue, love, knowledge and truth.[30]

In neonatal intensive care, this would mean that the adherents of this theory would assess decisions and policies in critical care according to the predicted outcomes for most neonates.[31] Where parties cannot agree on what would produce the maximum happiness or pleasure for an extreme preterm infant or critically-ill neonate, the court will have to be approached to decide whether an infant who is seriously ill should be treated.[32] The court might then decide that it would be better for such a baby to die rather than live a life of pain and suffering,[33] which would also have a negative impact on the quality of life of the infant.[34]

Miller points out the positive aspects of utilitarianism, namely that it is rational, situational and benevolent.[35] Utilitarianism has also been subject to criticism, namely that it puts too much faith in predictability; it does not account for incommensurable values or special obligations; it is inconsistent, and it has no concern for justice.[36] According to Herring,[37]

30 Fletcher ea 1995:10.
31 Beauchamp and Childress 1979:20; NCOB 2006:9.
32 Herring 2006:12.
33 Herring 2006:12.
34 A more detailed discussion on "quality of life" follows in par 4.4.
35 Miller 2007:56.
36 Miller 2007:57.
37 Herring 2006:12.

the question can be posed whether pleasure is all there is to life. Herring[38] also points out that different people experience pleasure differently. Further, utilitarianism might produce a result that we instinctively feel is wrong.[39]

In practice the application of this method would mean that a child born with Down's Syndrome[40] would be excluded from virtually all health care services.[41] These children often suffer from physical disabilities as well, which would necessitate the expenditure of considerable resources on them, but because they are unable to make an equal contribution to society, they would be excluded from most health care services.[42] This way of thinking does not take cognisance of the fact that Down's Syndrome patients are capable of purposeful activity, enjoyment and meaningful interpersonal relationships and can lead a more or less normal life.[43] Their lives are far more meaningful than the lives of those who are permanently comatose, or for whom there is no hope of recovery, like anencephalics (babies who have no brain above the cerebral cortex).[44]

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38 Herring 2006:12.
39 Herring 2006:13.
40 For a discussion see chapter 3 par 3.3.5.3 above.
41 Buchanan in Veatch (ed) 1997:340.
42 Buchanan in Veatch (ed) 1997:340.
43 Buchanan in Veatch (ed) 1997:341.
44 Buchanan in Veatch (ed) 1997:341. See also chapter 3 par 3.3.1.1 for an explanation of this term.

From the perspective of the neonate one might argue that death would be better than a life filled with pain and suffering, yet from the neonate's perspective these are two incommensurable states since the neonate has not had any life experience. From the perspective of the parents it might be better to live their lives without a seriously ill neonate, who will need specialised and expensive medical care.[45]

In 1991 the Priorities in Perinatal Care Conference in South Africa adopted a policy that babies weighing less than 1000 g were not to be treated in public hospital NICUs.[46] Since the adoption of this policy surfactant therapy was introduced. This has significantly improved the survival rates of babies weighing between 855 g and 1000 g who are admitted to NICUs.[47] The baby of a mother who attended an antenatal clinic at the hospital will automatically be admitted to a NICU if the baby weighs more than 999 g and/or is of a gestational age of at least 28 weeks.[48] If a baby's mother did not attend an antenatal clinic at the hospital, the baby has to weigh more than 1200 g or have a gestational age of at least 30 weeks before he or she will be admitted to NICU.[49] Studies have indicated that decisions regarding the aggressiveness of

45 See also Miller 2007:55-56.
46 Pieper and Hesseling 2007:58.
47 Pieper and Hesseling 2007:58.
48 Pieper and Hesseling 2007:59.
49 Pieper and Hesseling 2007:59.

treatment of premature babies should be based not only on birth weight and gestational age, but on other factors as well, such as the gender and income of the parents.[50]

The principle of utility should not be applied in isolation, but should be considered in conjunction with the principles of autonomy, non-maleficence, beneficence and justice.[51]

4.2.2.1 Designer babies/Saviour siblings

So-called "designer babies" (referred to in England as "Saviour Siblings")[52] have raised ethical questions, namely whether it is morally defensible to conceive a baby for the purpose of its becoming a donor for a sibling. In 2000 the Nash family from Colorado, California, caused an outcry when they conceived a baby, Adam, by way of genetic manipulation to ensure that he would be a suitable donor for his sister.[53] Adam's sister, Molly, suffered from Fanconi's anaemia[54] and the only cure was a bone marrow transplant.[55] A few years later, a case known

50 Pieper and Hesseling 2007:60.
51 Beauchamp and Childress 1979:144.
52 Madanamoothoo 2011:295.
53 Madanamoothoo 2011:294.
54 *Dorland's* 1985:1291. Also known as Fanconi's Syndrome: "a rare hereditary disorder, transmitted in a recessive manner and having a poor prognosis, characterized by pancytopenia, hypoplasia of the bone marrow, and patchy brown discoloration of the skin due to the deposition of melanin, and associated with multiple congenital anomalies of the musculoskeletal and genitourinary systems."
55 Madanamoothoo 2011:296.

as the *Hashmi* case[56] sparked controversy in England.[57] The Hashmi family of Leeds faced a similar dilemma to that of the Nash family: Their son Zain suffered from a rare genetic blood disease, beta-thalassemia.[58] The only means of saving his life was a bone marrow transplant.[59] They obtained permission from the health authorities to select an embryo that would match that of Zain.[60]

Section 11 Schedule 2 paragraph 3(1)(d) of the Human Fertilization and Embryology Act (HFE Act) 2008,[61] which applies to England and Wales, Scotland and Northern Ireland, now legalises the practice of saviour siblings.[62] Madanamoothoo[63] points out that the saviour sibling technique "may cause a concern for utilitarian sliding since the embryo in this practice is selected on genetic criteria (human leukocyte antigen

56 Reported as *R (On the Application of Josephine Quintavalle on Behalf of CORE v HFEA [2005] UKHL* 28).
57 Madanamoothoo 2011:296.
58 Madanamoothoo 2011:296. *Dorland's* 1985:1353: "a heterogeneous group of hereditary haemolytic anemias which have in common a decreased rate of synthesis of one or more haemoglobin polypeptide chains and are classified according to the chain involved (α, β, δ); the two major categories are α- and β-thalassemia. It is manifested in homozygotes by profound anemia or death in utero, and in heterozygotes by relatively mild red cell anomalies."
59 Madanamoothoo 2011:296.
60 Madanamoothoo 2011:296. See also "Boetie 'ontwerp' om siek suster se lewe te red" *Beeld* 5 October 2000.
61 "[I]n a case where a person ("the sibling") who is the child of the persons whose gametes are used to bring about the creation of the embryo (or of either of those persons) suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child, establishing whether the tissue of any resulting child would be compatible with that of the sibling"
62 Madanamoothoo 2011:296.
63 Madanamoothoo 2011:300.

[HLA system]),[64] to save the life of a child while the saviour child once born will not have any benefit." He comes to the conclusion that this controversial technique is not morally defensible.[65] Moreover, Madanamoothoo[66] is also of the opinion that this practice might be in conflict with the child's best interests standard, which is guaranteed in the United Nations Convention on the Rights of the Child.

4.2.3 Virtue ethics

Virtue ethics is not a new way of thinking, but dates back to the Greek philosophers Socrates, Aristotle and Plato.[67] It was revived in recent years in reaction to inadequacies in the deontological and utilitarian approaches.[68] In essence this approach postulates that a person's character, and not the consequences of a particular action, is the important factor that motivates his or her decision making.[69] Virtues are good habits such as benevolence, honesty, justice, truthfulness,

64 *Dorland's* 1985:90: "[Antigens] are important in cross-matching procedures and are partially responsible for the rejection of transplanted tissues when donor and recipient HLA antigens do not match."
65 Madanamoothoo 2011:300.
66 Madanamoothoo 2011:300.
67 Bryant ea 2005:29. See also Childress in Steinbock (ed) 2007:34; Herring 2006:30; Slabbert 2010:88-89.
68 Childress in Steinbock (ed) 2007:34.
69 Beauchamp and Childress 1979:233-243; Bryant ea 2005:29; Campbell ea 2005:8; NCOB 2006:9.

empathy, knowledge, friendliness, wisdom, respect for others and compassion, which guide human nature towards morally good actions.[70]

According to some of its critics, this approach is problematic, since in our diverse society conceptions of what is meant by "virtuous" differ from one culture to another.[71]

In terms of virtue ethics, the character of the neonate's parents and the health care professionals are important, because this will guide their decision making regarding treatment that will be in the best interests of the preterm baby or ill neonate.[72] The best interests of the child standard is the standard that is used whenever medical decisions regarding medical treatment have to be made on behalf of children, especially neonates and people who cannot decide for themselves.[73] It entails that the immediate and long-term interests of the incompetent patient should be taken into consideration.[74] Subsequently the benefits and burdens of the treatment should be weighed to determine whether the burdens outweigh the benefits.[75] This is exactly the test the court applied in the

70 Herring 2006:30-31. See also Campbell ea 2005:8.
71 Campbell, Gillett and Jones 2005:8-9, Van Niekerk in Moodley (ed) 2011:32.
72 NCOB 2006:9. See also Campbell ea 2005:8.
73 Kopelman in Perkin ea (eds) 2008:42.
74 Kopelman in Perkin ea (eds) 2008:42.
75 Kopelman in Perkin ea (eds) 2008:42.

case of *MB.*[76] The court balanced the benefits and burdens of continued treatment and actually drew up a list of the benefits and burdens of treatment. Even though the burdens by far outweighed the benefits of continued treatment, the court nevertheless came to the conclusion that it was not at that particular stage in the best interests of the child to withdraw treatment.[77] Kopelman[78] observes that the benefits of a long and healthy life outweighs the burdens of enduring intense pain for a short time.

4.3 Principles of biomedical ethics

Beauchamp and Childress recognise four principles of biomedical ethics, namely beneficence, non-maleficence, autonomy and justice.[79] These four principles are of equal importance, although autonomy is widely regarded as the primary principle.[80] Autonomy will therefore be discussed first.

76 An NHS Trust v MB [2006] EWHC (Fam).
77 See chapter 6 par 6.2.5.9 for a discussion of this case.
78 Kopelman in Perkin ea (eds) 2008:42.
79 Herring 2006:22. Childress in Veatch (ed) 1997:33 recognises beneficence, contract-keeping, autonomy, honesty, avoiding killing and justice.
80 Herring 2006:22-23.

4.3.1 Autonomy

Autonomy (also called respect for persons[81]) is the freedom of the individual to make his or her own decisions.[82] It entails that the doctor or health care professional must respect the final decision of the competent individual regarding his or her medical treatment or non-treatment once the patient has been given all the relevant information.[83] This is a well-established principle in medical law as almost a century ago it was held by the court that a person has absolute security of the person and that the law protects this security.[84]

While beneficence[85] imposes moral obligations on physicians, "the autonomy model takes the *values and beliefs of the patient* to be the primary moral consideration in determining the physician's moral responsibilities in patient care …"[86] It is possible that the principle of beneficence may conflict with the autonomy principle.[87] This happens when the patient's best interests, as seen from the perspective of the patient himself or herself, are in conflict with the patient's best interests

81 Childress in Veatch (ed) 1997:33.
82 Brazier and Cave 2007:52; Moodley in Moodley (ed) 2011:42; Slabbert 2010:95.
83 Beauchamp and Childress 1979:76; Beauchamp and McCullough 1984:14,44; Bryant ea 2005:29; Carstens and Pearmain 2007:879; Strauss 1991:4; Childress in Veatch (ed) 1997:33; Moodley in Moodley (ed) 2011:42.
84 *Stoffberg v Elliott* 1923 CPD 148. See also Carstens and Pearmain 2007:202, 500,879; Strauss 1991:31.
85 See the discussion on "beneficence" in par 4.3.3.
86 Beauchamp and Childress 1979:56; Beauchamp and McCullough 1984:42.
87 Beauchamp and Childress 1979:153; Beauchamp and McCullough 1984:23.

from the perspective of the physician.[88] Where there is conflict between the physician's view of the appropriate course of action[89] in a particular case and the patient's view on the matter, the physician has to respect the patient's right to self-determination and his or her right to make his or her own decisions regarding his or her fate.[90] Herring expresses the opinion that a patient cannot decide which medical treatment should be given,[91] but that a patient should decide on medical treatment together with a health care professional.[92]

Whenever there is conflict between the different principles, respect for autonomy is a *prima facie* principle and should therefore be the overriding principle.[93] When deciding on a particular course of action, the physician should ensure that the best interests of the patient are promoted.[94] The essence of the right to autonomy is that one cannot impose treatment on a patient unless it is necessary to prevent harm to others[95] (for example in the case of contagious diseases). The principle of autonomy is intertwined with the right to bodily integrity,[96] which

88 Beauchamp and McCullough 1984:50.
89 Herring 2006:20.
90 Beauchamp and McCullough 1984:42.
91 Herring 2006:23.
92 Herring 2006:20.
93 Beauchamp and McCullough 1984:15,42.
94 Beauchamp and McCullough 1984:20.
95 Herring 2006:23.
96 Section 12(2) of the Constitution of the Republic of South Africa, 1996. "Everyone has the right to bodily and psychological integrity"…

means that everyone is the master of his or her own fate and has the right not to have something done to his or her body without his or her consent, even if the decision to forego treatment will lead to death.[97] The principle of autonomy carries more weight than the health or life of an individual.[98] If a doctor or health care professional does not respect the autonomy of his or her patient and the patient is subjected to medical treatment, such as surgery, against his or her wishes, this would constitute assault.[99] If a patient relies on his or her autonomy and refuses to undergo treatment, this would conflict with the doctor's need to do good and prevent harm, which is the principle of beneficence.[100]

The principle of autonomy applies exclusively to persons who are capable of acting autonomously, and it cannot apply in the case of preterm infants and neonates who are non-autonomous. In this case decisions regarding treatment would have to be made by surrogate decision makers, like the parents or guardians, who have a special relationship with the child.[101] Since parents' or surrogate decision makers' decisions may be influenced by different factors, such as their own prejudices, emotional, social and economic pressures, they should

97 Strauss 1991:19.
98 Strauss 1991:31.
99 Strauss 1991:31. See also *Stoffberg v Elliott* 1923 CPD 148.
100 Moodley in Moodley (ed) 2011:45.
101 Beauchamp and Childress 1979:56-57,60,127; Beauchamp and McCullough 1984:137-138; Miller 2007:54,59.

only come to a decision after careful consultation with all relevant role-players.[102]

The autonomy of parents is restricted: They have a negative duty not to harm their child, and they cannot take decisions regarding the treatment or non-treatment of their children without considering the best interests of their child from the child's perspective.[103] This point was proved in *Hay v B and Others*.[104] In this case the respondents, the parents of Baby R, opposed an urgent application by the paediatrician, Dr Hay, to administer a blood transfusion in an attempt to save the life of the said baby. The respondents opposed the application on the basis that it was against their religious beliefs, although they were not Jehovah's Witnesses; they were also concerned about the risk of infection.[105] The court held that the child's best interests were of paramount importance in all matters concerning the child[106] and that the baby's right to life outweighed the parents' religious beliefs.[107] In cases such as the ones

102 See also Miller 2007:60.
103 Section 28 of the Children's Act 38 of 2005. Section 28(4)*(a)* reads as follows: "When considering such application the court must take into account the best interests of the child." See also Beauchamp and McCullough 1984:138; Miller 2007:54,59.
104 *Hay v B* 2003 (3) SA 492 (W).
105 *Hay v B* 2003 (3) SA 492:494.
106 Section 28(2) Constitution of the Republic of South Africa, 1996, which reads as follows:
"A child's best interests are of paramount importance in every matter concerning the child."
107 *Hay v B* 2003 (3) SA 492 pp 495-496. See also Kassan and Mahery in Boezaart (ed) 2009:218 and Malherbe in Boezaart (ed) 2009:441.

described above, where infants are at the centre of the decisions to be taken, the principle of autonomy cannot be followed and the principle of beneficence must be applied.[108]

The principle that parents may not refuse medical treatment or surgery for their children on the grounds of their religious beliefs has now been enacted in section 129(10)[109] of the Children's Act.[110] This means that there will be no further cases similar to that of *Hay v B*.[111] The principle of autonomy is "a fundamental ethical principle underlying informed consent"[112] and since preterm infants and neonates are not autonomous and cannot give informed consent, this concept will not be further explored in this thesis.

4.3.2 Non-maleficence

This principle implies that one should avoid inflicting harm on others (*primum non nocere*); one patient should not be harmed in order to help

108 Beauchamp and McCullough 1984:137.
109 "No parent, guardian, or care-giver of a child may refuse to assist a child in terms of subsection (3) or withhold consent in terms of subsections (4) and (5) by reason only of religions or other beliefs. Unless that parent or guardian can show that there is a medically accepted alternative choice to the medical treatment or surgical operation concerned."
110 Act 38 of 2005. See also Davel and Skelton (eds) 2007:7-36.
111 2003 (3) SA 492.
112 McQuoid-Mason and Dhai in Dhai and McQuoid-Mason 2011:70.

another.[113] This includes both intentional harm and the risk of harm.[114] The principle not to do harm is one of the ethical standards that are included in the classical version of the Hippocratic Oath: "I will keep them from harm and injustice."[115]

Brazier and Cave[116] point out that the principle of non-maleficence is not absolute, since medicine often involves doing harm, for example when surgery is performed. One example which illustrates this point is that of the conjoined twins.[117] Surgery to separate them would mean doing good to Mary, since she would survive, but doing harm to Jodie, since she would certainly die.[118]

Beneficence, which means that "practitioners should act in the best interests of patients"[119] and non-maleficence, which means that "practitioners should not harm or act against the best interest of patients",[120] should be weighed up against each other:[121] In instances

113 Beauchamp and Childress 1979:97; Herring 2006:24; Holland 2003:123. See also Bryant, ea 2005:29 and Campbell, ea 2005:12.
114 Beauchamp and Childress 1979:99.
115 http://www.pbs.org/wghb/nova/doctors/oath_classical.html and http://www.nlm.nih.gov/hmd/greek/greek_oath.html
116 Brazier and Cave 2007:54.
117 *In re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480. For a discussion of this case, see par 4.4, as well as chapter 6 paras 6.2.4.2, 6.2.5.1 and 6.2.5.6.
118 Brazier and Cave 2007:54.
119 Dhai and Etheredge in Dhai and McQuoid-Mason 2011:31.
120 Dhai and Etheredge in Dhai and McQuoid-Mason 2011:31.
121 Beauchamp and Childress 1979:143.

where treatment would offer no benefit, but would only inflict harm and suffering, and death is unavoidable, it would be better to discontinue treatment.[122] A physician is under no obligation to continue with treatment that is not beneficial to a patient.[123] The *Bland*[124] case confirmed that doctors and health care professionals do not have to provide futile treatment and that treatment can lawfully be withdrawn in such a case.[125]

Although it is a debatable point, many scholars distinguish between "killing" and "letting die".[126] Allowing a patient to die by withholding treatment or discontinuing treatment equals "letting die" but excludes "killing".[127] There is no moral obligation on a physician to save lives in all cases and at all costs. Biological life should not be preserved when its burdens outweigh its benefits for the patient or when the process of dying is irreversible, and when there is no prospect of continuing with a meaningful life.[128] This principle was underlined in *Clarke v Hurst and Others,*[129] where the judge remarked as follows regarding the prolongation of life at all costs:

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122 Beauchamp and Childress 1979:106; Miller 2007:62.
123 Beauchamp and Childress 2009:159.
124 *Airedale Trust v Bland* [1993] AC 789
125 See chapter 6 par 6.2.6 for a discussion of this case.
126 Beauchamp and Childress 1979:106.
127 Beauchamp and Childress 1979:106.
128 Beauchamp and Childress 1979:108,119,120.
129 1992 (4) SA 630 (D).

> "Patients may be resuscitated and maintained alive when there is not the remotest possibility that they would ever be able to consciously experience life. Within minutes after the supply of oxygenated blood to the brain has stopped the brain cells start dying off—that part of the brain which is responsible for intellectual life being the first to die. Inherent in resuscitation therefore is the very real danger that, by the time that the patient has been resuscitated, his brain may be all but destroyed while the autonomic nervous system and brain stem may nevertheless be able to keep the body biologically alive but securing only a life at the level of a plant or less."[130]

In this case the court ruled that if the curatrix authorised the removal of the nasogastric tube to allow her husband to die, she would not be acting wrongfully or unlawfully.[131]

If active killing were allowed by society, it could eventually lead to involuntary euthanasia, like the killing of defective newborns to avoid their being a burden to society.[132]

130 *Clarke v Hurst* 1992 (4) SA 630 (D):653H-I.
131 *Clarke v Hurst* 1992 (4) SA 630 (D):660J.
132 Beauchamp and Childress 1979:106,113.

In the case of seriously defective neonates the question that should be asked by those responsible for taking decisions on their behalf is whether providing aggressive treatment would be in their best interests.[133] The principle of non-maleficence is not served when the neonate will not survive beyond infancy, will suffer severe pain, and will not be able to participate in meaningful human interaction.[134]

In the case of neonates who are born with meningomyelocele (those born with spina bifida)[135] it is even more problematic, since some of them can live a meaningful life, although the chances are slim.[136] Niazi and Walker[137] point out that non-treatment of infants born with spina bifida is not an option nowadays, as the outcome has improvement with improvement in medical intervention. Early intervention and improvement in fetal medicine, such as intrauterine surgery now provides more hope.[138] It has been suggested by Dr John Corber that a decision regarding the course of action to be followed should be made on the first day after birth, having regard to the location of the spinal lesion and the degree of paralysis.[139] Such a decision could have a

133 Beauchamp and Childress 1979:114, 121.
134 Beauchamp and Childress 1979:121.
135 See chapter 3 par 3.3.1.3 for an explanation of this term.
136 Beauchamp and Childress 1979:122.
137 Niazi and Walker in Özek ea (eds) 2008:70.
138 Niazi and Walker in Özek ea (eds) 2008:70.
139 Beauchamp and Childress 1979:122.

negative impact should the neonate survive, for the neonate could be in a worse position if not treated timeously.[140] A decision regarding treatment or non-treatment should be taken with great care and should be sensitive to the burdens as well as the benefits of treatment.[141]

In contrast to the utilitarian approach, according to which a baby born with Down's Syndrome would be excluded from virtually all medical treatment, the principle of non-maleficence entails that a baby with Down's Syndrome should receive both basic and advanced medical treatment.[142]

Incompetent patients, such as neonates, cannot make their own decisions regarding the withholding or withdrawal of treatment, but this principle requires that their best interests should be protected by the surrogate decision makers.[143] It is suggested that such vital decisions should be taken by parents, who would act in the best interests of the neonate because of the special relationship that exists between them, after consultation with the physician and health care professionals.[144]

140 Beauchamp and Childress 1979:122.
141 Beauchamp and Childress 2009159.
142 Beauchamp and Childress 1979:125.
143 Beauchamp and Childress 1979:127.
144 Beauchamp and Childress 1979:127.

This would serve the principle of non-maleficence.[145] The family should be given priority as decision makers, and turning to a court should only be considered as a last resort.[146]

4.3.3 Beneficence

It is not easy to distinguish or draw a clear line between beneficence and non-maleficence. Beneficence is more altruistic and has more far-reaching effects than non-maleficence; it requires that positive steps be taken to do good to others.[147] Non-maleficence implies that harm is not inflicted on others.[148] When caring for their patients, health care professionals have a duty to act in a manner that will be to the benefit of their patients;[149] they have to ensure that harm will not be inflicted upon patients and that a contribution is made to their health and welfare.[150]

In terms of the principle of beneficence the medical professional has to consider the best interests of his or her patients before embarking on a specific course of action.[151] This principle can be problematic, since the

145 Beauchamp and Childress 1979:127.
146 See also Beauchamp and Childress 1979:128.
147 Beauchamp and Childress 1979:135; Brazier and Cave 2007:53; Slabbert 2010:93.
148 Beauchamp and Childress 1979:135.
149 Beauchamp and Childress 1979:135, 43; Brazier and Cave 2007:53; Herring 2006:25. See also Fletcher ea 1995:31.
150 Beauchamp and Childress 1979:135.
151 Beauchamp and McCullough 1984:28; Cohen 1990:65.

approach could be seen as paternalistic.[152] It focuses on the positive ethical obligations in medical contexts; there is a positive obligation on a health care professional to help others.[153] The doctor decides whether a patient should be treated, and if so which treatment should be given.[154] The purpose of medicine, as envisaged in the Hippocratic Oath, is not—as is often done in modern medicine—to preserve life above everything else.[155] The physician is only obliged to seek a cure for a disease or injury "if there is a reasonable hope of cure; the harms to be avoided, prevented, or removed are the pain and suffering of injury and disease."[156]

In essence the meaning of beneficence in the context of neonatal medical care is that a course of action is taken only if it is in the best interests of the infant.[157] The best interests of the infant should be paramount in the decision-making process, but from the perspective of the infant.[158] Since it is difficult to determine what the outcome of a particular action will be, it is difficult to determine what the best interests

152 Brazier and Cave 2007:53; Herring 2006:25.
153 Herring 2006:25.
154 Herring 2006:25.
155 Beauchamp and McCullough 1984:30.
156 Beauchamp and McCullough 1984:30.
157 Miller 2007:63. Section 28(2) of the Constitution of the Republic of South Africa, 1996, determines that the "a child's best interests are of paramount importance in every matter concerning the child." This is echoed in section 9 of the Children's Act 38 of 2005: "In all matters concerning care, protection and well-being of a child the standard that the child's best interest is of paramount importance, must be applied."
158 Miller 2007:63.

of a neonate are.[159] It should be borne in mind that it is not only the best interests of the neonate that should be taken into account, but also those of his family members, since the decision to treat or not to treat also has certain consequences for the family members.[160]

Followers of the beneficence principle argue that it is the physician's role to act for the benefit of the patient, even if the patient resists.[161] However, the principle of beneficence cannot be applied without taking cognisance of the autonomy of a patient.[162]

Under this principle it is important to understand that there is a duty to balance the good that could be done by the provision of benefits and the harm that could be inflicted by doing or not doing good, in other words, by providing or not providing the benefits.[163] Although doctors no longer take the Hippocratic Oath before they start practising as physicians, the "*Hippocratic Oath* contains the first basic ethical rules for accepted medical practice. According to these rules, physicians were obliged to refrain from all forms of medical malpractice."[164] Nowadays doctors and nurses take a modern version of this oath before becoming members of

159 Miller 2007:63-65.
160 Miller 2007:66.
161 Beauchamp and McCullough 1984:79.
162 Brazier and Cave 2007:53.
163 Beauchamp and Childress 1979:136.
164 Carstens and Pearmain 2007:610. See also Beauchamp and Childress 1979:136.

the profession. The ethical code of both nurses and doctors underpins the principles of beneficence and non-maleficence. Nurses take the Florence Nightingale Pledge, which reads as follows:[165]

> I solemnly pledge myself before God and in the presence of this assembly; To pass my life in purity and to practice my profession faithfully. I will abstain from whatever is deleterious and mischievous and will not take or knowingly administer any harmful drug. I will do all in my power to maintain and elevate the standard of my profession and will hold in confidence all personal matters committed to my keeping and family affairs coming to my knowledge in the practice of my calling. With loyalty will I endeavor to aid the physician in his work, and devote myself to the welfare of those committed to my care.

The World Medical Association Declaration of Geneva 1948 reads as follows:[166]

Physician's Oath

165 Dhai and Etheredge in Dhai and McQuoid-Mason 2011:17.

166 Dhai and Etheredge in Dhai and McQuoid-Mason 2011:17; Moodley (ed) 2011:357. There is also a modern version of the Hippocratic Oath, see Moodley (ed) 2011:354. Besides the Declaration of Geneva, there are also the Declaration of Tokyo, 1975 and the Declaration of Helsinki, last revised at Seoul 2008. Mason and Laurie 2011:Appendix C and D. The ethical code of conduct for physicians in South Africa is enacted in legislation, namely the Health Professions Act 56 of 1974.

At the time of being admitted as a member of the medical profession:

- I solemnly pledge myself to consecrate my life to the service of humanity;
- I will give to my teachers the respect and gratitude which is their due;
- I will practice my profession with conscience and dignity; the health of my patient will be my first consideration;
- I will maintain by all the means in my power, the honor and the noble traditions of the medical profession; my colleagues will be my brothers;
- I will not permit considerations of religion, nationality, race, party politics or social standing to intervene between my duty and my patient;
- I will maintain the utmost respect for human life from the time of conception, even under threat, I will not use my medical knowledge contrary to the laws of humanity;
- I make these promises solemnly, freely and upon my honor.

In terms of the Geneva Declaration of 1984, a physician is obliged to give medical assistance to people in need of medical care in all

circumstances, even when his or her life is threatened.[167] This is in line with section 27 of the Constitution.[168]

The principles of beneficence and non-maleficence are embodied in the Hippocratic Oath, the Geneva Declaration and the International Code of Medical Ethics.[169]

If, for example, a neonate is born with a disease like myelomeningocele,[170] the question can be asked whether the principle of beneficence will be served if the neonate is operated on, when there is a slim chance of improvement, but an even greater chance that the infant might not survive or survive with severe defects.[171] Applying the principles is always a balancing act: the different principles should be balanced against each other and the interests of society should also be balanced against those of individuals.[172]

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167 Oosthuizen and Verschoor 2008:37.

168 (1) Everyone has the right to have access to –
   (a) health care services, including reproductive health care;
   (b) sufficient food and water; and
   (c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance
   (2) The state must take reasonable legislative and other measures, within its available resources, to achieve, the progressive realisation of each of these rights.
   (3) No one may be refused emergency medical treatment."

169 McHaffie ea 1999:441.

170 For an explanation of this term, see chapter 3 par 3.3.1.3.

171 Beauchamp and Childress 1979:145.

172 Beauchamp and Childress 1979:144.

At the same time the individual's needs must be balanced against society's ability to provide financial help. In the case of defective neonates, for example those born with myelomeningocele,[173] the question that is asked is whether the principle of beneficence requires society to pay for such children and whether aggressive treatment should be provided even though the outcome might not be positive. The chances are that these children will not survive, and if they do, they will suffer from serious handicaps.[174]

The principle of non-maleficence requires that the interests of those who cannot decide for themselves should be protected.[175]

4.3.4 Justice

The principle of justice in the context of medical ethics requires that treatment should be fair, equitable and impartial for all persons who have the same needs.[176] Regarding extremely preterm infants, this principle dictates that such infants should be treated in the same way as other infants with the same condition.[177] In practice this would mean that

173 See chapter 3 par 3.3.1.3 for an explanation of this term.
174 Beauchamp and Childress 1979:145.
175 Beauchamp and Childress 1979:127.
176 Beauchamp and Childress 1979:174; Brazier and Cave 2007:54-55; NCOB 2006:225.
177 Miller 2007:68.

when the extremely preterm infant and the full-term infant both suffer from hydrocephalus,[178] they should be treated in the same way.[179]

The principle of justice could conflict with the beneficence principle.[180] It can be argued that the costs involved in providing treatment for an extremely preterm infant in neonatal intensive care, as well as the financial burden the treatment of disabled children places on society, are not justified as this threatens the overall welfare of society and the distribution of resources.[181]

4.4 Quality of life *versus* sanctity of life

"Quality of life" *versus* "sanctity of life" as well as "dignity" and "meaningful life" are fundamental issues that physicians face when they have to decide whether treatment of critically-ill patients is obligatory or optional.[182]

The "sanctity of life" doctrine has its origins in the Judeo-Christian tradition and in its extreme form it implies that human life should be

178 See chapter 3.3.1.3 fn 70 for an explanation of this term.
179 Miller 2007:68.
180 Miller 2007:68
181 Miller 2007:68.
182 Beauchamp and Childress 1979:123,24; Beauchamp and McCullough 1984:123; NCOB 2006:43.

preserved at all costs.[183] This principle is recognised internationally both in Article 2[184] of the European Convention for the Protection of Human Rights and Fundamental Freedoms, 1950, and in Article 6[185] of the International Covenant on Civil and Political Rights, 1966.[186] Followers of this doctrine regard it as morally wrong to fail to preserve or extend human life.[187] This doctrine has a strong religious foundation and followers of this doctrine are of the opinion that all human beings are creatures made in the image of God,[188] therefore all human life, no matter how ill or disabled, is sacred and of equal intrinsic value and should be treated with the same respect.[189] Only God may take the life of one of his creatures.[190]

According to this doctrine treatment should always be provided, no matter how hopeless the case may be, how disabled the infant may be or whatever the cost.[191] However, there are more moderate supporters of the "sanctity of life" doctrine, who prefer to distinguish between

183 Brazier 1996:321; Brazier and Cave 2007:58-59; Donelly 2010:12; Nel 1996:15,7.
184 "Everyone's right to life shall be protected by law."
185 "Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life."
186 Harper 1999:12.
187 Holland 2003:57; NCOB 2006:11,228.
188 Genesis 1:26.
189 Holland 2003:61; NCOB 2006:11,228. See also Cohen 1990:58; Nel 1996:15.
190 Holland 2003:63; Nel 1996:15.
191 Cohen 1990:58; Elliston in Norman and Greer (eds) 2005:374-375.

ordinary and extraordinary methods of providing treatment.[192] Ordinary methods of providing treatment would entail methods that can be applied without much trouble and would have a reasonable chance of success.[193] Extraordinary methods are expensive and otherwise burdensome on both the parents and the neonate.[194] Moderate supporters of the "sanctity of life" principle do not support extraordinary methods of preserving life.[195]

In opposition to this view, Beauchamp and McCullough suggest that the capacity for social relationships should be the minimum standard when deciding whether treatment is optional or obligatory.[196] This would imply that an anencephalic baby should not be treated, while a baby born with Down's Syndrome is entitled to treatment.[197] In the Bland case the House of Lords in the person of Lord Keith held that the sanctity of life principle is not violated when treatment that will only prolong suffering is withdrawn or withheld, but that sanctity of life is violated when active measures are taken to deliberately end life.[198]

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192 Nel 1996:15,57.
193 Nel 1996:16.
194 Nel 1996:16.
195 Nel 1996:16.
196 Beauchamp and McCullough 1984:124.
197 Beauchamp and McCullough 1984:124-125.
198 *Airedale NHS Trust v Bland* [1993] AC 789 at 859: "[The principle of the sanctity of life] does not compel the temporary keeping alive of patients who are terminally ill where to do so would merely prolong their suffering. On the other hand it forbids the taking of active measure to cut short the life of a terminally ill patient."

Beauchamp and Childress[199] are of the opinion that once it becomes clear to health care professionals that the treatment provided is merely life-prolonging, they may decide to change to palliative care.[200] Providing palliative care would afford the infant the opportunity to die with at little discomfort as possible and with dignity.[201] This would also be in line with the Constitution, as the right to dignity is one of the key values entrenched in the Constitution.[202]

The doctrine of "sanctity of life" is contrasted with "quality of life". In the case of the latter neither an absolute right to life, nor a duty to preserve it, is recognised, but the question is asked whether it is a life worth preserving in terms of quality.[203] It is questionable whether one can make value judgments regarding which lives are worth protecting, since people have different perceptions and views on what constitutes a life worth living and protecting.[204] McCormick (as quoted by Nel)[205] suggests that a distinction should be drawn between mere metabolic life and life where there is a potential for human interaction, as would be the case in

199 Beauchamp and Childress 2009:189.
200 The NCOB 2006:158 par 9.23 provides a definition of palliative care: “This is care that endeavours to relieve pain and distress in order to make the rest of a baby’s life as comfortable as possible.”
201 Beauchamp and Childress 2009:189.
202 Section 10. See also chapter 5, par 5.4.4.
203 NCOB 2006:11.
204 NCOB 2006:12. See also Nel 1996:57.
205 Nel 1996:18.

anencephalic babies.[206] The former should not be preserved at all costs, while the latter is worth preserving.[207]

In the case of extremely preterm infants and critically-ill neonates there are circumstances in which providing or continuing treatment to keep the infant alive could lead to unbearable pain and suffering; in such instances there would be no moral obligation to preserve that life.[208] *In re J*[209] the court performed a balancing exercise to weigh up the relative burdens and benefits of putting the baby on a mechanical ventilator. Elliston[210] warns that "[t]his approach is sometimes described as making a judgment on the quality of life of the infant and as such risks placing a lower value upon the lives of those who may be in most need of protection, the young, the sick and those who cannot speak for themselves".

One of the issues that were considered in the case of the conjoined twins[211] was the quality of life versus sanctity of life issue. The operation to separate the twins would save Jodie, but would kill Mary.[212] If the

206 Nel 1996:18-19.
207 Nel 1996:18.
208 NCOB 2006:12. See also Nel 1996:16.
209 *In re J (Wardship: Medical Treatment)* [1991] 2 WLR 140. This case is also discussed in chapter 6 par 6.2.7.
210 Elliston in Norman and Greer (eds) 2005:374.
211 *In re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480.
212 *In re A*:543.

operation was not performed both Jodie and Mary would probably die within a few months.[213] The parents were devout Roman Catholics and opposed the operation. The Roman Catholic Archbishop of Westminster also made written submissions regarding the proposed surgical separation, which the court accepted.[214] The Archbishop raised five points based on Roman Catholic faith and morality: The first is "that human life is sacred and inviolable. Secondly, a person's bodily integrity should not be invaded when that can confer no benefit. Thirdly, the duty to preserve one's life cannot without grave injustice be effected by a lethal assault on another. Fourthly, there is no duty on doctors to resort to extraordinary means in order to preserve life. Fifthly, the rights of parents should be overridden only where they are clearly 'contrary to what is strictly owing to their children'".[215] In this case the court could not balance the quality of life of each of the twins, since that would offend the principle of sanctity of life.[216] The court held that the doctors could proceed with the operation.[217]

213 *In re A*:543.
214 *In re A*:590.
215 *In re A*:590.
216 *In re A*:481.
217 This case is also discussed in chapter 6 paras 6.2.5.1 and 6.2.5.6.

The Nuffield Council on Bioethics[218] suggests that the concept of "intolerability" should be the criterion in determining whether life should be preserved or not.[219] According to the contributors (also known as the Working Party) from the Nuffield Council on Bioethics, "intolerability" has three meanings, namely, "no chance", "no purpose" and "unbearable."[220] This can be explained as follows: If providing treatment offers no chance of survival, except for a short period of time, the best interests of the baby should centre on palliative care and a peaceful death, instead of aggressive treatment.[221] Futile and distressing interventions that can only prolong life and delay death would result in unbearable suffering.[222] When the infant suffers severe pain that cannot be relieved, is incapable of having meaningful interactions with other human beings and will not be able to have an independent existence, it is doubtful that prolonging suffering by keeping the infant alive would serve any purpose.[223]

In the case of an extremely preterm infant with brain damage, judgments regarding the quality of his or her life and his or her best interests should be from the perspective of the disabled infant.[224] The Royal College of

218 See chapter 6 par 6.3 for a discussion on the NCOB.
219 NCOB 2006:12.
220 NCOB 2006:12.
221 Beauchamp and McCullough 1984:138-139; NCOB 2006:12. See also Nel 1996:80.
222 NCOB 2006:12.
223 NCOB 2006:12-13.
224 Miller 2007:84.

Paediatrics and Child Health (RCPCH) mention in their report[225] that people who are living with disabilities can still enjoy a life of quality and that a distinction should be made between those with disabilities who are able to live meaningful lives and those who are incapable of human interaction.[226]

Since it is difficult to make a judgment on behalf of infants who cannot express themselves, the "best interests"[227] argument should be employed in order to determine whether the benefits outweigh the burdens of the proposed treatment.[228] It can be very difficult to make decisions regarding the treatment of critically-ill neonates when the prognostic evidence is uncertain.[229]

4.4.1 Actions for wrongful life and wrongful birth

The actions for wrongful life and wrongful birth touch on the sanctity of life principle and will therefore be discussed under this subheading.

225 "Witholding (sic) or Withdrawing Life Sustaining Treatment."
226 RCPCH 2004:24-25.
227 This will be dealt with later on in the thesis based on section 28(2) of the Constitution of the Republic of South Africa, 1996 and sections 7 and 9 of the Children's Act 38 of 2005.
228 Miller 2007:80.
229 Miller 2007:84.

In *Friedman v Glicksman*[230] a clear distinction was drawn between the different actions for wrongful pregnancy/wrongful conception, wrongful birth and wrongful life. An action for wrongful pregnancy refers to those cases where the parents of a healthy child bring a claim on their own behalf for damages they themselves have suffered as a result of giving birth to an unwanted child."[231] "'Wrongful birth' are those claims brought by parents who claim that they would have avoided conception or terminated the pregnancy had they been properly advised of the risk of birth defects to the potential child. 'Wrongful life' actions are those brought by the child on the basis that the doctor's negligence—his failure to adequately inform the parents of the risk—has caused the birth of the disabled child. The child argues that, but for the inadequate advice, it would not have been born to experience the pain and suffering attributable to the disability."[232]

An action for wrongful birth is instituted by the parents (the plaintiffs) when an unwanted pregnancy has occurred as a result of the negligence of a doctor (the defendant), for example after a failed sterilisation

230 1996 (1) SA 1134 (WLD).
231 *Friedman v Glicksman*:1138A.
232 *Friedman v Glicksman*:1138B-C.

operation or if the operation was not performed at all.[233] The doctor is then sued for the costs of maintaining the child.[234] The action for wrongful birth was recognised in South African law in the case of *Edouard v Administrator, Natal*.[235] In the *Edouard* case, the couple requested that a tubular ligation be performed, since they felt that they could not afford another child. However, this was not done and an unwanted pregnancy ensued. The couple sued the doctor for damages on the basis of breach of contract and for maintenance of the child up to the age of eighteen years.[236] In a subsequent case, namely *Mukheiber v Raath and another*,[237] it was confirmed that an action for wrongful life is recognised in South African law. In this case a sterilisation operation was not performed as was alleged by the gynaecologist, Dr Mukheiber, and as a result of this, Mrs Raath became pregnant and a child was born. The court held the doctor liable to compensate the parents, Mr and Mrs Raath, for the damages claimed by them.[238]

An action for wrongful life is an action where there is an abnormality of the fetus that would have prompted the mother to undergo an abortion

233 Fletcher ea 1995:138; McQuoid-Mason and Dada 2011:447. It is interesting that McQuoid-Mason and Dada do not distinguish between the actions for "wrongful birth" and "wrongful life", but treat them as though these actions are the same.
234 McQuoid-Mason and Dada 2011:447. See also Neethling 2005:229.
235 *Edouard v Administrator, Natal* 1989 (2) SA 368 (D & CLD).
236 For a discussion of this case, see Carstens and Pearmain 389-393,727; Strauss 1991:175-180.
237 1999 (3) SA 1065 (SCA).
238 *Mukheiber v Raath*:1082A.

and this fact was either not noticed or revealed to the mother by the doctors and a handicapped baby was born.[239] The parents would have preferred this child not to have been born.[240] An action based on wrongful life was rejected in *Friedman v Glicksman* per Goldblatt J: "In my view, it would be contrary to public policy for Courts to have to hold that it would be better for a party not to have the unquantifiable blessing of life rather than to have such life albeit in a marred way."[241] The decision in *Stewart v Botha*[242] confirmed that an action for wrongful life is not recognised in South African law. The court per Louw J was of the opinion that the sanctity of life principle did not prevent the action for wrongful birth, "while, where the disabled child is the plaintiff, the sanctity of life argument is an insurmountable obstacle to the claim".[243] This decision was confirmed by the Supreme Court of Appeal.[244] The action for wrongful life is not recognised in the law of England and Wales either.[245]

If the wrongful life action were to be accepted as a legal claim in South African law, it would mean that the autonomy of parents over their

239 Fletcher ea 1995:138-139.
240 Fletcher ea 1995:138-139.
241 *Friedman v Glicksman*:1142I. For a discussion of this case, see Strauss 1995:12-13.
242 2007 (6) SA 247 (C).
243 *Stewart v Botha* 2007 (6) SA 247 (C):257.
244 *Stewart v Botha* 2008 (6) SA 310 (SCA).
245 Fletcher ea 1995:139; McLean and Elliston in Norman and Greer (eds) 2005:353.

children could go too far. It would imply that they have the power to decide whether a child should live or die.[246] The implication is that some lives are less valuable than others and that the life of a disabled child is less valuable than that of a child who is not disabled.[247] If the disability had been known prior to birth, the fetus could have been aborted and this would not be acceptable to people who hold the sanctity of life view.[248]

From a perusal of recent articles, it is clear that there is still no consensus among the legal fraternity on whether the action for wrongful life should be accepted in South African law or not. Chürr[249] is of the opinion that the *Stewart* case was correctly decided and that the action for wrongful life should not be recognised in South African law. However, there are other academics who are of the opinion that an action for wrongful life should be allowed since reliable means of prenatal screening are available and if a doctor is negligent in failing to inform parents of the possibility of deformities of a fetus "and in so doing create the impression of medical normality, then theirs is the responsibility to make the uncomfortable life as comfortable as can be made in the circumstances—by an award to parents for the damage they suffer in

246 Fletcher ea 1995:146.
247 Fletcher ea 1995:146.
248 Fletcher ea 1995:146.
249 Chürr 2009:168-174.

having to care for a handicapped child they would not otherwise have had, and an award to the child for his own suffering, which he would not have to endure were he not alive."[250]

Giesen[251] is of the opinion that an action for wrongful life should be allowed in South African law. He bases his arguments on the fact that if damages are awarded it would give the child the opportunity for a better life and such an action is in essence about the right to self-determination of the mother.[252] Neethling is also of the opinion that if a deformed child is born alive "he should be able to claim damages for the infringement of his physical integrity".[253]

More recently two academics, Human and Mills,[254] have also argued that an action for wrongful life should be recognised in South African law. They point out that the human rights in the Constitution, namely the right to human dignity,[255] the right to bodily and psychological integrity[256] and the right to life,[257] together with the provisions of section 6(2)*(c),*[258]

250 Lind 1992:445-446.
251 Giesen 2009:267-269.
252 Giesen 2009:268-269.
253 Neethling 2005:229.
254 Human and Mills 2010:67-89.
255 Section 10.
256 Section 12(2).
257 Section 11.
258 "treat the child fairly and equitably".

section 6(2)*(f)*[259] and section 11(1)[260] as well as section 7(1)*(h)* and *(i)*[261] of the Children's Act,[262] pave the way for claims for wrongful life.[263]

A detailed analysis of the arguments for and against an action for wrongful life falls outside the scope of this chapter, save for saying that this is not a one-sided issue and there are valid arguments for and against allowing a claim for wrongful life.

4.4.2 After-birth abortion?

In a very controversial article, Drs Francesca Minerva and Alberto Giubilini[264] recently advocated after-birth abortion. They argue that abortion after birth should be allowed in cases where abortion prior to birth would have been permissible:

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259 "recognise a child's disability and create an enabling environment to respond to the special needs that the child has."

260 "In any matter concerning a child with a disability due consideration must be given to –
(a) providing the child with parental care or special care as and when appropriate;
(b) making it possible for the child to participate in social, cultural, religious and educational activities, recognising the special needs that the child may have;
(c) providing the child with conditions that ensure dignity, promote self-reliance and facilitate active participation in the community and;
(d) providing the child and the child's care-giver with the necessary support services."

261 7(1) Whenever a provision of this Act requires the best interests of the child standard to be applied, the following factors must be taken into consideration where relevant, namely –
(h) the child's physical and emotional security and his or her intellectual, emotional, social and cultural development;
(i) any disability that a child may have.

262 38 of 2005.

263 Human and Mills 2010:86-88.

264 http://www.stormfront.org/forum/t869752/ See also Elsabé Brits "Aborsie na geboorte? Ja, sê 2 navorsers" Beeld, Dinsdag 2 Maart 2012. By the writing of this chapter, a copy of the article: "After-birth abortion: why should the baby live?" published in *The Journal of Medical Ethics* was not yet available in the Unisa library.

> "Therefore, WE CLAIM THAT KILLING A NEWBORN COULD BE ETHICALLY PERMISSIBLE IN ALL THE CIRCUMSTANCES WHERE ABORTION WOULD BE. Such circumstances include cases where the newborn has the potential to have an (at least) acceptable life, but the well-being of the family is at risk."[265]

They argue that a neonate is equal to a fetus and is only a potential human being, and consequently neither a fetus nor a neonate is a person or enjoys legal subjectivity.[266] According to them, during the first few days or weeks after birth neonates can be considered neither persons nor legal subjects because they do not have a minimum level of self-awareness and cannot have expectations.[267] According to Minerva and Giubilini, even a healthy neonate can be "aborted after birth".[268]

This view is not entirely new and a similar opinion was expressed by Michael Tooley in 1983: "neither abortion, nor infanticide, at least during the first few weeks after birth, is morally wrong".[269] According to Tooley,[270] a requirement for being a person and a human being is the

265 http://www.stormfront.org/forum/t869752/
266 http://www.stormfront.org/forum/t869752/
267 http://www.stormfront.org/forum/t869752/
268 http://www.stormfront.org/forum/t869752/ Elsabé Brits "Aborsie na geboorte? Ja, sê 2 navorsers" Beeld, Dinsdag 2 Maart 2012.
269 Tooley 1983:419.
270 Tooley 1983:421.

capacity for thought. Before this capacity has been acquired the neonate cannot be regarded as a person.[271]

These arguments are unacceptable in the light of present legislation in South Africa. The effect of this argument is that it would mean legalising infanticide, although the authors prefer not to use the terms “infanticide” or even “euthanasia”.[272] It is trite law that a person who commits infanticide can be criminally prosecuted for the common law crime of murder in South Africa.[273] After-birth abortion is also unacceptable in the light of all human rights documents, which protect children’s rights and the right to life.[274] This argument is also irreconcilable with the best interests of the child as entrenched in the Constitution of the Republic of South Africa, 1996.[275] It would also fly in the face of the “sanctity of life” principle discussed above.[276]

It should be noted that there are anti-abortion groups, such as the Christian Lawyers Association of South Africa, that hold an opposing view, namely that life starts at conception and that abortion would violate

271 Tooley 1983:421.
272 See chapter 2 for a discussion of infanticide.
273 Snyman 2008:454.
274 See chapter 5 par 5.2 for a discussion of the different human rights instruments.
275 Section 28(2).
276 See par 4.4.

the right to life contained in the Constitution.[277] The view held by the Christian Lawyers Association that life starts at conception was rejected by the court.[278]

In South Africa the position regarding abortion is regulated by the Choice on Termination of Pregnancy Act 92 of 1996. In terms of section 2(1)*(c)* a pregnancy may be terminated until right before birth if certain criteria are met in the case of a severe malformation of the fetus or if the continued pregnancy would pose a risk of injury to the fetus.[279] Therefore, once a neonate is born alive, no matter how deformed, he or she may not actively be killed.

In England there were two cases where after-birth abortion was practised. The first was the case of Baby Alexandra in1981, whose parents refused to allow life-saving surgery to be performed on her. She also suffered from Down's Syndrome and her parents' choice was that

277 Section 11.

278 See *Christian Lawyers Association of South Africa v The Minister of Health* 1998 (11) BCLR 1434 (T), 1998 (4) SA 1113 (T) and *Christian Lawyers' Association v Minister of Health* 2004 (10) BCLR 1086 (T). This case is also reported as *Christian Lawyers Association of South Africa v the Minister of Health (Reproductive Health Alliance* as Amicus Curiae) 2005 (1) SA 509 (T).

279 Section 2(1)*(c)* of the Act reads as follows:
A pregnancy may be terminated
(c) after the 20th week of the gestation period if a medical practitioner; after consultation with another medical practitioner or a registered midwife or registered nurse, is of the opinion that the continued pregnancy –
(i) would endanger the woman's life;
(ii) would result in a severe malformation of the fetus; or
(iii) would pose a risk of injury to the fetus.

she be left to die.[280] The other was the case of Dr Leonard Arthur, who ordered that a baby suffering from Down's Syndrome be given nursing care only, because the parents did not want the child to survive. The child died and Dr Arthur was criminally prosecuted.[281] Both these cases prove that after-birth abortion is also illegal and unacceptable in England and Wales. In the Netherlands the life of a critically-ill neonate may be ended if the criteria laid down in the Groningen Protocol are followed. It is important to note that the term "euthanasia" is not used in the case of neonates, the preferred term being "end-of-life decisions."[282]

4.5 Conclusion

Ethical principles might be the last thing on the minds of those who have to make critical care decisions, and when considered in isolation, might not appear to offer practical solutions to the dilemmas in which parents and health care professionals might find themselves when decisions have to be made about the health care of a premature or critically-ill neonate.[283] Health care professionals might not be deliberately taking different ethical principles into consideration when making critical care decisions, neither do they all subscribe to the same ethical theory, yet everyone has a sense of what is morally right in the circumstances. In

280 See the discussion of *In re B* in chapter 6 par 6.2.5.5.
281 See chapter 6 par 6.2.6.1 for a discussion of this case.
282 See chapter 7 for a discussion of the position in the Netherlands.
283 NCOB 2006:9.

spite of this, different people with different moral views might arrive at the same decision.[284]

284 NCOB 2006:10.

CHAPTER 5

INTERNATIONAL LAW, THE CONSTITUTION OF THE REPUBLIC OF SOUTH AFRICA, 1996, AND OTHER RELEVANT LEGISLATION IN SOUTH AFRICA

5.1 Introduction

Before considering South African legislation pertaining to children in general and neonates in particular, whether they are premature or critically-ill neonates, it is essential to peruse international human rights instruments, since the protection of human rights operates at both the national and the international level.[1] The provisions of these documents are given effect to in South African legislation. Various international human rights instruments, which will be discussed below, have been drawn up with the purpose of protecting people, in particular children.

1 Mubangizi 2002:343.

5.2 International human rights instruments

The right to life is guaranteed in article 12(1)[2] of the International Covenant on Economic, Social and Cultural Rights (hereinafter the ICESC) of 1966. An extremely high standard of health care is prescribed to States Parties in this article.[3] This Covenant also prescribes the steps to be taken by States Parties to attain the goal set in article 12(1). Article 12(2)(a) compels States Parties, among others, to provide for the reduction of the stillbirth-rate and the infant mortality rate; they also have to provide for the healthy development of the child.[4] This is echoed in Millennium Development Goal 4, which has as its aim the reduction of the infant mortality rate.[5]

The right to life is further entrenched in article 6 of the *International Covenant on Civil and Political Rights*, 1966.[6] This article is couched in

2 "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the hightest attainable standard of physical and mental health."

3 "The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health."

4 "The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
(a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child"

5 For a discussion, see par 5.3.

6 "Every human being has the inherent right to life. This right shall be protected by law."

peremptory language and States Parties are compelled to enact legislation to give effect to this right.[7]

This is echoed in article 4[8] of the *African Charter on Human and Peoples' Rights*, 1981, and the right to health is mandated in article 16.[9]

The *Universal Declaration of Human Rights,* 1948, is not a legally binding instrument,[10] but it nevertheless contains provisions which are of importance when considering the protection of premature infants and critically-ill neonates. Among others, the most fundamental right for a human being, namely the right to life, is guaranteed in article 3.

The *Convention on the Rights of the Child* (hereinafter CRC), 1989, is the first international human rights document that gives recognition to the fact that children have special needs that have to be taken into consideration and rights that need to be protected.[11] The CRC was

7 "Every human being has the inherent right to life. This right *shall* be protected by law." (My emphasis).
8 "Human beings are inviolable. Every human being shall be entitled to respect for his life and the integrity of the person. No one may be arbitrarily deprived of this right."
9 "Every individual shall have the right to enjoy the best attainable state of physical and mental health." South Africa ratified this document on 9 July 1996.
10 Brownlie and Goodwin-Gill 2010:23.
11 It is significant that in the CRC the obligation is mostly on States Parties to ensure protection of children. Most of the articles in this document start with the words: "States Parties shall…".

ratified by South Africa on 16 June 1995.[12] By December 1994, it had been ratified by over 160 countries; the only two countries that have not ratified the CRC are the United States of America and Somalia.[13] The preamble to the CRC echoes the Declaration of the Rights of the Child in which it is stated that a child needs "appropriate legal protection, before as well as after birth". In article 1 of the CRC a child is very broadly defined as a human being below the age of eighteen. The CRC recognises the fact that children need more than mere protection, and that they also have certain rights.[14] The "best interests of the child" standard is introduced in article 3.[15] The child's right to life is guaranteed in article 6 of the CRC. Of particular importance for this study is the second part of this article, which imposes an obligation on States Parties to "ensure to the maximum extent possible the survival and development of the child".[16] In article 24 various measures are set out to ensure that children receive the "highest attainable standard of health and ... facilities for the treatment of illness and rehabilitation of health". States parties have an obligation to take appropriate measures *inter alia* to

12 Büchner-Eveleigh 2009:27.
13 Büchner-Eveleigh 2009:26-27.
14 Sloth-Nielsen 1995:402.
15 Sloth-Nielsen 1995:409. The language that is used in this article does not impose the same degree of care on States Parties as is done in section 28(2) of the Constitution of the Republic of South Africa, 1996 and sections 7 and 9 of the Children's Act, 37 of 2005.
16 See also Sloth-Nielsen 1995:410.

*"*diminish infant and child mortality" in article 24(2)(a). This is in line with Millennium Development Goal 4.[17]

The African Charter on the Rights and Welfare of the Child was inspired by the CRC and it echoes many rights set out in the CRC. This charter was ratified by South Africa on 7 January 2000.[18] Article 4(1) contains the best interests of the child standard. The CRC introduced the best interests of the child standard; this is extended in article 4 of the African Charter on the Rights and Welfare of the Child, which provides that "the best interests of the child shall be the primary consideration".[19] Article 5(1) of the African Charter on the Rights and Welfare of the Child provides that every child has the right to life, which must be protected by law and goes on to provide in article 5(2) that States Parties have a duty to ensure "to the maximum extent possible, the survival, protection and development of the child". For the purpose of this study these articles (namely articles 5(1) and (2)) should be read together with article 14 of this document, which deals with health and health services. Of particular importance is article 14(1) and 14(2)(a), which read as follows: "Every child shall have the right to enjoy the best attainable state of physical,

17 See par 5.3.
18 Viljoen 1999:660-664.
19 See also Davel 2002:283.

mental and spiritual health." It also enjoins States Parties to take measures to reduce the infant and child mortality rate. These articles should not be read in isolation, but should be read together with article 20, which deals with parental responsibilities, since the obligation to ensure that the best interests of the child are attained at all times also falls within the ambit of parental responsibilities and rights.

5.3 Millennium Development Goals

The Millennium Development Goals (hereinafter MDGs) are a blueprint agreed upon by all the countries and leading development institutions of the world to achieve eight goals, the so-called MDGs, in key areas of global concern.[20] Of particular concern for this study is Goal 4, the objective of which is to reduce child mortality. The MDGs echo article 12(2)(a) of the ICESC and article 24 of the CRC mentioned above. The infant mortality rate is highest in the poorer countries, with the highest rate among low-income earners. The target of Goal 4 is to reduce the infant mortality rate of infants below five years of age by two-thirds

20 The eight goals are to: (1) eradicate extreme poverty and hunger, (2) achieve universal primary education, (3) promote gender equality and empower women, (4) reduce child mortality, (5) improve maternal health, (6) combat HIV and AIDS, malaria and other diseases, (7) ensure environmental sustainability and (8) develop a global partnership for development. http://www.unhttp://www.un.org/millenniumgoals/bkgd.shtml

between 1990 and 2015.[21] The Millennium Developments Goals were also adopted by the Department of Health of the South African Government.[22] One of the objectives of the National Department of Health is to reduce the neonatal mortality rate from 20 to 14 per 1000 live births.[23] The most recent figure available, released by the South African Demographic and Health Survey in 2003, was 57.6 per 1000 live births for infants under five years of age. This figure is still far from the target of 20 per 1000 live births.[24] Although some progress has been made towards realising this ideal, for example through the provision of free primary health care to children, Schäfer[25] points out that not all children in rural areas live close to clinics and that more needs to be done to give effect to this objective. Shäfer[26] further mentions that South Africa is one of the few countries where an increase in the infant mortality rate was recorded instead of a decrease. This can be ascribed partly to the high incidence of HIV/aids-related deaths among children.

21 South Africa. Millennium Development Goals. Mid-term Country Report. September 2007:3,6.
22 South Africa. Millennium Development Goals. Mid-term Country Report. September 2007.
23 South Africa. Millennium Development Goals. Mid-term Country Report. September 2007:23.
24 South Africa. Millennium Development Goals. Mid-term Country Report. September 2007:24.
25 Schäfer 2011:48.
26 Schäfer 2011:48.

The next question that arises is: To what extent has South African legislation given effect to the provisions of these international human rights instruments? The focus will therefore now fall on South African legislation pertaining to the health care of children.

5.4 The Constitution of the Republic of South Africa, 1996

5.4.1 Introduction

The purpose of this chapter is first and foremost to determine whether South African legislation gives sufficient recognition to the rights of the child as set out in the international human rights instruments discussed above and whether these rights are adequately embodied in the relevant South African legislation.

In the Constitution effect is given to the principles regarding the protection of human rights in general as enunciated in the international human rights instruments discussed above.

The first right that will be discussed is the right to life, since it is the most fundamental right in the Bill of Rights in the Constitution and without the

right to life all other rights would be meaningless.[27]

5.4.2 The limitation clause[28]

A discussion of the Constitution would be incomplete without a discussion of the general limitation clause. All rights in the Bill of Rights can be limited if certain criteria are met.[29] The criteria that have to be applied are spelt out in section 36 of the Constitution.[30] Section 36 of the Constitution reads as follows:

> (1) The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including—
>
> *(a)* the nature of the right;
>
> *(b)* the importance of the purpose of the limitation;
>
> *(c)* the nature and extent of the limitation;
>
> *(d)* the relation between the limitation and its purpose; and
>
> *(e)* less restrictive means to achieve the purpose.

27 Carstens and Pearmain 2007:27; Currie and De Waal 2005:280. See also Brazier 1996:317.
28 Section 36.
29 Currie and De Waal 2005:163,165.
30 Currie and De Waal 2005:163,165.

(2) Except as provided in subsection (1) or in any other provision of the Constitution, no law may limit any right entrenched in the Bill of Rights.

The force of this is that all the constitutional rights that are discussed below, including children's rights, may be limited in terms of section 36. If the criteria set out in section 36 are met, the limitation would not be unconstitutional. Currie and De Waal[31] point out that a two-stage approach is needed to determine whether the limitation can be justified in terms of section 36. During the first stage the question is asked whether a right in the Bill of Rights has indeed been infringed by a law or conduct.[32] The second stage of the approach consists in asking whether the infringement is justifiable in terms of this section.[33]

5.4.3 The right to life[34]

While a fetus is not recognised as a legal subject and as such enjoys no rights or protection,[35] a neonate who is born alive, albeit premature, is

31 Currie and De Waal 2005:165-167.
32 Currie and De Waal 2005:166-167.
33 Currie and De Waal 2005:166-167.
34 Section 11.
35 Boezaart in Boezaart (ed) 2009:4-5; Heaton 2008:7-8; Kruger & Skelton (eds) 2010:22-23. The exception to the rule, namely that the *nasciturus* fiction will be applied in the law of succession when it is to the advantage of the fetus, will not be discussed

entitled to full protection in terms of the Bill of Rights in the Constitution.

Health care professionals and parents often have to make difficult decisions regarding the treatment of premature babies or critically-ill neonates and all the parties might not agree on what the appropriate course of action in particular circumstances should be.[36] A child's life could be endangered or suffering prolonged by inappropriate decisions relating to his or her health.[37]

On the one hand a negative duty rests on the state as well as all individuals living in the country not to take a life; on the other hand a positive duty rests on the state to protect the lives of all people in the country.[38] Since the right to life is a right enunciated in the Bill of Rights, it may also be limited in terms of section 36 of the Constitution.[39]

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here, as it is not relevant for the subject under discussion. Furthermore it is accepted that when a neonate is born alive, he or she enjoys full legal subjectivity.

36 See also Fortin 2009:363.

37 Fortin 2009:363.

38 Currie and De Waal 2005:285.

39 (1) The rights in the Bill of Rights may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors, including –
(a) the nature of the right;
(b) the importance of the purpose of the limitation;
(c) the nature and extent of the limitation;
(d) the relation between the limitation and it purpose; and
(e) less restrictive means to achieve the purpose.

In the landmark decision in *S v Makwanyane,*[40] due consideration is given to the content of "the right to life" by the different judges. They emphasise the fact that it is an unqualified right.[41] Justice O'Regan[42] gives the most comprehensive description of the content of the right to life:

> "The right to life is, in one sense, antecedent to all the other rights in the Constitution. Without life, in the sense of existence, it would not be possible to exercise rights or to be the bearer of them. But the right to life was included in the Constitution not simply to enshrine the right to existence. It is not life as mere organic matter that the Constitution cherishes, but the right to human life: the right to live as a human being, to be part of a broader community, to share in the experience of humanity."

In the above quote Justice O'Regan provides the criterion that could be applied in deciding whether or not to treat a premature or critically-ill neonate. The moment a neonate is born alive, he or she gains legal subjectivity and is entitled to protection in terms of the Bill of Rights,

40 1995 (3) SA 391 (CC).
41 See for example Chaskalson par [39], Ackerman par [157], Sachs par [350], [351] and [354].
42 *S v Makwanyane* 1995 (3) SA 391 (CC):[326].

which would include the right to life.[43] "Arguably then, however, ill and disabled, a neonate is entitled to be kept alive by whatever means available."[44] If there is no possibility that the neonate will be able to participate in activities typical of the broader community, in other words will be capable of human interaction, and if medical intervention will merely prolong suffering, a dying baby also has the right to die with dignity.[45] It was held by the Constitutional Court that the right to life does not include the right to evade death, and this view was confirmed by the Constitutional Court in the *Soobramoney* case.[46]

The *Soobramoney*[47] case dealt with the right to life and its limitations. The Constitutional Court per Justice Sachs[48] held that "there is in reality no meaningful way in which it can constitutionally be extended to encompass the right indefinitely to efface death … dying is part of life, its completion rather than its opposite." The state cannot be expected to prolong the life of an individual indefinitely if there is no hope of recovery since there are not sufficient resources available and, moreover, the

43 Section 9 of the Constitution. See also Fortin 2009:374.
44 Fortin 2009:374.
45 Fortin 2009:376.
46 Carstens and Pearmain:2007:27. *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC).
47 *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC).
48 *Soobramoney:*[57].

available resources should rather be utilised for those individuals who can benefit from medical intervention.[49]

As was mentioned earlier in this chapter, it is trite in South African law that legal subjectivity begins at birth.[50] This means that a fetus does not enjoy a right to life that can be protected by the Constitution. In the *Soobramoney* case the court held that there is no meaningful way in which the right to life can be extended to evade death. "The state has to manage its limited resources in order to address all these claims.[51] There will be times when this requires it to adopt an holistic approach to the larger needs of society rather than focus on the specific needs of particular individuals within society."[52] On the one hand, this view could be problematic in the case of premature babies and critically-ill neonates, since it is not always clear whether the outcome of the treatment will be that the life of a premature baby or critically-ill neonate is protected or whether life is merely being prolonged. For this reason,

49 *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC):[11]. See also Carstens and Pearmain 2007:27.
50 Boezaart in Boezaart (ed) 2009:4; Heaton 2008:7-8.
51 These claims include claims for access to housing, food and water, employment opportunities and social security. See *Soobramoney*:[31].
52 *Soobramoney*:[31].

the practice is followed in private hospitals[53] of giving a baby the opportunity to prove whether he or she will be able to survive, before aggressive treatment is given.[54]

On the other hand, it implies that treatment can be withdrawn if it proves to be futile. If a patient is only entitled to free primary health care services in public hospitals, it would imply that extremely premature babies and critically-ill neonates would not be entitled to expensive care and treatment in a neonatal intensive care unit (NICU), unless there was a chance of recovery. Büchner-Eveleigh and Nienaber[55] criticise the fact that both the Children's Act and the National Health Act provide limited protection to the health care of children in general and, moreover, the Acts do not provide for a particular standard of health care. They also point out that the Children's Act does not refer to the child's right to primary health care, neither does it set a minimum standard of health care for children.[56] The fact that premature and critically-ill neonates who are admitted to hospital will not necessarily receive the same treatment

53 In the South African health system there are two health care systems, namely public hospitals, which are funded by the government, and private hospitals which are privately funded.
54 According to Dr Carin Maree, senior lecturer in Nursing Science, with specialisation in neonatal intensive care at the University of Pretoria.
55 Büchner-Eveleigh and Nienaber 2012:120,126.
56 Büchner-Eveleigh and Nienaber 2012:120.

in private and public hospitals is discriminatory against those whose parents do not have the means to pay for expensive treatment at private hospitals. As Ngwena[57] points out, the treatment of premature babies and those who are critically-ill is a polycentric issue and multiple aspects should be taken into account before a decision is reached regarding treatment. He suggests that issues such as medical, economic, moral and political considerations should be taken into account.[58] Ngwena[59] furthermore argues that since the right to life is such a fundamental right, health care "should be provided whenever it has a beneficial effect, however minimal" and the cost involved in treatment or the prolongation of life should be irrelevant.[60] This is even more important in the case of neonates, especially in the light of the provisions in international human rights instruments. However, once it becomes clear that treatment is futile and is merely prolonging suffering, it is suggested that it be withdrawn.

57 Ngwena 2000:18.
58 Ngwena 2000:18.
59 Ngwena 2000:19.
60 Ngwena 2000:19.

The right to life is closely related to the right to dignity. As these rights are often called "twin rights",[61] the right to dignity will subsequently be discussed.

5.4.4 The right to dignity[62]

In the CRC the dignity of a child is protected. The right to dignity is also entrenched in section 10[63] of the Constitution of the Republic of South Africa, 1996. The Constitutional Court per Justice Chaskalson reiterated the importance of the right to dignity in the following words: "The rights to life and dignity are the most important of all personal rights in chapter 3."[64] Justice O'Regan regards the right to dignity as "a founding value of the new Constitution".[65]

> "The capacity for enjoyment of the rights to life and human dignity is obviously significantly diminished by poor health. In the context of health care, situations which throw into stark relief the concepts of life and human dignity and their interdependence are those in which

61 Currie and de Waal 2005:281.
62 Section 10 Constitution of the Republic of South Africa, 1996.
63 "Everyone has inherent dignity and the right to have their dignity respected and protected."
64 *S v Makwanyane* 1995 (3) SA 391 (CC):[143].
65 *S v Makwanyane* 1995 (3) SA 391 (CC):[328].

patients are so severely injured that they can no longer function as human beings, yet remain, biologically speaking, alive."[66]

In *Clarke v Hurst*[67] the link between health care and dignity was discussed. The patient's wife brought an application to be appointed as his curatrix so that she could decide whether her husband should receive any further medical treatment or whether any medical treatment should be discontinued even though it would lead to the death of the patient. When he was still in good health, the patient held strong views on a person's right to die with dignity when he or she is in a continuous vegetative state and there is no hope of recovery.[68] Carstens and Pearmain[69] correctly argue that if a person no longer enjoys quality of life, his or her dignity is also impaired.

In *S v Makwanyane*[70] the Constitutional Court pointed out that the right to life and the right to dignity are the most important human rights.

66 Carstens and Pearmain 2007:29.
67 1992 (4) SA 630 (D).
68 *Clarke v Hurst* 1992 (4) SA 630 (D):633H.
69 Carstens and Pearmain 2007:29.
70 *S v Makwanyane* 1995 (3) SA 391 (CC):[144].

Justice O'Regan argues that the right to dignity is intricately linked to other human rights and is the foundation of other human rights.[71]

Since the right to life and the right to dignity are closely associated with other rights, such as socio-economic rights and the right to health care,[72] the focus will now fall on these rights.

5.4.5 Socio-economic rights[73]

Currie and de Waal[74] mention that the international instrument that is of particular significance regarding socio-economic rights is the International Covenant on Economic, Social and Cultural Rights, 1966 (hereinafter ICESCR). South Africa signed the ICESCR on 3 October 1994, but has not yet ratified it.[75] In the *Grootboom*[76] case the *amici curiae*, namely the Human Rights Commission, urged the court to consider the ICESCR, especially Article 11.1.[77]

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71 *S v Makwanyane* 1995 (3) SA 391 (CC):[328]. See also Currie and De Waal 2005:274.
72 Currie and de Waal 2005:290.
73 Section 26 and 27 of the Constitution.
74 Currie and de Waal 2005:574.
75 Currie and de Waal 2005:574, fn 33; *Government of the Republic of South Africa v Grootboom* 2001 (1) SA 46:63, fn 29.
76 *Government of the Republic of South Africa v Grootboom* 2001 (1) SA 46.
77 "The States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing, and to the continuous improvement of living conditions. The States Parties will take appropriate steps to ensure the realization of this right, recognizing to this effect the essential importance of international co-operation."

Section 26[78] of the Constitution is a socio-economic right that places an obligation on the state in no uncertain terms to do as much as it possibly can "to secure for all members of society a basic set of social goods—education, health care, food, water, shelter, access to land and housing".[79]

The reasonableness of one of these socio-economic rights, namely the state's housing policy, came under scrutiny in the *Grootboom*[80] case.[81] Squatters were forcibly evicted from private land that had been ear-marked for low-cost housing. Their homes were bulldozed and their possessions destroyed during the eviction process.[82] *In casu* the court per Justice Yacoob held that section 26 imposes both a negative and a positive obligation upon the government. "Although the subsection does not expressly say so, there is, at the very least, a negative obligation upon the State and all other entities and persons to desist from

78 26 (1) Everyone has the right to have access to adequate housing.
(2) The state must take reasonable legislative and other measures within its available resources, to achieve the progressive realisation of this right.
(3) No one may be evicted from their home, or have their home demolished, without an order of court made after considering all the relevant circumstances. No legislation may permit arbitrary evictions.

79 Currie and de Waal 2005:567.

80 *Government of the Republic of South Africa v Grootboom* 2001 (1) SA 46 (CC).

81 Liebenberg 2010:146-147; Proudlock in Boezaart (ed) 2009:298.

82 *Grootboom*:[10].

preventing or impairing the right of access to adequate housing."[83] On the other hand, subsection 2 places a positive obligation on the State: "It requires the State to devise a comprehensive and workable plan to meet its obligations in terms of the subsection."[84] The court held that the individual's socio-economic rights had been violated by the eviction and the court made a declaratory order compelling the State to meet its obligations as spelt out in section 26(2) of the Constitution.[85]

In *Khosa and others v Minister of Social Development and others; Mahlaule and others v Minister of Social Development*[86] the reasonableness test was developed further.[87] The applicants were Mozambican residents who permanently resided in South Africa and wanted the government to pay social assistance to their children, who were born in this country. The court stressed that sections 27(1) and 27(2) of the Constitution should not be read independently of each other, but that they are interrelated: "[S] 27(1) and s 27(2) cannot be viewed as separate or discrete rights creating entitlements and obligations independently of one another. Section 27(2) exists as an internal

83 *Grootboom*:[34].
84 *Grootboom*:[38].
85 *Grootboom*:[96].
86 2004 (6) SA 505 (CC).
87 See also Liebenberg 2010:158-161.

limitation on the content of s 27(1) and the ambit of the s 27(1) right can therefore not be determined without reference to the reasonableness of the measures adopted to fulfil the obligation towards those entitled to the right in s 27(1)."[88] The court per Justice Mokgoro confirmed that all socio-economic rights are, however, subject to the availability of state resources.[89] Therefore it follows that if the state lacks sufficient resources to address socio-economic rights, the non-provision of these rights will not be a violation of the rights enunciated in sections 26 and 27 of the Constitution.[90]

In *Khosa* the court also considered the meaning of the word "everyone" in section 26 and 27 of the Constitution, and after following a purposive approach to the interpretation of rights, it came to the conclusion that the meaning of "everyone" is not restricted to South African citizens.[91] According to this decision it would amount to unfair discrimination to exclude permanent residents from receiving social assistance.[92] This is in line with the approach followed by the court in the *Grootboom* and

88 *Khosa*:[43].
89 Khosa:[44],[45]; Carstens and Pearmain 2007:37; Currie and de Waal 2005:583.
90 Currie and de Waal 2005:583.
91 *Khosa*:[46],[37].
92 Currie and de Waal 2005:472-473.

Soobramoney[93] cases, where the court decided the cases on the interpretation of the rights of everyone in sections 26 and 27 and not on section 28 of the Constitution.[94]

5.4.5.1 Right of access to health care[95]

The first case where the Constitutional Court had to decide on socio-economic issues was the *Soobramoney*[96] case. In this case the court decided on the reasonableness of denying the applicant renal dialysis at a public hospital and by so doing denying him his right of access to health care services. The court held that the provision of socio-economic rights is subject to the availability of resources and since the health authorities in Kwazulu-Natal did not have sufficient resources to make renal dialysis available to all patients, but only to patients who were eligible for kidney transplants, their decision not to give the applicant dialysis was not unreasonable.[97]

93 See par 5.4.5.1 for a discussion of this case.
94 Proudlock in Boezaart (ed) 2009:299-300.
95 Section 27 of the Constitution.
95 Mubangizi 2002:344.
96 *Soobramoney v Minister of Health, KwaZulu-Natal* 1998 (1) SA 765 (CC).
97 Currie and de Waal 2005:570; Liebenberg 2010:146.

In article 24(1) the CRC recognises the fact that it is essential for a child to be in good health in order to reach his or her full potential.[98] The CRC uses peremptory language (i.e. by using the word “shall”) in article 24 to ensure that no child is deprived of his or her right of access to such health care services. Furthermore, article 24(1)(a) places an obligation on States Parties to reduce the infant mortality rate and in article 25(1)(b) the emphasis is on the development of primary health care services for children.

Carstens and Pearmain[99] argue that there is no specific right to health as a particular right in the Bill of Rights, as there is in international law. They go on to contend[100] that various other rights entrenched in the Constitution constitute a right to health, such as the right to life,[101] human dignity,[102] bodily integrity,[103] privacy,[104] an environment that is not harmful to one's health or well-being,[105] and access to health care services[106] and emergency medical treatment. [107]

98 Fortin 2009:363.
99 Carstens and Pearmain 2007:25.
100 Carstens and Pearmain 2007:26.
101 Section 11.
102 Section 10.
103 Section 12(2).
104 Section 14.
105 Section 24(a).
106 Section 27(1)(a).
107 Section 27(3).

Section 27(1)(a) of the Bill of Rights in the Constitution is a socio-economic right which guarantees the right to have access to "health care services, including reproductive health care". Mubangizi[108] points out that neither "health care services"[109] nor the quality of health care or emergency treatment as it appears in the Constitution is defined. It has been suggested that it should include proper medical care, prevention and diagnosis of diseases and vaccination.[110] Kling[111] asks whether "basic health care services" should be read as including costly treatment for "children with special needs that may be rare or expensive to treat, but that is necessary for their continued existence, growth, development and comfort". On the other hand, Büchner-Eveleigh and Nienaber[112] argue that in terms of section 4(3)(a) of the National Health Act all health care services must be provided for free to children under the age of six years and not only primary health care services.

The court also considered the aspect of reasonableness regarding the provision of one of the socio-economic rights, namely access to health

108 2002:344. See also Kling 2006:43.
109 Section 27(1)(a) Constitution of the Republic of South Africa, 1996.
110 Mubangizi 2002:344-345.
111 2006:43.
112 Büchner-Eveleigh and Nienaber 2012:114-115.

care services,[113] in *Minister of Health and Others v Treatment Action Campaign*.[114] The Treatment Action Campaign (hereinafter the TAC) challenged the government's policy of providing Nevirapine, an antiretroviral drug that reduces the risk of HIV/aids transmission from mother to baby at birth, only at certain pilot sites as being unreasonable. According to the TAC, the government policy was unreasonable as it violated the right of everyone to have access to health care in terms of section 27 of the Constitution.[115] The court held that the state's policy also had a negative impact on the right of children to have access to health care services in terms of section 28(1)(c) of the Constitution.[116] The court held that the fact that the drug Nevirapine was made available only at "hospitals and clinics which are research and clinic sites constitutes a breach of the State's obligation under s 27(2) when read with s 27(1)*(a)* of the Constitution".[117]

113 Section 27 of the Constitution.
114 2002 (5) SA 703 (CC).
115 Liebenberg 2010:147.
116 Proudlock in Boezaart (ed) 2009:298-299.
117 *TAC*:[80].

In *Grootboom* the court stressed the fact that socio-economic rights are difficult to adjudicate and each case must be decided on its own facts and merits.[118]

The right to health care services and emergency medical treatment may be applied horizontally and vertically: the horizontal application places a duty on private and public hospitals, as well as on health care professionals, to provide treatment.[119] Likewise, the vertical application places a duty on the government to provide medical treatment.[120]

The right to health care services is, however, subject to the internal limitation clause in section 27(2) of the Constitution in terms of which health care has to be provided if the state has enough available resources.[121] In this case the content of the right is limited by the availability of resources.[122] Section 11 of the Children's Act 38 of 2005 deals with children with disabilities or chronic illnesses. Since premature, and especially extremely premature, neonates are likely to suffer from a

118 Carstens and Pearmain 2007:38.
119 Mubangizi 2002:345.
120 Mubangizi 2002: 345.
121 Section 27(2) reads as follows: "The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights." Liebenberg 2010:96.
122 Carstens and Pearmain 2007:119.

physical or mental disability if they survive, it is submitted that this section will be applicable to them too and that they will be entitled to specialised care as envisaged in this section. It may be asked whether a critically-ill neonate, who may also be left physically or mentally disabled if he or she survived the illness, would also be entitled to specialised care as envisaged by section 11 of the Children's Act. This question can be answered in the affirmative, especially in the light of the provisions of the CRC.

Davel[123] points out that the Act frequently mentions children in especially difficult circumstances. The purpose of this section is to ensure that children with a disability or chronic illness are treated with dignity and not discriminated against.[124] Since there is no specific mention in the Act of premature or critically-ill neonates, it is submitted that they fall into this category and enjoy the protection afforded by this section, which would mean that they are entitled to specialised care.

Since neither the premature baby nor the critically-ill neonate is able to speak for himself or herself and therefore cannot consent to medical

123 Davel in Davel and Skelton (eds) 2007:2-15.
124 *A Guide to the Children's Act for Health Professionals* 2010: 6-7.

treatment, consent has to be provided by parents or care-givers or in exceptional circumstances by the superintendent, the person in charge of the hospital or the minister.[125] It is essential that the best interests of the child are seen as being of paramount importance when any decision regarding treatment or even non-treatment is taken. The best interests standard will be discussed below.[126]

5.4.5.2 The right to emergency medical treatment[127]

Section 27(3) provides that "[n]o one may be refused emergency medical treatment". The National Health Act 61 of 2003 also provides for emergency medical treatment in section 5.[128] Section 7(1)(e) provides that emergency medical treatment may be given without prior consent under certain circumstances.[129]

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125 See Children's Act section 129(6).
"The superintendent of a hospital or the person in charge of the hospital in the absence of the superintendent may consent to the medical treatment of or surgical operation on a child if-
(a) the treatment or operation is necessary to preserve the life of the child or to save the child from serious or lasting physical injury or disability; and
(b) the need for the treatment or operation is so urgent that it cannot be deferred for the purpose of obtaining consent that would otherwise have been required."

126 See par 5.4.7 for a detailed discussion on the best interests standard.

127 Section 27(3).

128 "A health care provider, health worker or health establishment may not refuse a person emergency medical treatment." See also Oosthuizen and Verschoor 2008:38.

129 "[A]ny delay in the provision of the health service to the user might result in his or her death or irreversible damage to his or her health and the user has not expressly, impliedly or by conduct refused that service."

Carstens and Pearmain[130] correctly point out that the term "emergency medical treatment" is too broadly qualified. The *Soobramoney* case sheds some light on what is meant by this term per Chaskalson: "The words 'emergency medical treatment' may possibly be open to a broad construction which would include ongoing treatment of chronic illnesses for the purpose of prolonging life. But this is not their ordinary meaning, and if this had been the purpose which s 37(3) was intended to serve, one would have been expressed in positive and specific terms."[131] Justice Chaskalson further points out that the right to emergency medical treatment is couched in negative terms. "The purpose of the right seems to be to ensure that treatment be given in an emergency, and is not frustrated by reason of bureaucratic requirements or other formalities."[132] Justice Madala also defines an emergency. According to him, "s 27(3) envisages a dramatic, sudden situation or event which is of a passing nature in terms of time".[133] Liebenberg[134] is of the opinion that

> "[s]ection 27(3) is clearly designed to carve out a specific aspect of the general health right of health care services, emergency medical treatment, which gives rise to special obligations. Thus this right is

130 Carstens and Pearmain 2007:160,164-165.
131 *Soobramoney*:[13].
132 *Soobramoney*:[20]. See also Carstens and Pearmain 2007:158.
133 *Soobramoney* [38]. See also Dhai and McQuoid-Mason (eds) 2011:44.
134 Liebenberg 2010:138.

not subject to the qualification in s 27(2) relating to reasonable measure, progressive realisation or resource availability. Its purpose is to ensure that every person is able to receive the treatment which is deemed medically necessary in a health emergency. The latter could be due to an accident or to a crisis such as a heart attack or stroke. Any limitations to this right would be subject to the stringent requirements of the general limitations clause, including the requirement of a law of general application in s 36(1)."

McQuoid-Mason and Dhai[135] define emergency medical treatment as follows: "Emergency medical treatment refers to situations where medical treatment is necessary because a person's life or health is in serious danger as a result if disease, injury or ill health."

Liebenberg[136] further points out that this right is subject to the availability of existing facilities and suggests that in cases where existing facilities are inadequate, they should be increased to make provision for the demands. It is submitted that neonatal intensive care falls into this category as it is standard practice to resuscitate an ill neonate shortly

135 McQuoid-Mason and Dhai (eds) 2011:178.
136 Liebenberg 2010:138.

after birth when his or her life seems to be in danger, before decisions regarding treatment are made. It is suggested that in terms of section 27(3) of the Constitution these facilities should be expanded where necessary to meet the demand.

5.4.6 The right to privacy[137]

By consenting to the admission of their neonate to the Intensive Care Unit, parents inherently also consent to the fact that the right of privacy of their neonate will be diminished. This does not mean, however, that confidential information about the infant in question may be disclosed or made public.[138] No right in the Bill of Rights is absolute and all rights may be limited; therefore the right to privacy may be limited while taking into account the best interests of the child standard.

5.4.7 The best interests of the child

The above sections (that is the right to life, the right to dignity, the right to privacy and the right of access to health care) should be read in conjunction with section 28(2) of the Constitution, which provides that

137 Section 14.
138 Carstens and Pearmain 2007:32.

the best interests of the child are of paramount importance in all matters concerning the child.

The concept “best interests of a child” is not a new one; it has been part of South African common law since the *Fletcher* case in 1948.[139] The *Fletcher* case emphasised the fact there was a shift away from parental rights to the rights of the child.[140] The best interests standard is also to be found in international law such as Article 3 of the CRC, and is articulated in even more emphatic language in Article 4(1) of the African Charter on the Rights and Welfare of the Child,[141] 1990. It is entrenched in the Constitution in section 28(2)[142] in emphatic language.[143] The protection of the best interests of the child is also enacted in Article 16(1)(d) of the Convention on the Elimination of all Forms of Discrimination against Women, 1979.[144] The protection of the best

139 See *Fletcher v Fletcher* 1948 (1) SA 130 (A).
140 Currie and de Waal 2005:617.
141 “In all actions concerning the child undertaken by any person or authority the best interests of the child shall be the primary consideration.”
142 See also Sloth-Nielsen 1995:417.
143 Skelton in Boezaart (ed) 2009:280.
144 “The same rights and responsibilities as parents, irrespective of their marital status, in matters relating to their children; in all cases the interests of the children shall be paramount.”

interests of a child is taken even further in sections 7,[145] 8[146] and 9[147] of the Children's Act, where the factors to be taken into account when determining the best interests of a child are listed.[148] Although this standard is mostly used in divorce cases and ensuing custody battles, in terms of section 9 the Act, the best interests standard should be considered in all matters affecting the well-being of a child and not only those rights enunciated in section 28[149] and should therefore also be used as a guideline when decisions are made regarding the treatment, continuation of treatment or withholding of treatment of critically-ill neonates.

It is, however, difficult to interpret this term objectively. Health care professionals and parents might differ on what exactly might be in the "best interests" of children; in such a case the High Court could be

145 Section 7 provides a comprehensive list of factors that should be taken into account whenever the child's best interests standard is applied.

146 (1) The rights which a child has in terms of this Act supplement the rights which a child has in terms of the Bill of Rights.
(2) All organs of state in any sphere of government and all officials, employees and representative of an organ of state must respect protect and promote the rights of children contained in this Act.
(3) A provision of this Act binds both natural or juristic persons, to the extent that it is applicable, taking into account the nature of the right and the nature of any duty imposed by the right."

147 "In all matters concerning the care, protection and well-being of a child the standard that the child's best interest is of paramount importance, must be applied."

148 Kruger and Skelton (eds) 2010:4.

149 Malherbe in Boezaart (ed) 2009:440.

requested to step in and intervene.[150] As the upper guardian of all minors, the High Court can intervene in the best interests of the neonate in cases where tension arises between the interests of the neonate and the parents' interests.[151] However, this is a power that will only be used in exceptional circumstances and upon request, since the High Court also recognises that parents as guardians of their children are in a better position to judge what is in their best interests and the High Court also has to respect the autonomy of parents.[152] It should be borne in mind that the best interests of the child standard has not been introduced for the protection of parental rights but for the protection of children and parents are compelled to act in the best interests of their children.[153]

The best interests standard is used by courts as the upper guardian of all minors in South Africa to exercise their discretion in cases where minors are involved in such a way that the best interests of all minors and not their parents are indeed promoted.[154] In a number of cases concerning various aspects pertaining to the rights of children (inter-country adoption, education, deportation of unaccompanied foreign

150 Fortin 2009:368.
151 Clark 2001:615.
152 Clark 2001:615; Nicholson and Politis 2001:601.
153 Pieterse 2003:2.
154 Currie and de Waal 2005:617-618.

children and child pornography), the courts have employed this standard in reaching a decision and in so doing have shed some light on what exactly this standard entails.

Minister of Welfare and Population Development v Fitzpatrick[155] was the first case in which the Constitutional Court elaborated on the ambit of section 28(2) and the fact that it "is a right, and not just a guiding principle".[156] This means that section 28(2) is taking the best interests standard further than the *Fletcher* case, where it was established as a common law principle, whereas it is now a right in itself.[157]

> "Section 28(1) is not exhaustive of children's rights. Section 28(2) requires that a child's best interests have paramount importance in every matter concerning the child. The plain meaning of the words clearly indicates that the reach of s 28(2) cannot be limited to the rights enumerated in s 28(1) and s 28(2) must be interpreted to extend beyond those provisions. It creates a right that is independent of those specified in s 28(1)."[158]

155 2000 (3) SA 422 (CC).
156 Skelton in Boezaart (ed) 2009:280.
157 Schäfer 2011:153; Skelton in Boezaart 2009:280.
158 *Minister of Welfare and Population Development v Fitzpatrick*:[17].

In *Laerskool Middelburg v Departementshoof, Mpumalanga*[159] Bertelsman J held that when there are competing interests between disagreeing parties, the rights of children and therefore the best interests of children should be the primary consideration and not those of the applicants and respondents.[160] The court per De Vos J[161] held that although the best interests standard is not a new concept in South African law, section 28(2) "goes considerably further than the original concept". In *AD and another v DW and others* (Centre for Child Law as Amicus Curiae; Department of Social Development as Intervening Party),[162] the court balanced the child's best interests against the country's international obligations to determine which the most weight should be attached to.[163] Likewise, the court weighed the best interests of the child, more particularly the child's right to parental care which would be disrupted if the primary caregiver were imprisoned, against the rights of the community to be protected from the effects of crime.[164]

159 2003 (4) SA 160 (TPA).
160 *Laerskool Middelburg*:178A-D.
161 *Centre for Child Law v Minster of Home Affairs* 2005 (6) SA 50 (TPD):[16].
162 2008 (3) SA 183 (CC).
163 *AD v DW (Centre for Child Law as Amicus Curiae; Department for Social Development as Intervening Party)* 2008 (3) SA 232 (CC):[55],[59].
164 Skelton in Boezaart (ed) 2009:284.

In *De Reuck v Director of Public Prosecutions, WLD*[165] the court held that, like any other right in the Bill of Rights, section 28(2) may also be limited in terms of section 36 of the Constitution. “This laid to rest the idea that, because of the paramountcy principle, children’s best interests could act as a trump, always overriding other rights.”[166] In *S v M (Centre for Child Law as Amicus Curiae)* Justice Sachs also recognised the fact that the best interests can indeed be limited in terms of section 36 of the Constitution: “Accordingly, the fact that the best interests of the child are paramount does not mean that they are absolute. Like all rights in the Bill of Rights their operation has to take account of their relationship to other rights, which might require that their ambit be limited.”[167]

A further problem with the standard is that not all parents have the same idea of exactly what is in their children’s best interests. In other words, this may differ from parent to parent. *Hay v B*[168] is an example of a case of conflict between parents' rights and the child’s best interests. *In casu* a paediatrician applied as a matter of urgency to the High Court to administer a blood transfusion to an infant who would not be able to

165 2004 (1) SA 406 (CC):[55].
166 Skelton in Boezaart (ed) 2009:282.
167 *S v M (Centre for Child Law as Amicus Curiae)*:[26].
168 2003 (3) SA 492 (W).

survive without a blood transfusion.[169] The infant's parents objected to the blood transfusion on two grounds: Their first objection was based on religious grounds as a blood transfusion was against the tenets of their religion. Their second objection was their concern about the risk of infection. The court granted the paediatrician permission to administer a blood transfusion on the following grounds:[170]

- In terms of s 28(2) of the Constitution a child's best interests are of paramount importance in every matter concerning the child.[171]
- The child's right to life is protected in terms of section 11 of the Constitution and as such is an inviolable right.[172]
- The parents' right to freedom of religion in terms of section 15(1) of the Constitution should be respected, but in this case the parents' beliefs are neither reasonable nor justifiable.[173]
- The High Court is the upper guardian of all minors in South Africa and in that capacity can order that medical treatment be given if such treatment is in the best interests of the minor.[174]

169 For a discussion of this case, see chapter 4 par 4.3.1.
170 See also McQuoid-Mason and Lotz 2005:315-321.
171 *Hay v B*:494.
172 *Hay v B*:495.
173 *Hay v B*:495.
174 *Hay v B*:495.

In conclusion, the court held that the parents' religious beliefs could be overridden by the best interests of the child and the child's right to life.[175] In *Hay v B*[176] the court erroneously referred to *In re T (a Minor Wardship: Medical Treatment)* [1997] 1 All ER 906 (CA)[177] as proof that "the paramount consideration in instances such as this was the welfare of the child and not the reasonableness of the parents' refusal of consent".[178] This case was criticised for the very fact that it did not take into consideration the fact that the child's best interests are of paramount importance, but instead the parents' interests were the overriding factor when they were not ordered to allow their child to have a lifesaving liver transplant.[179] It would have been more appropriate for the court to refer to *In re O (a Minor) (Medical Treatment)* [1993] 4 Med LR, which also dealt with a blood transfusion where the parents were Jehovah's Witnesses and as such refused a lifesaving blood transfusion. The court

175 See also Kassan and Mahery in Boezaart (ed) 2009:218. Similar cases involving parents who objected that blood transfusions be administered to their children because they were Jehovah's witnesses were reported in the press. Zelda Venter "Doctors get blood for baby in court" *Pretoria News* 25 October 2005, (also reported as follows: Cornelia du Plooy "Baby given blood after court ruling 'doing well' *Pretoria News* 26 Oktober 2005, Pieter du Toit "Bloedoortapping op baba gedoen al sê Jehova-ma nee" *Beeld* 29 October 2005), Bongani Mthethwa "Court rules against religious beliefs" *Sunday Times* 23 September 2007, Gareth Wilson "Judge orders baby to ge givne blood transfusion" *The Herald* 9 July 2008, Ingrid Oellerman "Judge orders blood transfusion for critically ill baby" *Witness* 6 November 2008, Kanina Ross "Court order saves Jehova's Witness girl's life: *Star* 20 February 2009.

176 *Hay v B*:495.

177 This case is also reported as *In re T (a Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

178 *Hay v B*:495.

179 This case is dealt with in more detail in chapter 6 par 6.2.5.5 below.

authorised a blood transfusion. The court could even have referred to *In re B (a Minor*) (*Wardship: Medical Treatment*) or any of the other cases discussed in chapter 6 where the best interests standard was applied.[180]

It is important to remember that children have different health needs from adults and likewise premature and critically-ill neonates have different health needs from normal neonates. Neonates, especially premature babies and critically-ill neonates, can die if timeous and appropriate medical treatment is not provided. It should be borne in mind that medical practitioners are not compelled to administer treatment that is futile.[181] Nowadays premature and critically-ill neonates can be kept alive for longer with the aid of new medicines and technology, however with a severe risk of being severely handicapped and with the possibility that they will be able to enjoy little personal interaction.[182] Treatment might not always be in the best interests of a neonate; it could even cause more pain than non-treatment. The irony is that the better the cognitive function of the baby, the more discomfort and suffering that neonate will experience when on life support.[183]

180 Both *In re O* and *In re B* are discussed in detail in chapter 6 par 6.2.4.1 and 6.2.5.5 respectively.
181 Fortin 2009:379.
182 Nel 1996:73.
183 Fortin 2009:380.

The best interests standard has been the subject of criticism because it is indeterminate.[184] This criticism is even more applicable with regard to this vulnerable group of infants than it is to healthy infants.

Heaton[185] lists certain requirements that should be in place before the best interests can be determined:

- All the available options must be known.
- All the possible outcomes of each option must be known.
- The probabilities of each outcome occurring must be known.
- The value attached to each outcome must be known.

When dealing with premature or critically-ill neonates, because of economic constraints all the options might not be available—certain options might only be available in private hospitals and would therefore be beyond the means of less wealthy parents. Parents who are paid-up members of a medical aid fund are able to have their child admitted to a private hospital where they can receive the best treatment possible, while those who cannot afford medical aid have to be admitted to public hospitals where they might not get the same treatment as those in

184 Heaton 1990:95; Schäfer 2011:154-155.
185 Heaton 1990:95.

private hospitals. Two recent newspaper articles illustrate this discrepancy between the treatment offered to premature babies in public and private hospitals. At the Jubilee Hospital, a public hospital in Hammanskraal, north of Pretoria, premature babies died after suffering burns as a result of "unsafe heating practices."[186] The babies were not put into incubators because the equipment was faulty, but instead Vacoliter fluid was heated and placed in the babies' cribs in order to raise their body temperature.[187] The same newspaper report mentions several other premature or low birth weight babies who died while they were still in the NICU of this hospital. Exactly the opposite case was reported in another newspaper: a baby girl was born at Netcare Blaauwberg, a private hospital in Cape Town, at 22 weeks and 4 days weighing only 515 grams at birth. A special incubator, a giraffe incubator, was borrowed from a private hospital in Johannesburg to ensure that the Lategan baby received only the best treatment. When this report was published baby Lategan was 8 weeks old, weighing less than 1 kilogram, but still alive.[188] These two newspaper reports illustrate

186 Thandi Sakde "City baby deaths are blamed on hospital staff. Report tells of 'unsafe practices'". *Pretoria News* 29 September 2011.

187 Thandi Sakde "City baby deaths are blamed on hospital staff. Report tells of 'unsafe practices'". *Pretoria News* 29 September 2011.

188 Elsabé Brits "Gebore op 22 weke, 4 dae. Medisyne word in haar are gesien." *Beeld* 21 September 2011.

the difference in the treatment that a premature baby or critically-ill neonate can receive at a public and a private hospital.

A child is born into a particular milieu—he or she may be born into a family with fewer resources at their disposal and no medical aid fund, which would mean that they do not have a choice when it comes to medical care. They would have to rely on state-funded public hospitals. A neonate should be entitled to the best possible medical care available, irrespective of whether his or her parents are wealthy.

Neither the possible outcomes nor the probabilities of treatment nor non-treatment might be known. Even more so than is the case with healthy infants, the best interests of premature and critically-ill neonates cannot always be determined with absolute certainty, and any assessment is largely speculative.[189] Subjective and objective approaches can be employed in an attempt to determine the best interests of premature and critically-ill neonates. The subjective approach entails that the child's subjective point of view should be the determining factor.[190] This approach entails that the parents (or health care professionals) put

189 Heaton 1990:96.
190 Heaton 1990:97.

themselves in the position of the neonate with the knowledge that they have, and then try to determine what the neonate would have decided had he or she been in a position to do so. The objective approach, on the other hand, would entail that the parents decide as objectively as possible, taking all relevant factors into consideration before reaching a decision, what would be in the best interests of a particular neonate. Heaton[191] suggests that a combination of the subjective and objective approaches should be applied.

Heaton[192] points out that a further problem with the best interests standard is whether the best interests of the child should be viewed from a short-term, medium-term or long-term perspective. The fact that physicians' knowledge "is not always reliable or certain in all cases, and the wishes of all parents are also not necessarily realistic or reasonable"[193] makes it even more difficult to determine what would be in the best interests of vulnerable neonates in the short, medium or long term.

191 Heaton 1990:97.
192 Heaton 1990:96.
193 Miller 2007:34.

Since neonates (this includes premature and critically-ill babies) are in no position to decide for themselves regarding possible treatment, parents usually have to exercise their discretion regarding treatment. The decisions they have to take include whether to apply treatment, continue treatment or withhold treatment. In such a case the issue that may arise is whether a court could override the parents' decision,[194] in other words whether a court would interfere with parents' autonomy when it comes to decision making.[195]

It is even more difficult to determine the best interests of neonates, since the collective interests of the family should also be considered.[196] There is a potential for conflict where the parents' view of what would be in the best interests of the neonate differs from the view of the health care professionals. When there is a premature and critically-ill neonate in a family where there are already other siblings, the best interests of all family members should be considered. This complicates the determination of the best interests standard. Ultimately the combined interests of the parents and other family members may outweigh the

194 Clark 2001:607. This article deals with older children, but the question is even more imminent when it comes to neonates.
195 This issue will be dealt with comprehensively in chapter 6 in which the English case law will be discussed.
196 Clark 2001:617.

interests of a particular neonate.[197] The best interests of children may not necessarily be the same as the best interests of the parents.[198] The best interests of the different parties should be weighed up before reaching a decision.

McClaren[199] argues that the best interests concept should not be regarded as a right, but rather as a principle. This reasoning is based on the consideration that "best interests" would then apply in relation to all other children's rights. "It would be a tool of interpretation counting in favour of an interpretation of the particular right which is perceived to be in the child's best interest. This would have the effect of a greater number of cases having outcomes that are in children's best interests. This is clearly the approach supported by the Convention on the Rights of the Child".[200]

McClaren goes on to argue that if the "best interest" concept is regarded as a right rather than a principle, this would have a negative effect on the protection of children, since a right can be limited in terms of section 36

197 Clark 2001:617.
198 Pieterse 2003:7.
199 McClaren 2005:126.
200 McClaren 2005:126.

of the Constitution.[201] This would have a severe impact on the protection of this vulnerable group of infants, since their rights to protection could be limited because resources are not available, as happened in the *Soobramoney* case.

Social and economic rights, the so-called second generation rights, will also need to be considered in conjunction with the best interests of the child. These rights require the government to take positive action to ensure that they are realised.[202]

5.4.8 Section 28(1)(c) of the Constitution

Section 28(1)(c) of the Constitution reads: "Every child has the right to basic nutrition, shelter, basic health care services and social services." Normally the court will only intervene when requested to do so by hospital authorities when parents refuse to consent to life-saving treatment.

As was seen from a discussion of the *Soobramoney* case above, these rights are also subject to limitations, in this case the internal limitation in

201 McClaren 2005:125-126.
202 De Vos 1995:238. This article was written before the Constitution came into operation in 1996 and therefore still refers to the interim Constitution.

terms of section 27(2) of the Constitution, namely the availability of resources. Since this will have serious implications for decisions on whether or not to treat premature and critically-ill neonates, some of the rights that will impact on the treatment of these infants will be discussed below. The problem lies with the enforcement of these second-generation rights. Does the government have to respect these rights or does the government have to provide these rights?[203] Or does the state only step in when these rights are endangered by private individuals or bodies, such as the parents or health care professionals?[204] Pieterse[205] observes that normally the state (i.e. the public sphere) would not interfere in family life (i.e. the private sphere). However, the CRC and the permeation of its values into the Constitution actually imply the opposite of this argument.[206] "In contrast, children's rights to basic nutrition, shelter, basic health care services, and social services, do not have an internal limitation and are phrased as rights 'to' as opposed to rights 'to have access to'".[207]

203 See also De Vos 1995:253.
204 See also De Vos 1995:255.
205 Pieterse 2003:2.
206 Pieterse 2003:3-4.
207 Proudlock in Boezaart (ed) 2009:294.

South African legislation will also be scrutinised to determine whether effect is given in legislation to the rights of children enunciated in International Human Rights Instruments and the Constitution of the Republic of South Africa, 1996.

5.5 South African legislation

5.5.1 The National Health Act 61 of 2003

The National Health Act was enacted to give effect to section 27 of the Constitution of the Republic of South Africa, 1996.[208] The Act sets out its objects, which are among others to protect, respect, promote and fulfil the rights of vulnerable groups, such as women, children, older persons and persons with disabilities.[209] Neonates, which would include both premature babies and critically-ill neonates, would fall into this group. However, no definition of "neonate" is provided in the Act. Neither is specific mention made of this group anywhere in the Act. It is a fact that

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208 27(1) Everyone has the right to have access to –
(a) health care services, including reproductive health care;
(b) sufficient food and water; and
(c) social security, including, if they are unable to support themselves and their dependants, appropriate social assistance.
(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.
(3) No-one may be refused emergency treatment.

209 Section 2(c).

infants in this group would often be left with disabilities if they survive and would then be offered protection under this Act. However, the Act does not state how they should be protected, what form of protection should be provided or how their rights should be respected or fulfilled. The only form of protection that is mentioned is the provision that this vulnerable group, including pregnant and lactating women and children below the age of six years, are eligible for free health services.[210] It is uncertain whether these health services are limited to primary care and emergency treatment, or whether they would include specialised treatment, for example in a neonatal intensive care unit. Büchner-Eveleigh and Nienaber[211] are of the opinion that all medical services are available to children under the age of six years at public hospitals, although the standard of the medical service is not defined.

The government only has to provide the minimum core of health services and the provision of health care services is subject to the availability of resources.[212] Since health care is such an important

210 Section 4(3)*(a)*: subject to any condition prescribed by the Minister, the State and clinics and community health care centres funded by the State must provide –
(a) pregnant and lactating women and children below the age of six years, who are no members or beneficiaries of medical aid schemes, with free health services".
See also Oosthuizen and Verschoor 2008:38.

211 Büchner-Eveleigh 2012:114-115.

212 Section 3. See also section 27(2) of the Constitution.

component of the right to life, the provision of health care should not be limited to the availability of resources. This is true, especially regarding the treatment of neonates, both premature and critically-ill neonates.

5.5.2 *The Children's Act 38 of 2005*

In the Children's Act[213] a child is broadly defined as a person under the age of 18 years. This does not take into account the different stages of development of a child between birth and 18 years and the fact that children at different stages of development need different forms of protection. However, the other forms of protection built into this Act, into other South African legislation and embodied in case law will ensure some form of protection to all children, including neonates.

5.5.2.1 Consent to medical treatment

As early as 1923, the principle was established in South African law that consent to medical treatment is necessary before a doctor can continue with an operation.[214] Without the necessary consent any operation would be an unlawful infringement of the patient's right to security of the person. In the *Stoffberg* case an operation was performed without the

213 Section 1.
214 *Stoffberg v Elliott* 1923 CPD 148. See also Oosthuizen and Verschoor 2008:38.

necessary consent and as such it was “a wrongful act and, an infringement of the plaintiff’s rights, not justified by urgency or any other ground”.[215] If a doctor continues to perform an operation or to give medical treatment without the necessary consent, this amounts to assault “for which the doctor may be held liable in a civil action for damages and be criminally prosecuted”.[216] This principle was confirmed in a subsequent case, that of *Castell v De Greeff*.[217] *In casu* permission for the operation was obtained, but the doctor’s failure to warn the patient of the material risk attached to the operation constituted lack of informed consent. “It is important in my view, to bear in mind that in South African law (which would seem to differ in this regard from English law) consent by a patient to medical treatment is regarded as falling under the defence of *volenti non fit injuria*, which would justify an otherwise wrongful delictual act.”[218]

Consent is usually implied by the patient’s conduct, but it could also be express written or verbal consent.[219] In the case of neonates, the

215 *Stoffberg v Elliott*:150. See also Carstens and Pearmain 2007:500.
216 Strauss 1991:31.
217 1994 (4) SA 408.
218 *Castell v De Greeff* 1994 (4) SA 408:420H.
219 Carstens and Pearmain 2007:898.

question of consent is regulated by section 129 of the Children's Act 38 of 2005.[220]

Section 129(1) provides that consent is needed before a child can be subjected to medical treatment or a surgical operation. In certain cases the child may consent to his or her own treatment,[221] but in the case of neonates, the parent, guardian or care-giver can consent to medical interventions.[222] The term "treatment" is not defined in the Act, but it is submitted that it means any medical treatment that does not involve surgical intervention.[223] In terms of section 129(4)[224] a parent, guardian or care-giver may consent to medical treatment, other than surgery.[225] This form of consent is subject to section 31, which deals with major decisions involving the child. Of particular significance is section 31(2)*(a),* which provides that "[b]efore a person holding parental

220 Certain sections of the Children's Act 38 of 2005 came into force on 1 July 2007, but section 129 only came into force on 1 April 2010. In section 7 of the National Health Act it is also stipulated that informed consent is necessary before a doctor can lawfully continue with any form of medical intervention. Section 7(a)(ii) is relevant in this context. It provides that consent can also be obtained from a person authorised to give such consent in terms of any law or court order in cases where the patient cannot give consent himself. See also Oosthuizen and Verschoor 2008:38.

221 Section 129(2),(3).

222 Section 129(4),(5).

223 Sloth-Nielsen in Davel and Skelton (eds) 2007:7-35.

224 "The parent, guardian or care-giver of a child may, subject to section 31, consent to the medical treatment of the child if the child is –
(a) under the age of 12 years; or
(b) over that age but is of insufficient maturity or is unable to understand the benefits, risks and social implications of the treatment."

225 See also Kassan and Mahery in Boezaart (ed) 2009:210.

responsibilities and rights in respect of a child takes any decision contemplated in paragraph *(b)*, that person must give due consideration to any views and wishes expressed by any co-holder of parental responsibilities and rights in respect of the child". This section should be read with section 30, which deals with co-holders of parental responsibilities and rights, and especially section 30(2), which provides that co-holders of parental responsibilities may act without the other party's consent, except when this Act, any other law or court order provides otherwise. Decisions concerning the medical treatment of a child are major decisions involving the child, and therefore co-holders of parental responsibility need to consult with each other when making these decisions. However, this does not mean that the consenting party necessarily needs to act in accordance with the wishes and views of the other party.[226] It should be emphasised that any decision should be made bearing in mind what is in the best interests of a child.

In urgent cases the superintendent or person in charge may consent to medical treatment or surgical intervention.[227] This section sets out which

226 Kassan and Mahery in Boezaart (ed) 2009:210.

227 Section 129(6): "The superintendent of a hospital or the person in charge of the hospital in the absence of the superintendent may consent to the medical treatment of or a surgical operation on a child if –

circumstances should be regarded as an emergency. This is in line with section 6(4)*(b)*,[228] which provides that a delay should be avoided as far as possible in any matter concerning the child. In this respect the Children's Act differs from section 7(1)*(e)* of the National Health Act, which provides that a health service may not be provided unless a delay in medical treatment would prove to be fatal to the patient or cause irreparable harm to his or her health and the patient has in no way, neither tacitly, impliedly or by conduct refused service.[229]

The Children's Act also makes provision for the Minister of Social Development to consent to medical treatment in cases where the parents unreasonably withhold permission, cannot give consent, cannot be traced or are deceased.[230] In the last instance the Children's Act provides that the High Court or a children's court may consent to

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(a) the treatment or operation is necessary to preserve the life of the child or to save the child from serious or lasting physical injury or disability; and
(b) the need for the treatment or operation is so urgent that it cannot be deferred for the purpose of obtaining consent that would otherwise have been required."

228 In any matter concerning a child –
(b) a delay in any action or decision to be taken must be avoided as far as possible."

229 See also Kassan and Mahery in Boezaart (ed) 2009:211.

230 Section 129(7): "The Minister may consent to the medical treatment of or surgical operation on a child if the parent or the guardian of the child –
(a) unreasonably refuses to give consent or to assist the child in giving consent;
(b) is incapable of giving consent or of assisting the child in giving consent;
(c) cannot readily be traced; or
(d) is deceased."
See also McQuoid-Mason and Dhai in Dhai and McQuoid-Mason 2011:79.

medical treatment if the parent, guardian or some other person with legal capacity to do so refuses to give consent or is unable to give consent.[231] This route is the one preferred by legal practitioners since it causes the least delay.[232]

5.5.2.2 Children with disabilities and chronic illnesses: Section 11 of the Children's Act

In section 11 of the Children's Act some form of protection is afforded to a particularly vulnerable group of children, namely children with disabilities or chronic illnesses. The group of neonates under discussion, namely premature and critically-ill neonates, would fall into this category, although no specific mention is made of this category of infants. In section 11(1)*(a)* it is provided that in the case of a child with disabilities "due consideration" should be given to the provision of special care for this vulnerable group of infants. In terms of section 11(1)*(d)* a child with disabilities and his or her care-giver are guaranteed the right to the "necessary support services". However, no definition of the term "support services" is provided in section 1. Neither is it defined in section

231 Section 129(9): "A High Court or children's court may consent to the medical treatment of or a surgical operation on a child in all instances where another person that may give consent in terms of this section refuses or is unable to give such consent."
232 Kassan and Mahery in Boezaart (ed) 2009:212.

11 of the Act. Furthermore, in section 11(2) reference is made to "special care" for children with a chronic illness. As in the case of "support services", no definition is provided for "special care" in either section 1 or section 11 of the Act. The protection afforded to children with disabilities and chronic diseases is primarily aimed at providing a child with a disability with "education, training and health services"[233] with the purpose of preparing him or her for employment when he or she reaches adulthood.

In section 106(2)*(c)*[234] further protection is given in the form of therapeutic programmes. Again, this is not defined and it is uncertain in which circumstances "therapeutic programmes" should be provided and what exactly the therapeutic programmes would entail.

Although neonates are not specifically mentioned in the Children's Act, they are included as a group and enjoy the rights enunciated in international human rights instruments and South African legislation. This is also in line with legislation in England and Wales, Scotland, Northern Ireland and the Netherlands.

233 Davel and Skelton (eds) 2007:2-16.
234 According to this subsection national norms and standards must, among others, relate to therapeutic programmes.

5.6 Green Paper on National Health Insurance in South Africa

National Health Insurance (hereinafter NHI) is envisaged by the government of South Africa for all South African citizens, which will have far-reaching consequences for the health system in South Africa. It aims to reform the health care system so that affordable, quality health services are provided to all South Africans. At the moment the public sector has to render services to the largest part of the population with the least resources, while medical schemes, which are the biggest consumer of medical services, render medical services to only 16.2% of the population.[235] There are also a disproportionately high number of health care professionals per patient in the private sector in comparison to the public sector.[236] The aim is to transform the current South African health system into an improved and more equitable health system.[237]

Section 2.1.2 of the NHI is devoted to maternal, child and infant mortality. It is stated in this section that the perinatal and neonatal mortality rates are still higher in South Africa than in other countries at a similar stage of socio-economic development. In a footnote the report draws the following distinction between the perinatal mortality rate and

235 NHI Policy Paper 2011:4.
236 NHI Policy Paper 2011:10.
237 NHI Policy Paper 2011:5,15.

the neonatal mortality rate: according to the Green Paper, the perinatal mortality rate is "the death of a baby who was born live after 20 weeks of pregnancy or dies within 7 completed days after birth measured 1000 births".[238] The neonatal mortality rate is defined as "the death of a live born baby within 28 days of birth and is measured per 1,000 live births".[239]

Hospitals will operate at different levels and will be able to provide different levels of treatment as staff members will have the qualifications and skills appropriate for each level of hospital.[240] Hospitals will be divided into the following categories:

- District hospital (the smallest type of hospital, which will provide generalist medical services)
- Regional hospital (will offer a range of general specialist services and will receive referrals from district hospitals)[241]
- Tertiary hospital (these hospitals will render super-specialist and sub-specialist care. They will also serve as a platform for

238 NHI Policy Paper 2011:8 fn 6.
239 NHI Policy Paper 2011:8 fn 7.
240 NHI Policy Paper 2011:29.
241 NHI Policy Paper 2011:30.

the training of health care workers and researchers.)[242]

- Central hospital (national referral hospitals, attached to a medical school, that will render very highly specialised care with high technology and highly trained staff)[243]
- Specialized hospital ("The specialized hospitals are usually one discipline focused and are extremely vertical in the range of services offered at the hospital.")[244]

In order to address the exceptionally high maternal and infant mortality rate, the following specialists will be based at district hospitals: A principal obstetrician and gynaecologist, a principal paediatrician, a principal family physician, a principal anaesthetist, a principal midwife and a principal primary health care professional nurse.[245] According to the Green Paper, patients will be transferred to a higher or lower level of care as required.

Since this is only a Green Paper, it is uncertain what the effect will be once it has been implemented. It seems to be a commendable effort on

242 NHI Policy Paper 2011:30.
243 NHI Policy Paper 2011:30.
244 NHI Policy Paper 2011:30.
245 NHI Policy Paper 2011:24.

the part of the government to provide equal and affordable medical treatment to all South African citizens and permanent legal residents, but how effective it will be remains to be seen. Although mention is made of the infant and child mortality rate, no specific reference is made to neonates. Neither is mention made of NICUs. It is suggested that these will be located at tertiary hospitals, central hospitals or even specialised hospitals. It is submitted that a neonate might be born in a district hospital that does not have specialised facilities such as a NICU and will have to be transferred to a bigger hospital with suitable facilities and trained staff. The transfer, together with the associated risk and trauma, could be fatal for such an infant. Moreover, valuable time before treatment is initiated may be lost when the neonate has to be transferred. It is submitted that more research will have to be done by the compilers of this Paper before this policy can be implemented, to make provision for premature and critically-ill neonates.

5.7 Conclusion

The right to life as the most fundamental right is protected in all international human rights instruments, including our Constitution, where it is protected in section 11. States Parties to the International Covenant

on Economic, Social and Cultural Rights (ICESC) and the Convention on the Rights of the Child (CRC) also undertook to reduce the infant mortality rate by introducing a high standard of health care, which implies more than primary health care alone. The standard of the right to physical and mental health proposed in the African Charter on Human and People's Rights is very high: "Every individual shall have the right to enjoy the best attainable state of physical and mental health."[246] The CRC goes even further and requires "the highest attainable standard of health and the facilities for the treatment of illness and rehabilitation of health".[247] The best interests of the child standard was introduced in the CRC in Article 3 and was reiterated in the African Charter on Human and Peoples' Rights and the African Charter on the Rights and Welfare of the Child in Article 4 in even more peremptory language.

The right to life is entrenched in the Constitution, but there is no right to health. Instead there is a right of “access to health care services”[248] and “emergency medical treatment”.[249] Children's rights are protected in section 28; of particular importance is section 28(2), which contains the

246 Article 16.
247 Article 24.
248 Section 27(1)(a).
249 Section 27(3).

“best interests” standard. This section gives effect to Article 3 of the CRC.

A perusal of the Children's Act and the National Health Act reveals that in neither of these two pieces of legislation is any concerted effort made to reduce the infant mortality rate, and to ensure the survival of infants as enunciated in MDG 4. The protection afforded by the Constitution, the Children’s Act and the National Health Act is inadequate and fails to protect neonates despite the requisites of international human rights instruments to which South Africa is a signatory, namely the CRC and the African Charter on Human and Peoples' Rights.

CHAPTER 6

THE LEGAL PROTECTION OF NEONATES IN ENGLAND AND WALES

6.1 Introduction

In order to be able to formulate a framework for the legal protection of preterm infants and critically-ill neonates, it is essential to investigate the legal systems of other countries. This will enable us to incorporate tried and tested practices from other countries into our legal system. The first legal system that will be studied is that of England and Wales. The legal principles as they are applied in England and Wales can best be learnt by perusal of the judgments of the courts in these judicial systems.[1] Where applicable, brief reference will be made to relevant legislation in Scottish law, as well as to that the law of Northern Ireland. Since no relevant cases have as yet reached the courts of either Scotland or Northern Ireland, unlike England and Wales, the former two jurisdictions will not be dealt with in detail.

The law will not be studied in isolation; relevant court cases will be analysed as well. The focus of this chapter will be on the right to health care of neonates, especially premature and critically-ill neonates.

1 Brazier and Cave 2007:380.

6.2 The law of England and Wales

From a perusal of the legislation, it appears that three jurisdictions operate in the United Kingdom, namely England and Wales, Scotland and Northern Ireland. As far as could be ascertained, the only jurisdiction within the United Kingdom in which cases were heard where the court was asked to intervene when there was disagreement between parents and health care personnel on whether to withdraw or withhold life-saving treatment, or sanction a particular course of action, was in England and Wales.[2] Therefore, the focus will be on England and Wales. It is assumed that should similar cases reach the courts of Scotland and Northern Ireland the English precedent will be followed,[3] as far as it is consistent with the legislation of these jurisdictions.[4] When there is conflict with the legislation of Scotland and Northern Ireland, the courts will not be bound by these decisions and English case law will then only have persuasive power.[5]

6.2.1 Background

Preterm infants and neonates do not have a voice of their own and are therefore vulnerable and dependent upon others, usually their parents,

2 Meyers 2005:308. See also Lloyd (ed) 2001:68.
3 Lloyd (ed) 2001:68.
4 Lloyd (ed) 2001:54.
5 Lloyd (ed) 2001:54.

health care professionals or, as a last resort, the court, to make decisions regarding their emotional, physical and financial well-being.[6]

In England and Wales, the fetus is not regarded as a person and consequently has no rights;[7] therefore a deformed fetus can be aborted any time before live birth.[8] When it is certain that a fetus has been born alive, he or she becomes a legal person and is awarded all the rights of a legal person.[9] He or she also acquires all the rights associated with personhood as set out in the United Nations Convention on the Rights of the Child, 1989 (CRC), which the British government ratified in 1991.[10] Although the CRC is not directly enforceable in courts in the United Kingdom, it does give guidelines on how the law in the UK should be developed.[11] Articles 3, 6 and 24 of the CRC are of particular importance regarding the health care of children. Article 3(1) of the CRC places an obligation on States Parties.[12] Article 6 protects a child's right to life.[13] Article 24 of the CRC requires States Parties to "recognize the right of

6 Bridgeman 2007:8; Tripp and McGregor 2006:67.
7 Alderson ea 2005:32.
8 Brazier 1996:318.
9 Brazier in Goldworth ea (eds) 1995:327; Brazier 1996:318; Elliston in Norman and Greer (eds) 2005:389.
10 Alderson ea 2005:32,47.
11 NCOB 2006:47.
12 In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.
13 6(1) States Parties recognize that every child has the inherent right to life.
(2) States Parties shall ensure to the maximum extent possible the survival and development of the child."

the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health". The first of the five outcomes listed in the document "Every Child Matters" embodies this right by stating that the first outcome is "being healthy".[14]

Young children are given the right to health care in section 1(2) of the Children and Young Persons Act 1933 and also more recently in various sections of the Children Act 1989. In England and Wales this means that a baby is "entitled to state services such as free neonatal care".[15]

Children's rights differ from those of adults as children are dependent upon adults for their day-to-day care and other basic needs and this, in turn, imposes duties upon parents.[16]

14 Fortin 2009:364.
15 Alderson ea 2005:40.
16 Bridgeman 2007:16.

6.2.2 Parental responsibility

The promulgation of the Children Act introduced a move away from parental rights to parental responsibilities.[17] Children are no longer considered to be the property of their parents, but since the emphasis has shifted, parents now have a responsibility to protect their children and their interests.[18] This Act also highlights the fact that the responsibility for their children rests primarily with their parents and not the state.[19]

Article 8[20] of the European Convention on Human Rights and Fundamental Freedoms, 1950 (ECHR), has been given legal effect in the Children Act 1989, and this means that it is state policy not to interfere in the private realm of family life as set out in section 1(5).[21] The state only fulfils the role of protector of children and families in need.[22]

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17 Bainham in Probert ea (eds) 2009:23; Bridgeman 2007:228; Featherstone in Wallbank ea (eds) 2010:36; Fortin 2009:324; Mitchell 2006:64.

18 Fletcher ea 1995:152.

19 Bridgeman 2007:228.

20 8(1) Everyone has the right to respect for his private and family life, his home and his correspondence.
8(2) There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

21 Bridgeman 2007:20; Featherstone in Wallbank ea (eds) 2010:36. Section 1(5) of the Children Act 1989 reads as follows: "Where a court is considering whether or not to make one or more orders under this Act with respect to a child, it shall not make the order or any of the orders unless it considers that doing so would be better for the child than making no order at all."

22 Bridgeman 2007:228.

The state will only intervene in the family realm and request care proceedings in terms of section 31A of the Children Act if there is significant harm[23] to the child in question.[24]

Although parents are the primary caretakers of their children, they are dependent on others with expert knowledge to enable them to fulfil their responsibilities.[25] The importance of parental responsibility in this context is that legal consent for medical intervention in the case of a very young patient can only be obtained from someone who has parental responsibility over that child.[26] Consent from one person with parental responsibility, usually a parent, is needed before a doctor can proceed with the proposed treatment.[27] Although the concept "parental responsibility" is defined in section 3 of the Children Act as meaning "all the rights, duties, powers, responsibilities and authority which by law a parent has in relation to the child and his property",[28] parental responsibility is further given content in the case law.[29]

23 Section 31(2) A court may only make a care order or supervision order if it is satisfied –
(a) that the child concerned is suffering, or is likely to suffer, significant harm …
24 Freeman 1997:370.
25 Bridgeman in Walbank ea (eds) 2010:239.
26 Elmalik and Wheeler 2007:627.
27 Bridgeman 2007:99; Elliston in Norman and Greer (eds) 2005:366; Hagger in Probert ea (eds) 2009:186.
28 Mitchell 2006:63. See also Harper 1999:81-82.
29 Bridgeman in Probert ea (eds) 2009:256; Mitchell 2006:63-73.

Section 2 of the Children Act 1989[30] clearly defines who has parental responsibility in respect of a child. In England and Wales parents who are married to each other at the time of the birth of the child automatically have parental responsibility for that child.[31] In a case where the parents are not married to each other, the mother automatically acquires parental responsibility.[32] Unmarried fathers of children born before December 2003 do not automatically have parental responsibility. On the other hand, unmarried fathers of children born after December 2003 automatically obtain parental responsibility if their names are registered on the child's birth certificate.[33] Section 4 of the Children Act 1989 determines that parental responsibility can also be awarded to certain other persons, such as a second female partner or step parent, by an order of court.[34] Although a person with parental responsibility and rights may not transfer or surrender those responsibilities to another person, he or she may, however, arrange with

30 See the addendum for the full text.
31 See addendum for the full text of this section. See also Scherpe in Probert ea (eds) 2009:51-53; Mitchell 2006:65-66 for the different ways in which parental responsibility can be acquired.
32 Section 2(2) of the Children Act 1989. See also Scherpe in Probert ea (eds) 2009:52.
33 Elmalik and Wheeler 2007:629.
34 Elmalik and Wheeler 2007:629. It is submitted that the suitable court to hear such cases will be the High Court, particularly the Family Division. See Fletcher ea 1995:25,28-29.

someone else to take over particular responsibilities or to act on his or her behalf.[35]

There is a similar provision in Scottish legislation.[36] Both parents acquire parental responsibility if they were married at the time of the child's conception or birth or any time after the child's birth.[37] Parental responsibility thus acquired is not lost after divorce.[38] In the case of parents who have never been married, the mother automatically has parental responsibility,[39] while the father may acquire parental responsibility only after formal procedures have been adhered to.

35 Section 2(9) of the Children Act 1989 which reads: "A person who has parental responsibility for a child may not surrender or transfer any part of that responsibility to another but may arrange for some or all of it to be met by one or more persons acting on his behalf." And section 5(8) of the Children (Northern Ireland) Order 1995: reads: "A person who has parental responsibility for a child may not surrender or transfer any part of that responsibility to another but may arrange for some or all of it to be met by one or more persons acting on his behalf."

36 In section 1 of the Children (Scotland) Act 1995, the plural form, namely, "parental responsibilities", is used instead of the singular form in the Children Act 1989 and section 5 of the Children (Northern Ireland) Order 1995.

37 Section 3(1)(b) of the Children (Scotland) Act 1995: "without prejudice to any arrangements which may be made under subsection (5) below and subject to any agreement which may be made under section 4 of this Act, his father has such responsibilities and rights in relation to him only if married to the mother at the time of the child's conception of subsequently." See also Elliston in Norman and Greer (eds) 2005:366.

38 Elliston in Norman and Greer (eds) 2005:366.

39 Section 3(1)(a) of the Children Act (Scotland) 1995: "a child's mother has parental responsibilities and parental rights in relation to him whether or not she is or has been married to his father". See also Elliston in Norman and Greer (eds) 2005:366.

Article 5 of the Children (Northern Ireland) Order 1995 echoes the provisions of the Children Act 1989 and the Children (Scotland) Act 1995.

In England and Wales, parents with parental responsibility have, among others, a legal obligation to ensure that their children receive appropriate medical care.[40] If parents fail to seek appropriate medical assistance or fail to take steps to provide such assistance when necessary, this is an omission or neglect that constitutes a criminal offence in terms of section 1(1) and (2) of the Children and Young Persons Act 1933, which can lead to care proceedings.[41]

In Scotland one of the responsibilities that falls under parental responsibility is to be found in section 1(1)(a) of the Children Act (Scotland) 1995,[42] namely that a parent is responsible for the health care of his or her child. In terms of section 12 of the Children and Young Persons (Scotland) Act 1937 any form of cruelty to or neglect of a person under the age of 16 years constitutes a statutory offence.[43] "These are aimed at providing criminal sanctions against parents who

40 Hagger in Probert ea (eds) 2009:185.
41 See addendum for the full text of these sections. See also Bridge in Bainham ea 2002:276; Fortin 2009:3; Hagger in Probert ea (eds) 2009:185-186.
42 See addendum for the full text of this section.
43 See addendum for this section.

neglect their children, for example, by failing to seek appropriate medical assistance."[44]

6.2.3 Consent to medical treatment

Generally it is accepted that, except in the case of an emergency, parental neglect, abandonment of a child or where the parents cannot be found, doctors are not allowed to proceed with medical treatment before obtaining consent from a person who is authorised to give the required consent.[45] In the case of a minor or a mentally immature person who is not Gillick competent,[46] the necessary consent will have to be obtained from a parent or a person who has parental responsibility over the minor.[47] Consent may be verbal or written, save the abovementioned exceptions, and in the absence of consent, the medical treatment or invasion would constitute assault, no matter how beneficial the proposed treatment might be in the physician's opinion.[48] Section 3(5) of the

44 Elliston in Norman and Greer (eds) 2005:372.
45 Harper 1999:8.
46 The "Gillick-competence" test was established in *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112. It entails that a child under the age of sixteen can consent to medical treatment if he or she has a sufficient understanding and intelligence to understand the nature and implications of the proposed treatment. See Bridgeman in Sheldon and Thomson (eds) 1998:101; Harper 1999:8.
47 Fortin 2009:367; Harper 1999:8.
48 Brazier 1996:320; Brazier and Cave 2007:104; Elmalik and Wheeler 2007:627; Fletcher ea 1995:44-45. See also section 8(1) of the Family Law Reform Act 1969: "The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian."

Children Act 1989 provides that a person in whose care a child is left, although such a person does not have parental responsibility, may "do what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare." Article 6(5) of The Children (Northern Ireland) Order 1995[49] contains a similar provision.

The case of David Glass[50] is a landmark decision in this regard. *In casu* the principle was laid down that health care professionals are obliged to consult with the parents of a child, or the person with parental responsibility, where they are available, before proceeding with a particular course of action.[51] This decision stresses the importance of the fact that parental consent must first be obtained, or where this cannot be obtained, an order of court to that effect must be obtained before treatment can be withheld or before proceeding with a particular treatment, the only exception being in the case of an emergency where consent need not be obtained first.[52] Where parental consent cannot be obtained or in the case of disagreement between parents and health

49 A person who—
(a) does not have parental responsibility for a particular child; but
(b) has care of the child, may (subject to the provisions of this Order) do what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare.

50 *Glass v United Kingdom* [2004] 1 FLR 1019. See par 6.2.9.1 for the facts of the case.

51 Hagger 2009:66.

52 Kennedy and Grubb 2000:823.

care professionals, authorisation must be obtained from a court.[53] Consent from only one parent with parental responsibility will suffice to allow medical professionals to proceed with treatment.[54]

Where the patient is a neonate, Scottish law also dictates that consent be obtained from another person, such as a parent or a person with parental responsibility, or a person older than sixteen years in whose care the child is.[55] Where this cannot be obtained the court as *parens patriae* must be approached for consent before proceeding with treatment.[56] Parents usually consent to treatment,[57] but in exceptional circumstances, for example in the event of an emergency, where it would be impossible or impracticable to obtain consent before commencing with treatment, doctors can continue to give life-saving treatment without the required consent.[58] Doctors can give emergency treatment even against the wishes of the parents in cases where a delay would cause harm or death.[59] To date no ruling has been made in a Scottish court on this aspect.[60]

53 See also Brazier and Cave 2007:390-391; Bridgeman 2005:100-105, 109-111, 112-116; Bridgeman 2007:164-170; Bridgeman in Wallbank ea (eds) 2010: 247-248; Fortin 2009:367; Hagger 2009:65-66.
54 Elliston in Norman and Greer (eds) 2005:366.
55 Section 5(1)(a) and (b). See addendum for the text of this section.
56 Lloyd (ed) 2001:55,63.
57 Elliston in Norman and Greer (eds) 2005:366.
58 Harper 1999:81; Kennedy and Grubb 2000:823; Lloyd (ed) 2001:56.
59 Kennedy and Grubb 2000:823; Lloyd (ed) 2001:56.
60 Lloyd (ed) 2001:56.

6.2.4 Disagreement between parents and health care professionals

In certain cases, there may be disagreement between parents and health care professionals on the question whether a particular treatment of a child patient would be in the best interests of the child. In such an instance, the court should be approached for a specific issue order in terms of section 8 of the Children Act.[61] The purpose of this provision is "to resolve a situation in which there is disagreement over the exercise of parental responsibility".[62] A local authority can also approach the High Court under section 100(3), (4) and (5)[63] to seek an order to treat a child without consent.

The court's decision will ultimately be based on what would be in the best interests of a particular child patient and this is achieved by balancing the burdens and benefits of the proposed treatment.[64] This is no mean feat in the case of preterm infants as there are many uncertainties on the prognosis of the child even with treatment.[65] In most cases, courts are hesitant to dictate to doctors how they should treat their patients, and prefer to be led by their professional discretion,

61 Harper 1999:12. There are similar provisions in section 11(2)(e) of the Children (Scotland) Act 1995 and section 8(1) of the Children (Northern Ireland) 1995.
62 Lloyd (ed) ea 2001:47.
63 See addendum for these sections.
64 Bridgeman 2007:99; Bridgeman in Walbank ea (eds) 2010:240; Elliston in Norman and Greer (eds) 2005:375; Fortin 2009:368; Hagger in Probert ea (eds) 2009:186.
65 Elliston in Norman and Greer (eds) 2005:377.

although they are not unsympathetic towards the parents' views or wishes.[66]

Disagreement regarding treatment may result, firstly, from religious or cultural views; for example Jehovah's Witnesses strongly object to blood transfusions.[67] Secondly, disagreement may arise from different interpretations of autonomy and this could give rise to differences of opinion between parents and health care professionals regarding what would be in the best interests of the child.[68] Thirdly, disagreements could result from a difference of opinion regarding what would be in the medium- or long-term interests of a neonate.[69] This may be very difficult To determine as there are many uncertainties involved. Lastly, opinions may well differ on the quality of life the neonate may be experiencing.[70]

Cases in which parents objected to blood transfusions for their offspring for religious reasons will now be discussed.

66 Elliston in Norman and Greer (eds) 2005:377.
67 Hagger 2009:67; Tripp and McGregor 2006:68.
68 Tripp and McGregor 2006:68.
69 Tripp and McGregor 2006:68.
70 Tripp and McGregor 2006:68.

6.2.4.1 Objection to blood transfusion

There is no doubt that the court will overrule parents' religious objections, for example in the case of Jehovah's Witnesses, and authorise a life-saving blood transfusion when this is in the child's best interests.[71]

A case in point is *In re O*.[72] In this case a baby girl was born more than 12 weeks prematurely and suffered from respiratory distress syndrome, which causes red blood cell levels to fall. The treatment for this condition is a blood transfusion. The doctors agreed that the baby would die if she were not given emergency medical treatment in the form of a blood transfusion. The baby's parents were devout Jehovah's Witnesses, and consequently there was a conflict of interests between their religious beliefs and their baby's best interests. The court was asked to intervene and authorised a life-saving blood transfusion.[73] By ordering the blood transfusion, the court overruled the parents' right to religious freedom in favour of the best interests of their baby.

71 Bridge in Bainham ea (eds) 2002:276.
72 *In re O (a Minor) (Medical Treatment)* [1993] 2 FLR 149. This case is similar to the South African case *Hay v B* 2003 (3) SA 492 (W) discussed in chapter 4 par 4.3.1 and chapter 5.4.7.
73 For a discussion of this case see Bridgeman 2007:144; Fortin 2009:383.

In a more recent case in 2008, that of Baby M,[74] the father of the child was a practising Muslim and as such he was not in favour of withholding or withdrawing mechanical life support from his child, because according to his faith it was not right for people to decide whether someone should live or die.[75] He believed that this decision had to be left to God.[76] However, Holman J did not uphold this view in his decision and held that the best interests of M had to be taken into account.[77] Holman J consequently ordered that ventilation be withdrawn, but only when the parents were ready to make that decision.[78]

If a life and death situation exists, doctors can rely on justification in the common law doctrine of necessity to authorise a blood transfusion or to proceed with emergency medical treatment without first obtaining consent from a person with parental responsibilities and rights.[79]

6.2.4.2 Objection to surgical separation of conjoined twins[80]

The twins Jodie and Mary had been joined at the pelvis from birth. Each girl had her own brain, heart, lungs, other vital organs, arms and legs.

74 *An NHS Trust v MB* [2006] EWHC 507 (Fam):[49].
75 *An NHS Trust v MB*:[49].
76 *An NHS Trust v MB*:[49].
77 *An NHS Trust v MB*:[50].
78 *An NHS Trust v MB:*[108].
79 Bridge in Bainham ea (eds) 2002:277; Fortin 2009:383; Harper 1999:7.
80 *In re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480.

However, they shared a common artery. Their parents, who were devout Roman Catholics, opposed surgery to separate the two, since it would mean that the weaker of the two, Mary, would die within minutes of the operation. St Mary's hospital, Manchester, brought an application to the High Court to order that the surgeons could proceed with the operation. Since the proposed surgery would kill Mary, the doctors and hospital staff wanted confirmation from the court that it would not amount to murder and that no prosecution would follow the surgical procedure. According to the parents' belief system, it would be a "sin" to separate Mary from Jodie and thereby kill her.[81] Lord Justice Ward in an *obiter dictum* asked the question, but left it unanswered, whether the parents would not be guilty of the murder of Jodie if they refused to allow her to be surgically separated from Mary, because if surgery was not performed neither of the twins would survive beyond a few months. After weighing up the best interests of the twins, all three judges agreed that the surgical procedure to separate the twins should go ahead.

81 Brazier and Cave 2007:383.

6.2.5 Best interests of the child

As in South African law,[82] the best interests of the child standard is not without its problems, since it is indeterminate and therefore it is uncertain whether this standard will provide adequate protection for children.[83] Moreover, family law has found it difficult to balance parents' interests and children's interests.[84] This will be illustrated by the discussion of the cases that follow; although the best interests standard has been applied in all the cases, the outcome is not always consistent.

6.2.5.1 The relationship between the welfare principle and the best interests standard

Section 1 of the Children Act 1989 provides that "the child's welfare shall be the court's paramount consideration".[85] Section 1(3) provides the court with guidelines that could be used in the assessment of the welfare of the child.[86] It is interesting to note that the welfare principle is mentioned in the relevant legislation, yet the courts use the best interests standard. It is uncertain whether these two terms are

82 See chapter 5 par 5.4.7 for a discussion of the best interests standard in South African law.

83 Fortin 2009:367. For a discussion on the problems surrounding the "best interests" principle see also Bridgeman 2007:103-104; Eekelaar 2002:237-249.

84 Herring 1999:223.

85 See addendum for section 1(3) of the Children Act. See also section 16(1) of the Children (Scotland) Act 1998 and section 3(2) of the Children (Northern Ireland) Order 1995.

86 Bridgeman 2007:100. See section 3(3) of the Children (Northern Ireland) 1995 which also provides a checklist of factors that can assist a court in determining the welfare or "best interests" of a child.

interchangeable, whether the “best interests” standard forms part of the welfare principle or *vice versa*.

The best explanation of the relation between the welfare principle and the best interests standard is to be found in the case of the conjoined twins, where Lord Justice Ward stated:

> “The question of Mary’s best interests is one of the key and one of the difficult issues in the case and it calls for thorough exposition. That Mary’s welfare is paramount is a trite observation for family lawyers. Welfare dictates the outcome of the question relating to her upbringing which is before the court. It means no more and no less than that the court must decide what is best for her, taking all her interests and needs into account, weighing and then bringing into the balance the advantages against disadvantages, the risks of harm against the hopes of benefit which flow from the course of action under consideration.”[87]

It seems that the courts tend to treat the welfare principle[88] and the best interests standard as interchangeable in matters concerning medical

87 *In re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR:516. For more evidence that the terms are used as synonyms, see Eekelaar 2002:240.

88 In this regard see for example, *In re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480, especially at 507,512-513,516; *Portsmouth Hospitals*

treatment.[89] However, there is also another opinion regarding exactly what the relation between the best interests standard and the welfare principle is, namely that the welfare principle is "less demanding on those who make decisions for children".[90] Mason and Laurie,[91] however, are of the opinion that "the English courts in their anxiety to maintain the welfare principle, have tended to confuse the two tests". The author is of the opinion that a scrutiny of cases in which the "best interests" standard and the "welfare principle" were applied would lead one to conclude that these two terms are synonymous.

Likewise, the Children (Scotland) Act 1995 section 11(7)(a) determines that in deciding any matter relating to parental responsibilities and rights, the child's welfare should be the "paramount consideration".[92] In the case of *Finlayson*[93] the parents refused to allow their child to be given blood products, but preferred to treat their child, who was suffering from haemophilia, with homeopathic medicines. This was regarded as wilful

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NHS Trust v Wyatt [2005] 1 WLR 3995 *especially* at 4012,4013,4019,4022; *In re T (a Minor) (Wardship: Medical Treatment)* 1997 1 WLR 242,248,251,252,253,254.

89 Bridgeman 2007:101.
90 NCOB 2006:15 fn 16.
91 Mason and Laurie 2011:483.
92 Lloyd (ed) 2001:70.
93 *Finlayson, applicant, sub nom Finlayson v I* 1989 SCLR 601.

neglect and lack of parental care by the court, “despite the fact that the parents believed they were acting in the best interests of their child”.[94]

The Children (Northern Ireland) Order 1995 in Article 3 also determines that the child's welfare should be the court's paramount consideration in any proceedings in which any question with respect to the upbringing of a child arises.

6.2.5.2 The best interests standard places a limitation on parents' autonomy

Determining what is in the best interests of a particular child might not always be possible because of financial constraints or the interests of other siblings.[95]

Freeman[96] suggests a line drawing exercise where a line is drawn between parents' interests and the child's interests, provided that the line is not drawn too close to the parents' interests and too far from the child's interests, since that could be prejudicial to a child. In other words, although parents' autonomy should be respected, in certain cases there

94 Lloyd (ed) 2001:66.
95 Bridgeman 2007:105.
96 Freeman 1983:70-91.

should be constraints upon their autonomy in the form of court reviews to protect their child's interests.[97]

6.2.5.3 The opinion of medical experts in determining the best interests of a child patient

Since preterm infants and critically-ill neonates are the most vulnerable and in need of protection, it is of the utmost importance that no decision regarding their health care be made without taking into account the best interests of an individual child.[98] In order to determine what is in the best interests of a particular child, the court would consider the views of medical experts, as well as the views of the parents.[99] The doctors' opinions are influenced by their expert knowledge and experience.[100]

6.2.5.4 The parents' views regarding the "best interests" of their child

Parents usually make these decisions according to their frame of reference and their understanding of what would be in the best interests of their child.[101] Parents' opinions would generally be influenced by what they consider to be in the best interests of their child, taking into consideration, among others, the needs of the child, "the views and

97 Bridgeman 2007:99.
98 Bridgeman 2007:9.
99 Fortin 2009:368.
100 Fortin 2009:368.
101 Bridgeman 2007:104.

mores of the whole family",[102] the needs of other family members and available resources.[103]

When the patient is a premature or critically-ill neonate, the course of action should be discussed with the parents first, but they might be emotionally distressed in the circumstances, and this could influence their ability to make decisions.[104] Where there is disagreement between the parents, the court can be approached to give the required consent.[105] It is important to note that parents' wishes do count, yet they do not have absolute power over their children and their responsibility should always be exercised in accordance with the best interests of the child.[106] The child's welfare places a limitation on the exercise of parental powers.[107]

6.2.5.5 Disagreement between parents and health care professionals: Different interpretations of the best interests of the child

Doctors and health care professionals cannot pursue a specific course of action if it is against the wishes of the parents, unless they obtain a

102 Fortin 2009:368.
103 Bridgeman 2007:104.
104 Elliston in Norman and Greer (eds) 2005:368.
105 Elliston in Norman and Greer (eds) 2005:366.
106 Bridge in Bainham ea (eds) 2002:272; Elliston in Norman and Greer (eds) 2005:366-367.
107 Bridge in Bainham ea (eds) 2002:272.

court order.[108] A classic example is to be found in *Re B,*[109] where a baby girl (also known as baby Alexandra) was born suffering from Down's Syndrome and an intestinal blockage as well. The doctors wanted to operate to remove the blockage and thereby save her life. Her parents refused to consent to the operation, since they believed "it would be unkind to this child to operate upon her".[110] In their view it was in their baby's best interests that she did not undergo the operation, because although Baby B would probably survive, she would be severely physically and mentally handicapped. In this case there was also a difference of medical opinion: One surgeon felt that the parents' views ought to be respected, while another was of the opinion that it was in the baby's best interests to be operated upon despite her parents' objections.

The question the court had to determine was whether it was in the best interests of the child to allow her to die or to operate on her and remove the blockage, in which case she would have the normal life span of a

108 Elliston in Norman and Greer (eds) 2005:367.

109 *In re B (a Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421. A year later a similar case, that of Baby Doe [cited as *Infant Doe v Bloomington Hospital*, 464 U.S. 961, (1983)] reached the Indiana State Court. Baby Doe was also suffering from Down's Syndrome and needed an operation to connect his esophagus to his stomach. Baby Doe's parents did not want to consent to the operation, but preferred that their child starve to death. The court and physicians agreed that the parents were acting within their rights to allow Baby Doe to die. See Gostin 1985:33,59 and Klitsch 1983:143-146 for a discussion of this case.

110 *Re B*:1422.

child suffering from Down's Syndrome, albeit with physical and mental handicaps. In this case the decision regarding what was in the best interests of the child no longer lay with the parents, but with the court. The Court of Appeal overruled the parents' wishes and ordered that the operation be performed.[111] This case also established the principle that parents' autonomy is restricted and that they do not have the power of life and death over their children; "parents cannot dictate whether their children should live or die".[112] Brazier[113] points out that this case also emphasises the fact that a handicap (such as Down's Syndrome) does not *per se* justify withholding treatment.

In the author's opinion this decision is subject to criticism, because it does not take the position of parents into consideration. They might not have adequate financial means to provide the necessary specialised care for a child who is physically and mentally disabled. It is also possible that the parents may feel that they are not emotionally or psychologically equipped to care for a severely disabled child. On the one hand the right to life and the best interests of the infant in question should be protected, but on the other hand, the interests of other family

111 For a discussion of this case, see also Brazier and Cave 2007:380-381; Elliston in Norman and Greer (eds) 2005:372-374; Fletcher ea 1995:148-149; Fortin 2009:382-383; Harper 1999:51-52; Mason and Laurie 2011:480-481.
112 Fortin 2009:382.
113 Brazier in Goldworth ea (eds) 1995:333-334.

members, particularly those of other siblings should also be taken into consideration when such a decision is made.

However, in terms of section 1(1) of the Children Act such an approach would not be possible, since "the present law's understanding of the welfare principle is individualistic. By this is meant that the child and his or her welfare are viewed without regard for the welfare of the rest of his or her family, friends and community."[114] Eekelaar[115] also criticises this aspect of the "best interests" standard: "… it prevents proper consideration being paid to the interests of participants other than the child".

The *In re B* decision was criticised by scholars in the United Kingdom and "sparked off considerable controversy".[116] On the one hand there were those who felt that ultimately the decision whether a severely handicapped neonate should be treated lay with the parents of that child and that such a decision should be made without intervention by a court.[117] On the other hand there were those who were of the opinion that parents cannot decide whether a child should live or die and that

114 Herring 1999:225.
115 Eekelaar 2002:238.
116 Freeman 1983:88.
117 Freeman 1983:88.

court intervention is the correct route to follow, since the court is the *parens patriae* of a child whether he is a ward of court or not.[118]

The court in *In re T*[119] appears to have reached a contrasting decision, because the court refused to permit a liver transplant in the absence of parental consent, despite strong medical opinion to the contrary. The court performed a balancing exercise:

> "It can only be said safely that there is a scale, at one end of which lies the clear case where parental opposition to medical intervention is prompted by scruple or dogma of a kind which is patently irreconcilable with principles of child health and welfare widely accepted by the generality of mankind; and that at the other end lie highly problematic cases where there is genuine scope for a difference of view between parent and judge. In both situations it is the duty of the judge to allow the court's own opinion to prevail in the perceived paramount interests of the child concerned, but in cases at the latter end of the scale, there must be a likelihood (though never of course a certainty) that the greater the scope for genuine debate between one view and another the stronger will be the inclination of the court to be influenced by a reflection that in the

118 Freeman 1983:88-89; Harper 1999:26.
119 *In re T (a Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of its life will be taken for it by the parent to whom its care has been entrusted by nature."[120]

There has been divided opinion on the outcome of this case: On the one hand, some believe that it was correctly decided that parents' interests should also be taken into account, while others felt that parents now have the autonomy to decide whether their children should be allowed to live or die.[121] Freeman[122] is of the opinion that the case of *In re T*[123] was not correctly decided on the bests interests ground. He is critical of the application of the best interests standard and continues by saying: "Who should take the decision as to which lives are worth living? There is surely a distinction, which *best interests* does not acknowledge, between giving parents some autonomy, and allowing someone else to review the decisions they take."[124] Herring[125] also felt that in this case too much weight was put on the parents', especially the mother's views, "and

120 *Re T*:254.
121 Hagger in Probert ea (eds) 2009:189-190. See also Brazier and Cave 2007:387-389,406; Bridgeman 2007:17-18,102-103,137-142; Fortin 2009:368,384-385; Hagger 2009:63-65; Harper 1999:13-14; Mason and Laurie 2011:495-497.
122 Freeman 1997:376.
123 *In re T (a Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.
124 Freeman 1997:377.
125 Herring 1999:226.

insufficient weight on the child's right to life." Fortin[126] is also sceptical of the outcome of this decision and says, "hopefully it has now been relegated to the history books." Bridgeman,[127] on the other hand, agreed with this decision: "The judgment of the Court of Appeal is to be welcomed for the attempt to acknowledge the role of C's mother and to recognise her expertise and interest in his well-being."

6.2.5.6 Disagreement between parents and health care professionals regarding the best interests of the child: weighing of the best interests

In the Wyatt[128] case the court was asked to intervene when there was disagreement between Charlotte Wyatt's parents and health care professionals about the question whether mechanical ventilation would be the appropriate course of action and in her best interests should she encounter respiratory infection. While the medical team was of the opinion that mechanical ventilation would be futile, her parents believed that her condition was improving and that she should be artificially ventilated if necessary.

126 Fortin 2009:384.
127 Bridgeman 2007:141-142.
128 *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181 1 WLR 3995.

Charlotte Wyatt was born at 26 weeks' gestational age and weighed about 458 g. She suffered from chronic respiratory and kidney problems as well as brain damage. In its decision the court referred with approval to *Re A* where it was held that "best interests encompasses medical, emotional and all other welfare issues". [129] In order to determine what is in the best interests of the baby, the court has to draw up a balance sheet to enable it to balance the benefits of the proposed course of action against the harm that will be caused by the course of action.[130]

In the case of the conjoined twins,[131] the weighing up of the best interests of Jodie and Mary was an even more complex issue. It was necessary not only to weigh up the best interests of the twins, but also the parents' views. Separation would be in the best interests of Jodie, since this would afford her the opportunity to survive and she would be able to grow up and live a worthwhile life as her brain was fully developed. If the separation was not carried out, she would die of heart failure within months, because of the strain that carrying Mary was placing on her organs. Lord Justice Ward was convinced that the operation would not be in the best interests of Mary, since she would die

129 *Re A (Male Sterilisation)* [2000] 1 FLR 549 at 555.
130 *Wyatt*:[87]. See also Brazier and Cave 2007:392-393; Bridgeman 2007:159; Fortin 2009:378; Hagger 2009:58; Mason and Laurie 2011:485.
131 *In re A (Children) (Conjoined Twins: Surgical Separation)* [2001] 2 WLR 480.

moments after the separation.[132] Eventually all three judges agreed that it would be in the best interests of both if the operation were performed.[133] Mason and Laurie[134] make the interesting remark that the judges could have escaped a moral dilemma by using the "doctrine of double effect"[135] to decide this case. The good effect would have been Jodie's long-term survival, while the bad effect would have been Mary's premature death.[136]

6.2.5.7 No disagreement between parents and health care professionals, yet the baby is a ward of court

In a subsequent decision[137] the principles laid down in *Re B*[138] were followed, although the facts in this case can be distinguished from those in *Re B*.

132 *In re A*:523.
133 See also Brazier and Cave 2007:387; Bridgeman 2007:128-133. This case is also discussed in Fortin 2009:375-377.
134 Mason and Laurie 2011:489.
135 The courts have drawn a distinction between medical treatment that is intended to kill and medical treatment that is not intended to kill, although death is foreseeable. This distinction is called the doctrine of double effect. This doctrine entails that medication is given to relieve pain, such as analgesics and sedatives. However, these substances can hasten death. The administering of the treatment has two outcomes, a good one and a bad one. See Brazier 1996:323; Elliston in Norman and Greer (eds) 2005:371; NCOB 2006:20.
136 Mason and Laurie 2011:489.
137 *Re C (a Minor) (Wardship: Medical Treatment)* [1989] 3 WLR 240.
138 In re B (a Minor) (Wardship: Medical Treatment) [1981] 1 WLR.

Re C[139] concerns baby C, who was made a ward of court shortly after her birth because the social services feared that her parents would not be able to care for her.[140] Since baby C was a ward of court any major decision regarding her care had to be made by the court. Baby C was born prematurely with congenital hydrocephalus[141] and also malformation of the brain. By the time this application was heard, she was dying and her prognosis was hopeless. The question the court had to decide was what treatment C should be given that would be in her best interests. The court held that it would be in the best interests of baby C if only palliative care were given and that baby C should be allowed to die peacefully and with dignity.[142]

A decision whether treatment should be withheld as in the cases of *Re B* and *C* above depends on the degree of suffering continued life may cause. A balance needs to be struck between the suffering the neonate might endure if he or she continued to live and the finality of death.[143]

139 *Re C (a Minor) (Wardship: Medical Treatment)* [1989] 3 WLR 240.
140 *Re C*:242. For a discussion of this case see also Brazier 2007:385-387; Bridgeman 2005:114-115; Bridgeman 2007:160-161; Campbell in Goldworth ea (eds) 1995:316; Elliston in Norman and Greer (eds) 2005:374-375; Fortin 2009:375-376; Fletcher ea 1995:149; Harper 1999:51; Mason and Laurie 2011:482.
141 For an explanation of this term, see chapter 3 par 3.3.1.3 fn 70.
142 *Re C:*241.
143 Brazier 2007:385.

6.2.5.8 No disagreement between parents and health care professionals, but court order sought as confirmation of the course of action decided upon

A few years later, in 1996, another baby C[144] was born prematurely and contracted meningitis which resulted in brain damage, deafness and blindness. As her parents and the doctors agreed that it would be in her best interests to discontinue mechanical ventilation, they approached the court to make an order to that effect. The court ordered that life support be withdrawn. In this case there was no disagreement between baby C's parents and the medical professionals; they merely wanted the court to sanction their decision so that no party could be prosecuted later.[145] The importance of this case is that the law had developed to such an extent since the case of *B* (baby Alexandra) that by the time baby C's case was heard the court was prepared to acknowledge that a child's life need not be maintained at all costs.

6.2.5.9 Disagreement between health care professionals and parents regarding quality of life

Recently, in 2006, the court also attached a great deal of weight to the opinion of the mother of the baby regarding the quality of life of her baby

144 *Re C (a Baby)* [1996] 2 FLR 43.
145 Brazier and Cave 2007:386.

and refused to grant an order that mechanical ventilation be discontinued, notwithstanding the fact that according to medical opinion her baby's condition was deteriorating. In this case, a few weeks after M was born, his parents realised that he was not well and sought medical help. M was diagnosed as suffering from the congenital disease Spinal Muscular Atrophy (SMA).[146] M suffered from the severest form of this disease and consequently the doctors treating him felt that his quality of life was so low that it was unethical to keep him alive, hence the application that mechanical ventilation be discontinued.

The legal question that the court had to decide was whether it was in the best interests of M to continue with mechanical ventilation. The court was asked to issue an order that it was lawful to withdraw or withhold treatment.[147] In order to weigh the benefits and burdens to determine the best interests of the child, a list of the benefits and burdens was drawn up. In the words of Holman J, "[t]he test is one of best interests, and the task of the court is to balance all the factors. The Court of Appeal suggested that the best and safest way of reliably doing this is to draw up a list on which is specifically identified, on the one hand, the benefits or advantages and, on the other hand, the burdens or disadvantages of

146 See chapter 3 par 3.3.1.5 for an explanation of this medical condition.
147 *MB*:[24].

continuing or discontinuing the treatment in question."[148] In this case the court correctly did not allow the views of the medical professionals to outweigh those of the parents, but also considered the parents' views. The parents felt that they were emotionally and psychologically equipped to take care of their profoundly ill baby, whereas in *Re B*, discussed above,[149] the parents felt that they would not be able to cope with a severely mentally and physically handicapped child. The court per Holman J stressed that each case is unique and each case should be decided individually on its own merits.[150]

Subsequent to the *MB* case, Holman J had to decide a case that was the opposite of the above. Whereas baby M's parents wished to continue with medical treatment against the advice of the medical team, Baby A's parents did not want her to suffer more and undergo invasive medical treatment in the form of a bone marrow transplant, which the doctors recommended.[151] In this case Holman J considered the views of the parents and their autonomy, but said: "The matter must be decided by the application of an objective test. That test is the best interests of the patient. Best interests are used in the widest sense and include

148 *MB*:[58].
149 See paras 6.2.5.5 and 6.2.5.7.
150 *MB*:[109].
151 *The NHS Trust v A* [2007] EWHC 1696 (Fam).

every kind of consideration capable of impacting on the decision."[152] The court considered the views of both the parents and the medical experts, but after weighing the benefits and burdens of a bone marrow transplant, ordered that the operation should be performed.[153]

6.2.6 Criminal offence

In England and Wales criminal law draws a sharp distinction between a positive act which causes death and the omission to perform an act which would have prevented death.[154] Usually an omission to prevent death will not give rise to a conviction for murder or manslaughter, unless it can be proved that the accused stood in such a relation to the victim that he or she was under a duty to act and he or she neglected this duty.[155] The House of Lords held in the *Bland*[156] case that cessation of artificial nutrition and hydration constituted an omission and not an act. In the words of Lord Goff:[157]

> "The distinction appears, therefore, to be useful in the present context in that it can be invoked to explain how discontinuance of life support can be differentiated from ending a patient's life by a

152 *The NHS Trust v A*:[40, iv and v].
153 *The NHS Trust v A*:[61-67].
154 Fletcher ea 1995:214; Harper 1999:37.
155 Fletcher ea 1995:214; Harper 1999:37.
156 *Airedale NHS Trust v Bland* [1993] AC 789.
157 *Airedale NHS Trust v Bland*:866.

lethal injection. But in the end the reason for that difference is that, whereas the law considers that discontinuance of life support may be consistent with the doctor's duty to care for his patient, it does not, for reasons of policy, consider that it forms any part of his duty to give his patient a lethal injection to put him out of his agony."

If a doctor or a health care professional takes deliberate steps to end the life of a premature baby or critically-ill neonate in England or Wales, such an act would constitute the crime of murder or manslaughter.[158] Likewise, there is no legal basis for deliberately terminating the life of a premature infant as this would amount to culpable homicide in Scotland.[159]

The right of people, regardless of their age, to have their lives protected, is enforced under Article 2 of the European Convention on Human Rights.[160]

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158 Elliston in Norman and Greer (eds) 2005:368-369; Fletcher ea 1995:148.
159 Elliston in Norman and Greer (eds) 2005:368-369.
160 Elliston in Norman and Greer (eds) 2005:369.
Article 2 of the Convention reads:
1 Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.
2 Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is not more than absolutely necessary:
(a) in defence of any person from unlawful violence;
(b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;

If a person is endowed with the responsibility of caring for or treating a child, and such a person withholds treatment and this results in the death of the child, such an act also constitutes murder.[161]

6.2.6.1 The case of Dr Leonard Arthur

This principle was proved in the case of Dr Leonard Arthur.[162] A baby, John Pearson, was born suffering from Down's Syndrome. His parents made it clear that they did not want their baby to survive. Dr Arthur then ordered that he be given nursing care only and a sedative. The baby subsequently died. Dr Arthur was initially charged with murder, but after it became known that John Pearson also suffered from abnormalities of the heart, lungs and brain, which could have contributed to his death the original charge was reduced to attempted murder. Eventually Dr Arthur was acquitted because it was found that he did not perform a positive act to kill John Pearson. In this case, a distinction was drawn between an act and an omission.[163]

(c) in action lawfully taken for the purpose of quelling a riot or insurrection.

161 Fletcher ea 1995:148.

162 *R v Arthur* [1981] Crim L.R. 298, 111 SJ 435. For a discussion of this case, see also Fletcher ea 1995:145-147; Fortin 2009:372-373; Mason and Laurie 2011:479-480.

163 Elliston in Norman and Greer (eds) 2005:369.

Elliston[164] correctly argues that a prosecution can also be instituted on the basis of an omission in cases where there is a legal duty to act. There was undoubtedly a legal duty upon Dr Leonard Arthur in his professional capacity to take positive steps to preserve the life of the baby, until it was certain that any treatment would be futile. Mason and Laurie[165] remark that "there is a world of difference between withholding treatment from a dying patient and refusing sustenance to one who shows firm evidence of a will to live". At the time when the order was given to give only nursing care to John Pearson, neither Dr Arthur nor the baby's parents knew that the baby was also suffering from other congenital defects. If the principles of beneficence and non-maleficence[166] in medical ethics were observed, it is clear that these principles placed an obligation on Dr Arthur to preserve the life of the baby, rather than to allow him to starve to death.

Campbell[167] is sceptical about the outcome of this case. According to this author, the outcome is inconsistent with the earlier decision in *Re B*,[168] discussed above, where the court held that life-saving treatment should be given and that the life of a child born with Down's Syndrome

164 Elliston in Norman and Greer (eds) 2005:370.
165 Mason and Laurie 2011:480.
166 See chapter 4 paras 4.3.2 and 4.3.3 for an explanation of these terms.
167 Campbell in Goldworth ea (eds) 1995:314-316.
168 *In re B* (a Minor) (Wardship: Medical Treatment) [1981] 1 WLR 1421.

should be saved.[169] *In casu* the court per Lord Templeman held that the child should live, since her life would not be "demonstrably awful".[170]

The principle applies in South African law that an omission can be punishable if a legal duty rests on somebody to perform a certain type of active conduct.[171] Such a duty may arise from the position a person holds, for example a medical practitioner has a duty of care towards a patient.[172]

According to the law of England and Wales, there is still a distinction between actively killing and "allowing to die".[173] This does not imply that life should be prolonged "at all costs and in all circumstances", but parents and health care professionals have a duty to provide appropriate care that is in the best interests of the child.[174]

169 *In re B*:1424.
170 *In re B*:1424.
171 Snyman 2008:59,60. See also *Minister van Polisie v Ewels* 1975 (3) SA 590 (A):797A-B.
172 Snyman 2008:60.
173 Fletcher ea 1995:148.
174 Fletcher ea 1995:148.

6.2.7 Futile medical treatment

Article 2[175] of the European Convention on the Protection of Human Rights (ECHR) does not place an obligation on doctors to provide treatment that is futile, for example in cases where a patient is in a permanent vegetative state and has no cognitive ability.[176] The decision in *NHS Trust A v M; NHS Trust B v H*[177] confirms the decision in the *Bland*[178] case. Although the *Bland* case was heard before the Human Rights Act 1998 came into force,[179] it has been confirmed that the decision is compatible with the Human Rights Act.[180] The principle that a doctor is not obliged to continue with treatment that is futile was laid down in the case of Tony Bland.[181]

A case that proves that a doctor is not obliged to provide futile treatment is the following: Baby J[182] was born prematurely after 27 weeks' gestation and neonatologists agreed that he would probably develop

175 "Everyone's right to life shall be protected by law."
176 *NHS Trust A v M; NHS Trust B v H* [2001] 2 WLR (Fam) 942.
177 [2001] 2 WLR 942.
178 *Airedale NHS Trust v Bland* [1993] (Fam) AC 789.
179 The Human Rights Act 1998 came into force on 2 October 2000. See Kennedy and Grubb 2000:27.
180 Bridgeman in Wallbank ea (eds) 2010:248-249.
181 *Airdedale NHS Trust v Bland* [1993] AC 789. In 1989, when he was only 17 years old, Tony Bland was seriously injured in a stampede at the Hillsborough football ground. He suffered several injuries, but among others, the oxygen supply to his brain was interrupted which led to irreparable brain damage that left him in a permanent vegetative state. He was artificially kept alive, by means of mechanical ventilation, artificial nutrition and hydration. The hospital authorities sought a declaration that they could lawfully withdraw all life-sustaining treatment so that he could die peacefully. The order was granted.
182 *In re J (a Minor) (Wardship: Medical Treatment)* [1991] 2 WLR 140.

serious spastic quadriplegia. He appeared to be blind and deaf, but unfortunately it seemed as though he was able to experience pain. The court had to decide whether he should be mechanically ventilated if he stopped breathing. The court per Lord Donaldson held that a balancing exercise had to be performed when considering the best interests of the infant. The opinions of family members and medical experts should also be weighed. This case illustrates that decisions concerning the treatment of a critically-ill neonate should be taken jointly by the parents, health care professionals and the court. The court per Lord Donaldson held:

> "No one can dictate the treatment to be given to the child – neither court, parents, nor doctors. There are checks and balances. The doctors can recommend treatment A in preference to treatment B. They can also refuse to adopt treatment C on the grounds that it is medically contra-indicated or for some other reason is a treatment which they could not conscientiously administer. The court or parents for their part can refuse to consent to treatment A or B or both, but cannot insist upon treatment C. The inevitable and desirable result is that choice of treatment is in some measure a joint decision of the doctors, and the court or the parents."[183]

183 *In re J*:145. See also Bridgeman in Sheldon and Thomson 1998:100.

After considering the benefits of the treatment and the burdens of life when severely handicapped, the court came to the conclusion that it would not be in J's best interests to prolong his life by ventilating him, should he suffer another relapse.[184] Lord Donaldson made the following remarks, which should be noted in cases of this kind:[185]

- "…the starting point is not what might have been, what is."[186]
- "There is without doubt a very strong presumption in favour of a course of action which will prolong life."[187]
- "…account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment itself."[188]
- This has to be done "from the assumed point of view of the patient."[189]

Fortin[190] mentions that the importance of this case is that it emphasises that an infant does not have to be dying before a decision can be made by the medical team to withhold treatment.

184 See also Elliston in Norman and Greer 2005:374-375; Fletcher ea 1995:149-151; Harper 1999:13
185 See also Bridgeman in Freeman (ed) 2006:105.
186 *In re J (a Minor) (Wardship: Medical Treatment)* [1991] 2 WLR:147.
187 *In re J*:149.
188 *In re J*:149.
189 *In re J*:150.
190 Fortin 2009:377-378.

The courts are loath to make an order compelling a doctor to provide treatment that is contrary to his or her clinical judgment and that he or she firmly believes will not be in the best interests of his or her patient.[191] "The law is clear. The question whether artificial ventilation should or should not be applied is, so the argument proceeds, an entirely medical one with which the courts will not interfere."[192] In *In re J* the court was asked to decide whether baby J, who had sustained severe head injuries as a result of an accidental fall and has since the accident been microcephalic,[193] suffered from cerebral palsy, cortical blindness and severe epilepsy and had to be fed by way of a naso-gastric tube, should receive mechanical ventilation. The doctors agreed that baby J would not make any further progress and was in fact dying. Artificial ventilation would only prolong his suffering. After considering the evidence of medical experts, the Court of Appeal granted an order that baby J need not be artificially ventilated.

6.2.8 The Children and Young Persons Act 1933

Sections 1(1) and (2) of the Children and Young Persons Act places an obligation on persons with parental responsibility to seek appropriate medical treatment when necessary—and should parents fail to seek

191 In r*e J (a Minor) (Child in Care: Medical Treatment)* [1992] 3 WLR 507. See also Bridgeman in Freeman (ed) 2006:116.
192 *Re J (a Minor) (Child in Care: Medical Treatment):*514.
193 For an explanation of this term, see chapter 3 par 3.3.1.2.

appropriate medical treatment for their child, this could amount to a criminal offence or could lead to care proceedings.[194] In terms of section 1 of the Children and Young Persons Act 1933, it is a criminal offence to neglect a child and this section makes provision for criminal sanctions against parents who neglect their children by failing to provide them with suitable medical care.[195] The Act uses the term "wilful neglect". According to Kennedy and Grubb,[196] a doctor cannot be held liable under this Act, since it is only applicable to persons with parental responsibility. In terms of section 1 of this Act, parents can be found guilty of wilful neglect if they fail to provide a child with adequate treatment and the consequence is to cause the child suffering and an injury to health.[197]

In terms of section 12 of the Children and Young Persons (Scotland) Act 1937 any form of cruelty or neglect (this includes failure to seek appropriate medical assistance) to a person under the age of sixteen years constitutes a statutory offence. "These are aimed at providing criminal sanctions against parents who neglect their children, for example, by failing to seek appropriate medical assistance."[198]

194 Hagger 2009:57.
195 Elliston in Norman and Greer (eds) 2005:372.
196 Kennedy and Grubb 2000:2165.
197 Kennedy and Grubb 2000:2165.
198 Elliston in Norman and Greer (eds) 2005:372.

6.2.9 The Human Rights Act 1998

The European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 is given effect in the Human Rights Act 1998.[199] This Act protects the individual's rights in two ways: Firstly, the Act is directly enforceable against public authorities and secondly, in terms of section 3 of the 1998 Act, all legislation must be interpreted in line with the Convention rights.[200] It has been argued that the Convention does not adequately protect the rights of children, as there are no articles with specific reference to children.[201] The counterargument is that since children have all the rights that adults have, they will receive the same protection as adults under this Convention. It will be seen below, in the discussion of court cases, how this has been applied in practice by the courts.

Articles 2, 3 and 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 have been incorporated into Schedule 2 of the Human Rights Act.[202] Article 8[203] of

199 Choudhry, Herring and Wallbank in Wallbank ea (eds) 2010:3.
200 Choudhry, Herring and Wallbank in Wallbank ea (eds) 2010:3; Herring 1999:227. In section 29(2)(d) and 57(2) of the Scotland Act specific reference is made to the fact that an Act of the Scottish Parliament must be compatible with the rights enunciated in the ECHR.
201 Herring 1999:227.
202 Meyers 2005:312.
203 1 Everyone has the right to respect for his private and family life, his home and his correspondence.

this convention protects a patient's right to respect for private life and family life. This would include the patient's right to make an autonomous decision to either accept or reject treatment.[204]

6.2.9.1 The case of David Glass

Although David Glass was neither a premature baby nor a neonate when this case was heard, he was profoundly ill. He was physically and mentally disabled. When he was admitted to hospital there was serious disagreement between his mother and the health care professionals regarding his treatment. Without obtaining his mother's permission, or court intervention, a notice was put up that he should not be resuscitated and that he should be administered diamorphine—a course of action that his mother firmly believed was not in David's best interests. According to Carol Glass, David's mother, the doctors believed that his quality of life was so low that it was not worthwhile treating him, hence the "Do not resuscitate" order.[205] The hospital staff believed that David was dying, hence this decision to withhold treatment. David's mother, Carol, initially approached the English courts. However, when she was

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2 There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

204 Meyers 2005:312.

205 Bridgeman in Freeman (ed) 2006:103.

unsuccessful, she approached the European Court of Human Rights. The European Court of Human Rights held that the health care professionals had infringed on David's right to respect for private life, which is guaranteed in article 8 of the European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (ECHR), by neither obtaining his mother's consent as proxy decision maker, nor seeking a court order.[206] Hagger[207] criticises the outcome of the *Glass* case, arguing that when a court order is sought, the views of the health care professionals will still carry more weight than that of the parents of the child.

Article 2 of the European Convention on Human Rights guarantees the "right to life". Doctors and health care professionals are under an obligation to protect life, but this does not mean that doctors are obliged to treat a patient should life-prolonging treatment prove to be futile or not in the best interests of the patient.[208] This principle was also established in the *Bland*[209] case mentioned earlier in this chapter. In such an

206 See also Donnelly 2010:219-220.
207 Hagger 2009:66. See also Fortin 2009:370,373-374 and 380-381 for a discussion of this case.
208 Elliston in Norman and Greer (eds) 2005:387; Meyers 2005:312. See also *NHS Trust A v M NHS Trust B v H* [2001] 2 WLR (Fam) 942. Fortin 2009:369. Article 2 of the ECHR does not oblige doctors to provide treatment that will be futile.
209 *Airedale NHS Trust v Bland* [1993] AC 789.

instance “withdrawal or withholding has been deemed compatible with the Act”.[210]

Article 3 has been used in this case to assert a right to die with dignity.[211] In this context the ability of the premature infant to experience pain or suffering must also be taken into account when considering treatment.[212]

6.3 Nuffield Council on Bioethics

The report, entitled “Critical care decisions in fetal and neonatal medicine: ethical issues”, which was compiled by the Working Party[213] of the Nuffield Council on Bioethics (hereafter NCOB), is dealt with under a separate heading, since this applies to all the jurisdictions in the United Kingdom.

The Working Party recognised the fact that high demands are made on both parents and health care professionals when they are required to

210 Meyers 2005:312.
211 *No one shall be subjected to inhuman or degrading treatment or punishment.*
212 Elliston in Norman and Greer (eds) 2005:388.
213 The members who contributed to the compiling of this report, are known as the Working Party (see page ix of the report). In a guide to the Report:1 it is stated that the Working Party consisted of neonatologists, an obstetrician, a children’s nursing professor, philosophers, social scientists, lawyers, a health economist, and individuals who have worked with families of extremely premature babies and disabled children.

make critical care decisions during pregnancy and after the baby is born.[214]

6.3.1 Intolerability as the criterion in deciding whether to withdraw or withhold treatment[215]

Various recommendations were made in respect of different aspects of critical care. One aspect that was dealt with is the point at which to discontinue treatment, in other words, the threshold at which only palliative care should be provided and no treatment should be given that would only prolong life and suffering.[216] The Working Party decided on the concept of "intolerability".[217] "It would not be in the baby's best interests to insist on the imposition or continuance of treatment to prolong the life of the baby when doing so imposes an intolerable burden upon him or her."[218] In arriving at this recommendation, the Working Party also considered a report that was compiled by the Royal College of Paediatrics and Child Health (RCPCH), entitled "Witholding (sic) or

214 NCOB 2006:3.
215 *In re J (a Minor) (Wardship: Medical Treatment)* [1991] 2 WLR:158 Lord Donaldson considers the concept of "intolerability" and how it should be applied: "I consider the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all the circumstances such a life would be so afflicted as to be intolerable to that child. I say 'to that child' because the test should not be whether the life would be tolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable." See also Bridgeman in Freeman (ed) 2006:106.
216 NCOB 2006:12.
217 NCOB 2006:12.
218 NCOB 2006:12.

Withdrawing Life Sustaining Treatment in Children: A Framework for Practice".[219]

In the RCPCH report, five situations are mentioned in which "it may be ethical or legal to consider withholding or withdrawal of life sustaining medical treatment":[220]

- When the child is "brain dead".
- When the child is in a "permanent vegetative state".
- In a "no chance situation", that is when the child is dying and treatment will only prolong suffering. This can also be called the "no hope" situation.[221]
- In a "no purpose" situation, that is when the child might survive, but with such severe physical or mental impairments that it would be unreasonable to expect him or her to bear them.
- In an "unbearable" situation when the illness is progressive and irreversible and further treatment is more than can be borne.

219 Kling and Kruger in Moodley (ed) 2011:198 find this report "a very useful framework to guide end-of-life decisions making in the clinical situation."
220 RCPCH 2004:10-11.
221 McHaffie ea 1999:441.

The RCPCH draws attention to the fact that withholding treatment does not mean that no nursing care is provided; palliative care would always be provided.[222]

The Working Party of the Nuffield Council on Bioethics regards the "no chance" situation as "intolerable".[223] "Where treatment offers 'no chance' of survival other than for a short period of time, the best interests of the baby focus on the relief of any suffering and a peaceful death. We consider that to mandate distressing and futile interventions that can do no more than delay death would be a clear case of an intolerable burden."[224] The Working Party further recognised the fact that there is a presumption in favour of life, but this presumption is rebuttable when life would be intolerable.[225]

6.3.2 The best interests standard

The "best interests" principle is included in international human rights instruments[226] and in legislative instruments in the United Kingdom.[227] Whenever decisions have to be made regarding when and how a child

222 RCPCH 2004:13.
223 NCOB 2006:12.
224 NCOB 2006:12.
225 NCOB 2006:13.
226 United Nations Convention on the Rights of the Child.
227 The Children Act 1989, Children (Northern Ireland) Order 1995 and Children (Scotland) Act 1995; NCOB 2006:15.

patient should be treated, the best interests of the child must be central in the decision-making process.[228] It is interesting to note that the Nuffield Council on Bioethics recognises the fact that the best interests of other family members should also be taken into consideration and not only those of the child patient.[229] In none of the cases discussed above was any mention made of the best interests of other family members, such as other siblings, although some weight was attached to the views of the parents.

Guidelines in assessing the best interests of the neonate are given to doctors concerning the instances in which life support and mechanical ventilation should be started immediately after birth:[230]

"(a) The gestational age of the baby at birth.

(b) The evidence available indicating the likelihood of survival and incidence of severe disability among babies born at that gestational age.

(c) The evidence available from the initial assessment on:

(i) the baby's vitality at birth; and

(ii) any significant abnormalities.

228 NCOB 2006:15.
229 NCOB 2006:17.
230 NCOB 2006:160-161.

(d) The views and feelings of the parents, in the light of that evidence, and accorded the significance proposed above."

6.3.3 Withholding treatment

The Working Party of the Nuffield Council on Bioethics agrees with withholding treatment, but unreservedly rejects taking deliberate steps to end the life of a neonate, for example by way of a lethal injection, even when that life is "intolerable".[231] The Working Party is of the opinion that such an action cannot be ethically justifiable. They also reject the notion that there should be legislation that sanctions the deliberate ending of the life of a neonate.[232]

However, it is morally acceptable to provide treatment that is pain-relieving, but at the same time, might have the effect of hastening death.[233] Parents, doctors and nurses are warned, however, not to feel that they are under pressure to allow babies to die, merely because they might suffer a disability, since people with disabilities can still have meaningful lives.[234]

231 NCOB 2006:19,20.
232 NCOB 2006:157.
233 NCOB 2006:20. See the explanation on the "doctrine of double effect" par 6.2.5.6 fn 135.
234 NCOB 2006:20-21.

Guidelines which operate in the Netherlands[235] suggest that babies born before 25 weeks' gestation should not be resuscitated.[236] However, the NCOB does not support enacting this guideline in legislation. They are, however, in favour of clearer guidelines concerning when a baby should be resuscitated.[237]

The NCOB reached the conclusion that there is no need to differentiate between withdrawing treatment and not initiating it, as long as such a decision is in the best interests of the baby.[238] Guidelines are provided on when to institute full intensive care for babies below 26 weeks' gestational age:[239]

- Between 24 weeks, 0 days and 24 weeks, six days' gestational age: A baby should be given full invasive intensive care and support from birth and be admitted to a neonatal intensive care unit, unless the parents and health care professionals agree that in the light of the baby's condition, it would not be in his or her best interests.
- Between 23 weeks, 0 days and 23 weeks, six days' gestation age: Since it is difficult to predict the outcome, the parents'

235 The position in the Netherlands will be dealt with in more detail in chapter 7.
236 NCOB:154.
237 NCOB 2006:154. See also Mason and Laurie 2011:492.
238 NCOB 2006:155.
239 NCOB 2006:155-156.

views regarding resuscitation and invasive medical treatment should be the deciding factor. However, when the baby is hopelessly ill, and it is certain that any medical treatment would be futile, health care professionals are not legally compelled to provide such treatment against their clinical judgment.

- Between 22 weeks, 0 days and 22 weeks, six days' gestation age: It should be standard practice not to resuscitate the baby and provide intensive care, except when parents insist that the baby be resuscitated and all treatment possible be given.
- Below 22 weeks' gestational age: The same practice as above should apply.
- When intensive care is not given, palliative care should be provided until the baby dies.

Hydration and oral nutrition should never be withheld except when it is clear that they are causing the baby discomfort.[240]

6.3.4 Partnership in critical care decisions

It is recognised that in critical care decisions there should be a partnership between health care professionals and the parents of premature and critically-ill neonates and that disputes should be

240 NCOB 2006:158.

resolved by way of agreement.[241] They suggest that the potential advantages of mediation as an alternative form of dispute resolution should be examined:[242]

> "We consider that misunderstandings lie at the heart of many disputes and that providing routes for swift and effective resolution will be best for all parties. Approaching a committee could even add to frustration or delay the case reaching the court. In such cases, we propose that mediation may be beneficial, to help the parties work towards a negotiated agreement of their dispute or difference as an alternative litigation. The mediator will seek to help the parties to find 'a principled resolution' and remain available to help with follow up. Whether or not agreement is reached, and with implementation of any agreement even if resolution is ultimately not possible, mediation may improve communication and reduce acrimony, leading to a better mutual understanding of the issues that remain to be resolved by the courts. The substantial human and economic cost of taking a case to court should not be underestimated."

241 NCOB 2006:23,160,62.
242 NCOB 2006:163. See also NCOB 2006:147.

In view of the advantages of mediation set out above, the report suggests that the Department of Health should examine the benefits of mediation in critical care.[243]

6.3.5 NCOB can merely make recommendations

It should be noted that these are merely recommendations and that they are not contained in legislation in any of the jurisdictions in the United Kingdom. It is up to each jurisdiction to decide whether they want to include any of the recommendations in legislation.

6.4 Conclusion

Although there has not been a plethora of cases in England and Wales in which the court was asked to intervene regarding the treatment of a critically-ill neonate, several cases did reach the courts. The first case to be heard by an English court, in which the court was required to intervene, was that of *In re B*,[244] which was decided in 1981.[245] This case was a landmark decision and set the precedent for subsequent cases. The importance of this decision was that the "best interests" of an infant had to be determined in making major decisions concerning the health of

243 NCOB 2006:147,163.
244 See par 6.2.5.5 for a discussion of this case.
245 Meyers 2005:307.

children; this decision runs like a golden thread through all the subsequent decisions.

Ten years later in *In Re J*,[246] the court held that a balancing exercise has to be performed by the courts: "In the balance were to be weighed the pain and suffering and the quality of life the child would likely experience if treatment was undertaken to prolong life, as well as the pain and suffering involved in the treatment itself."[247]

Although the courts are not unsympathetic towards the parents' views of what is in the best interests of their baby, the courts will not easily make a judgment that would prescribe to health care professionals what course of action they should follow.[248] If the decisions in *In Re B*[249] and *In Re T*[250] are compared, it seems that in the former too much emphasis was placed on the best interests of the child and too little on the autonomy of the parents, while the opposite is true of *In Re T.*[251]

In the United Kingdom, in addition to legislation enacted by parliament, a system of common law operates, and the way it is applied can best be

246 *In re J (a Minor) (Child in care: Medical Treatment)* [1992] 3 WLR 507.
247 Meyers 2005:309. See also Harper 1999:14.
248 Meyers 2005:310.
249 *Re B (a Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421.
250 *Re T (a Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.
251 *Re T (a Minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242.

learnt from judicial decisions. The Netherlands, like most countries on the European continent, is governed by a civil code.[252] In only two countries in Europe have cases of this kind been heard, namely the United Kingdom, specifically England and Wales, and the Netherlands.[253] The legal system governing the treatment of critically-ill babies in the Netherlands will therefore be discussed next.

252 McHaffie ea 1999:441.
253 McHaffie ea 1999:443.

CHAPTER 7

THE LEGAL PROTECTION OF NEONATES IN THE NETHERLANDS

7.1 Introduction

The law concerning the treatment or non-treatment of premature and critically-ill neonates as applicable in the Netherlands will now be examined. The law as it applies in the Netherlands has been chosen for comparative study, as this country represents a jurisdiction on the European continent that has a more liberal approach to end-of-life decisions than either South Africa or England and Wales, and a few cases have reached the Dutch courts.

In a study that was undertaken in neonatal intensive care units (NICUs) in the Netherlands, it was found that most of the deaths that occurred were preceded by decisions to deliberately terminate life-support treatment and many of these decisions were based on the predicted poor quality of life the neonate would experience, should he or she survive.[1] A clear legal and moral distinction is drawn between the withholding or withdrawing of life-preserving treatment on the one hand, and the deliberate ending of a neonate's life on the other.[2] The former is

1 Verhagen ea 2009b:900.
2 Verhagen ea 2009b:899.

considered to be a medical decision to which no consequences are attached, while the latter is considered to be a criminal offence, namely murder[3] or manslaughter.[4] However, it will be pointed out that the physician can escape prosecution in the latter case if certain strict requirements are met on the grounds of "necessity".[5] This principle was laid down in the Prins[6] and Kadijk[7] cases that will be discussed below.[8]

Guidelines were drafted by relevant organisations to assist physicians in end-of-life decisions in neonatal intensive care. These guidelines will be examined below.

It should be noted that it would be incorrect to use the term neonatal "euthanasia", since one of the requirements for euthanasia is that it can only be done after the patient has explicitly requested the physician to end his or her life.[9] A neonate does not have a voice of his or her own

3 *Wetboek van Strafrecht, Artikel 289: " Hij die opzettelijk en met voorbedachten rade een leven berooft, wordt, als schuldig aan moord, gestraft met levenslange gevangenisstraf of tijdelike van ten hoogste dertig jaren of geldboete van de vijfde categorie."*

4 *Wetboek van Strafrecht, Artikel 287: "Hij die opzettelijk een ander van het leven berooft, wordt, als schuldig aan doodslag, gestraft met gevangenisstraf van ten hoogste vijftien jaren of geldboete van de vijfde categorie."* See also Dorscheidt ea 2011:3; Verhagen ea 2009b:89 and the report by Centre for Ethics and Health 2007:9.

5 Jochemsen 1998:448.

6 Prins. Court of Alkmaar, 26 April 1995, TGR 1995/41 and Court of Appeal of Amsterdam, the Netherlands. 7 November 1995, TGR 1996/1.

7 *Tijdschrift voor Gezondheidsrecht,* No 5/1996:284-291.

8 See par 7.3.4.

9 *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding.*

and therefore the preferred term in such cases is “end-of-life decisions” (abbreviated as EoL).[10] This is the term that will be used in the remainder of this thesis. End-of-life decisions include decisions to withhold or withdraw treatment, as well as decisions to deliberately end the life of the neonate.[11]

7.2 Medical treatment in general

7.2.1 Consent to medical treatment

Article 11 of the Dutch Constitution,[12] which deals with the right to physical integrity and self-determination, requires a physician to obtain prior consent before he or she can commence with medical treatment.[13] Medical treatment without prior consent could lead to or would amount to

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Artikel 2(2): “Indien de patient van zestien jaren of ouder niet langer in staat is zijn wil te uiten, maar voordat hij in die staat geraakte tot een redelijke waardering van zijn belangen terzake in staat werd geacht, en een schriftelijke verklaring, inhoudende een verzoek om levensbeëindiging, heeft afgelegd, dan kan de arts aan dit verzoek gevolg geven. De zorgvuldigheidseisen, bedoeld in het eerste lid, zijn van overeenkomstige toepassing.”
Artikel 2(3): “Indien de minderjarige patient een leeftijd heeft tussen zestien en achttien jaren en tot een redelijke waardering van zijn belangen terzake in staat kan worden geacht, kan de arts aan een verzoek van de patient om levensbeëindiging of hulp bij zelfdoding gevolg geven, nadat de ouder of de ouders die het gezag over hem uitoefenen dan wel zijn voogd bij de besluitvorming zijn betrokken.”
Artikel 2(4): “Indien de minderjarige patiënt een leeftijd heeft tussen de twaalf en zestien jaren en tot een redelijke waardering van zijn belangen terzake in staat kan worden geacht, kan de arts, indien een ouder of de ouders die het gezag over hem uitoefent of uitoefenen dan wel zijn voogd zich met de levensbeëindiging of hulp bij zelfdoding kan of kunnen verenigen, aan het verzoek van de patient gevolg geven. Het tweede lid is van overeenkomstige toepassing.”

10 Verhagen ea 2007:e22.
11 Verhagen ea 2009a:e113.
12 Article 11 of the Dutch Constitution reads as follows: *“Ieder heeft, behoudens bij of krachtens de wet te stellen beperkingen, recht op onaantastbaarheid van zijn lichaam.”*
13 Leenen ea 1993:17

a criminal offence, namely assault.[14] A physician who imposes treatment without the prior consent of the patient, even if he or she strongly believes the treatment will be in the best interests of the patient, can, in addition to being prosecuted for a criminal offence, also expose himself or herself to disciplinary proceedings and civil action.[15] In the case of a minor who is twelve years of age or younger, consent by someone with parental authority is required before necessary medical treatment may be given, but if the parents unreasonably withhold their consent, a *"kinderrechter"* can grant consent instead.[16] Substituting consent (*"vervangende toestemming"*) can only be granted if it is essential to prevent a serious threat to the health of a child.[17]

7.2.2 Parental authority ("ouderlijke gezag")

Parental authority is exercised by both parents or by one parent only, while guardianship is exercised by a person other than the parents.[18] While they are married, parents exercise parental authority jointly; this

14 Jost 2007:291; Leenen ea 1993:164.
15 Jost 2007:291.
16 *Burgerlijk Wetboek Boek 1 Artikel 264: "Indien een medische behandeling van een minderjarige jonger dan twaalf jaren noodzakelijk is om ernstig gevaar voor diens gezondheid te voorkomen en de ouder die het gezag heeft zijn toestemming daarvoor weigert, kan deze toestemming op verzoek van de gezinsvoogdij-instelling worden vervangen door die van de kinderrechter."*
17 Nieuwenhuis ea (eds) 2003:359.
18 *Burgerlijk Wetboek Boek 1. Artikel 245(3): "Ouderlijk gezag wordt door ouders gezamenlijk of door één ouder uitgeoefend. Voogdij wordt door een ander dan een ouder uitgeoefend." Titel 14, Bugerlijk Wetboek, Artikels 245-377* extensively deal with parental authority over minors.

does not change in the event of divorce, unless a children's court judge awards parental authority to one parent only.[19]

Should a situation arise where it is in the best interests of a minor that consent for medical treatment be obtained urgently, that child may be removed from the guardianship of his or her parents temporarily and placed in the care of a child protection agency.[20] This is regulated by Article 241 of the Civil Code, Book 1.[21]

7.3 Withholding or withdrawing treatment

7.3.1 General

Verhagen and Sauer[22] recognise that one of the most difficult decisions a paediatrician can be faced with is when to start life-sustaining treatment and when to withhold life-sustaining treatment. It is an even

19 *Burgerlijk Wetboek Boek 1. Afdeling 2; Ouderlijk gezag. Artikel 251(1): "Gedurende hun huwelijk oefenen de ouders het gezag gezamentlijk uit."*
Artikel 251(2): "Na ontbinding van het huwelijk anders dan door dood of na scheiding van tafel en bed blijven de ouders die gezamentlijk het gezag hebben, dit gezag gezamentlijk uitoefenen, tenzij de ouders of een van hen rechtbank in het belang van het kind te bepalen dat het gezag over een kind of de kinderen aan een van hen alleen toekomt."

20 Leenen ea 1993:103.

21 *Bugerlijk Wetboek, Boek 1, Afdeling 3. De raad voor de kinderbescherming. Artikel 241(2): "Indien dit ter voorkoming van ernstig gevaar voor de zedelijke of geestelijke belangen of voor de gezondheid van zulk een minderjarige dringend en onverwijld noodzakelijk is, kan de kinderrechter een voogdij-instelling als bedoeld in artikel 60 van de Wet op de jeugdhulpverlening, belasten met die voorlopige voogdij over de minderjarige. De raad voor de kinderbescherming wend zich in dit geval binnen zes weken tot de rechter teneinde een voorziening in het gezag over dezer minderjarige te verkijgen."*

22 Verhagen and Sauer 2005b:736.

more difficult decision in the case of a severely ill neonate with a very poor prognosis who is suffering unbearable pain that cannot be alleviated in any way.[23] While it is accepted practice among neonatologists to withdraw or withhold treatment from severely handicapped neonates, the deliberate termination of the life of such an infant is not standard practice, even though in certain instances it might seem like the merciful thing to do.[24]

There are three categories of end-of-life decisions in the case of neonates: firstly, withholding of medical treatment, also called abstention.[25] This is the end-of-life decision that is most frequently made and entails withdrawing or withholding life-prolonging treatment, such as resuscitation and mechanical ventilation.[26] The second category is the administration of painkillers and sedatives that will hasten death, although this is not the intended outcome.[27] In English law this is known as the "doctrine of double effect".[28] The third category is euthanasia, which is the deliberate ending of the life of a competent patient after various requests by the patient.[29] It is important to note that the deliberate ending of the life of a neonate is still illegal in the Netherlands;

23 Verhagen and Sauer 2005b:736.
24 De Wachter 1992:24.
25 Moratti 2010:471.
26 Moratti 2010:471.
27 Moratti 2010:471.
28 See chapter 6 par 6.2.5.6 fn 135.
29 Moratti 2010:472.

however in certain circumstances the physician could escape prosecution, as mentioned above.[30]

It has been pointed out by some scholars that in the case of neonates life-sustaining treatment is usually initiated before the prognosis or future quality of life of the neonate can be assessed with certainty.[31] The effect is that in most cases an end-of-life decision will centre on the withdrawal of life-sustaining treatment or the deliberate ending of the life of a nonviable neonate.

In all countries, it is a requirement that palliative care be provided when a decision has been made to withhold or withdraw treatment. In terms of Article 255 of the Dutch Penal Code[32] it is a criminal offence not to provide ordinary palliative care when treatment is withheld or withdrawn.[33]

In conclusion it can be said that deliberate ending of life can be justified if it is necessary to put an end to the suffering of a severely defective

30 Verhagen and Sauer 2005b:737. See par 7.1.
31 Van der Heide ea 1997:255.
32 *Wetboek van Strafrecht, Titel XV, Artikel 255: "Hij die opzettelijk iemand tot wiens onderhoud, verpleging of verzorging hij krachtens wet of overeenkomst verplicht is, in een hulpeloze toestand brengt of laat, word gestraft met gevangenisstraf van ten hoogste 2 jaren of geldboete van de vierde categorie."*
33 See also McHaffie 1999:443 and Artikel 255 of the *Wetboek van Strafrecht* quoted in footnote 32.

neonate, if the parents consent to it. The doctor must report the death as "not natural" to the prosecutorial authorities.[34] The decision-making process must include consultation with an independent doctor, and the decision deliberately to terminate the baby's life must be discussed with the health care team, including the nurses.[35]

Dutch civil law requires parents to take care of their children and to raise them, and making decisions regarding the health care of their children forms part of this responsibility.[36] Neonates do not have a voice of their own, and therefore their parents act as their proxy decision makers.[37] Parental consent must be obtained before a physician can initiate, withhold or withdraw medical treatment.[38] However, parents need to be well informed before making a decision regarding the health care of their offspring.[39] Parents can consent to treatment, they can refuse life-saving treatment, request doctors to withdraw or withhold treatment or even request doctors to terminate the life of their child.[40]

34 Moratti 2010:484.
35 Moratti 2010:484.
36 Dorscheidt ea 2011:3.
37 Dorscheidt ea 2011:3.
38 Dorscheidt ea 2011:3.
39 Dorscheidt ea 2011:3.
40 Dorscheidt ea 2011:3.

7.3.2 Disagreement between health care professionals and parents

In a study undertaken by Verhagen and others,[41] it was found that there are two reasons for conflict between parents and health care professionals, namely religion and poor communication on the part of health care professionals.

Furthermore there are two forms of disagreement between parents and health care professionals that are commonly encountered: Firstly, parents may want treatment, while doctors would prefer to withhold treatment.[42] Secondly, doctors may want to give treatment, while parents prefer treatment to be withheld.[43] In the case of the former, the parents' wishes should be respected unless treatment would lead to unbearable pain and suffering.[44]

If doctors favour treatment, but parents are opposing treatment, the Working Group suggests that either another neonatologist should be called in, or that the neonate should be transferred to another hospital.[45] When the parents refuse, for religious reasons, to permit a blood transfusion to be performed, for example in the case of Jehovah's

41 Verhagen ea 2009a:e117.
42 Moratti 2010:478-480.
43 Moratti 2010:478-480.
44 Moratti 2010:478.
45 Moratti 2010:480.

Witnesses, the prosecutor is involved and parental guardianship is temporarily removed to enable the doctor to continue with treatment.[46]

In all the cases mentioned above, the doctor can seek a court order to temporarily remove the child from parental custody, which would allow the doctor to pursue his or her course of action, despite objections from the parents.[47] This is done in terms of Article 241(2) of the Civil Code, quoted above.[48]

7.3.3 Dutch Association of Paediatrics ("Nederlandse Vereniging voor Kindergeneeskunde" (NVK))

In the mid-1980s the Dutch Association of Paediatrics formed a "Perinatology Section" which in turn appointed a Working Group, Ethics in Neonatology, to draft guidelines for end-of-life decisions in neonatology.[49] The Working Group concluded that it is as much part of the responsibilities of a neonatologist to withdraw life-preserving treatment when it has become clear that such treatment would be futile, as it is to initiate such treatment in the first place.[50] The Working Group also held that "there is no ethical difference between withholding of

46 Moratti 2010:480.
47 Moratti 2010:478.
48 See par 7.3.1 fn 21.
49 Moratti 2010:475.
50 Moratti 2010:476.

treatment and withdrawal of treatment".[51] They also drew a distinction between medical treatment that is *"kansloos"* (that is when death is inevitable) and medical treatment that is deemed *"zinloos"* (that is medical treatment that would serve no purpose, in other words, treatment would be futile).[52] The following criteria for deciding when medical treatment would be futile were laid down:[53]

- suffering and pain, permanent functional impairments, anxiety, bleak prospects for the future;
- life expectancy;
- capacity to communicate, verbally and non-verbally;
- possibilities for personal development, i.e. learning to read, write, and work;
- self-sufficiency, i.e. capacity to sit, walk, live and take care of oneself independently;
- dependency on medical care in the baby's future, i.e. frequency of hospitalisations.

51 Moratti 2010:476.
52 Moratti 2010:477.
53 Moratti 2010:477,489 fn 64.

The Working Group issued a warning that the criteria should be flexible, since disability and suffering are subjective experiences, but that the baby's future should be assessed in an objective way.[54]

The role of the parents in the decision-making process was recognised by the Working Group, and they stressed the importance of the fact that parents should be part of decisions made about the future of their offspring.[55] It was also mentioned that there might not be sufficient time to involve parents in decisions regarding the withholding of treatment since such decisions often have to be made within minutes of birth.[56] However, before a decision is made to withdraw life-sustaining treatment or to end the life of the neonate, parents have to be actively involved in the decision-making process.[57] Before a decision is made parents have to be thoroughly informed; they must express their opinions and give consent before physicians can proceed with the proposed course of action.[58] It is possible that conflict may arise between health care professionals and parents, based on different interpretations of what is in the best interests of the neonate.[59]

54 Moratti 2010:477.
55 Moratti 2010:478.
56 Moratti 2010:478.
57 Moratti 2010:478; Verhagen ea 2009a:113.
58 Verhaben ea 2009a:113.
59 Verhagen ea 2009a:113.

In 1992 the Dutch Paediatrics Association, and in 1997 the Royal Dutch Medical Association, issued guidelines on the circumstances under which life-sustaining treatment for neonates may be withheld or withdrawn. The report by the Dutch Paediatrics Association is entitled "*Doen of Laten: Grenzen van het Medisch Handelen in de Neonatologie"*, and the report by the Royal Dutch Medical Association is entitled "*Medisch Handelen rond het Levenseinde bij wilsonbekwame Patiënten".*[60] These guidelines were based on the decisions by the different courts in the Prins[61] and Kadijk[62] cases (which will be discussed below) and formed the basis of the Groningen Protocol.[63]

7.3.4 Case studies

The Netherlands is the only country where the active ending of life has been tested by the courts.[64]

The case of baby Ross is worth mentioning.[65] Baby Ross was suffering from Down's Syndrome and duodenal atresia[66] and in addition had

60 Moratti 2010b:4.
61 Prins. Court of Alkmaar, 26 April 1995, TGR 1995/41 and Court of Appeal of Amsterdam, the Netherlands. 7 November 1995, TGR 1996/1.
62 *Tijdschrift voor Gezondheidsrecht,* No 5/1996:284-291.
63 Centre for Ethics and Health 2007:19.
64 McHaffie 1999:444.
65 The case was reported as Nr. 46. Hoge Raad (Strafkamer) DD89.398. *Nederlandse Jurisprudentie. Uitspraken in burgerlijke en strafzaken* 1990:200.
66 See chapter 3 paras 3.3.3.4 and 3.3.5.3 for an explanation of this medical condition.

twelve fingers.[67] The paediatrician decided not to operate on Baby Ross, since the parents of the child refused to give consent to the operation, but instead the paediatrician sedated the child, who eventually passed away on 17 May 1985. The physician who was in charge of the paediatric unit of the Academisch Ziekenhuis, Rotterdam, was charged with murder (*"doodslag"*) but was acquitted by the court of first instance at Maastricht. The case was taken on review (*"cassatie"*) by the Attorney-General. However, the *"hoge raad"* confirmed the decision of the Maastricht court. The court held that the parents had not consented to the operation, and there was no obligation on the paediatrician to obtain the necessary consent in this case. *"In de hiervoren bedoelde overwegingen heeft het hof immers slechts als zijn oordeel gegeven dat de verdachte niet gehouden was te trachten toestemming te verkrijgen tot een operatie op de, aan een niet met het leven verenigbare afwijking lijdende, pasgeborene, nu – naar's hofs oordeel – de niet te verwaarlozen kans bestond dat hij door zo 'n operatie voor het kind en zijn ouders de weg naar een leven van zeer ernstig lijden zou openen."*[68]

67 The case of Baby Ross is similar to that of *In re B*, discussed in chapter 6 par 6.2.5.5.

68 Nr. 46. Hoge Raad (Strafkamer) DD89.398. *Nederlandse Jurisprudentie. Uitspraken in burgerlijke en strafzaken* 1990:200.

Two cases have proved that doctors are not obliged to provide medically futile or inappropriate medical treatment.[69] The first case was the Prins case, which concerned a neonate born with the severest form of spina bifida, hydrocephalus,[70] a spinal cord lesion and brain damage.[71] When the baby was four days old, Prins actively terminated her life because, according to medical opinion, her prognosis was so poor that surgical intervention would be futile.[72] The baby's parents also repeatedly requested the physician to actively terminate their baby's life, because it was clear from her screaming and crying that she was experiencing unbearable pain.[73] The District Court at Alkmaar acquitted Dr Prins, and formulated the minimum requirements that a physician must adhere to in order to succeed in the defence of necessity:[74]

- that the baby's suffering was unbearable with no hope of improvement;
- that the decision making *"hebben beantwoord aan maatstaven van zorgvuldigheid, wetenschappelijk verantwoord medisch inzicht en in de medische ethiek geldende normen"*;

69 McHaffie 1999:442-443. See also Centre for Ethics and Health 2007:22.
70 See chapter 3 par 3.3.1.3 fn 70 for an explanation of this term.
71 Prins. Court of Alkmaar, 26 April 1995, TGR 1995/41 and Court of Appeal of Amsterdam, the Netherlands. 7 November 1995, TGR 1996/1. See also Jochemsen 1998:451.
72 Nr 602. ARR.-Rechtbank Alkmaar (Strafkamer) 26 April 1995. *Nederlandse Jurisprudentie* 1995:2877-2878.
73 *Nederlandse Jurisprudentie* 1995:2878.
74 *Nederlandse Jurisprudentie* 1995:2878. See also Jochemsen 1998:452; Nadasen 1997:124-127.

- that the parents had expressly and repeatedly requested the doctor to terminate the life of their baby

The court came to the conclusion that the doctor had acted *"in de door de raadsman bedoelde noodtoestand"*.[75] Prins had experienced a conflict of duties: on the one hand he had a duty to care for the patients entrusted to him and to preserve life, but on the other hand, he was under an obligation to alleviate the suffering of his patient, in this case, baby R.[76] The defence of necessity (*"noodtoestand"*) was confirmed on appeal.[77]

The second case is the so-called Kadijk case.[78] A baby was born on 1 April 1994 suffering from a chromosomal defect, diagnosed as Trisomy 13,[79] as well as other congenital malformations. The paediatrician discussed the baby's diagnosis and prognosis with the parents and explained to them that the baby had between a week and a few months to live as 90 percent of children suffering from Trisomy 13 died before their first birthday. The baby was taken home, where she was cared for

75 *Nederlandse Jurisprudentie* 1995:2878.
76 Nadasen 1997:125.
77 Nr 113. Hof Amsterdam (Strafkamer) 7 November 1995. *Nederlandse Jurisprudentie* 1996:554-555.
78 This case is reported in *Tijdschrift voor Gezondheidsrecht,* No 5/1996:284-291. See also Jochemsen 1998:451.
79 See chapter 3 par 3.3.5.1 for an explanation of this term.

by her parents, but then complications arose (tissue bulged through an opening in the skull) and it was clear that the baby was experiencing pain; painkillers did not seem to have the desired effect. The doctor, with the permission of the parents, administered a high dose of Stesolid and about half an hour later, Alloferin, knowing that this combination would be lethal. The court acquitted Kadijk on the following grounds:

- The diagnosis, as well as the prognosis, was clear to both the doctors and the parents.
- The parents consented to the end-of life-decision.
- The doctor had consulted with an independent and experienced general practitioner and a paediatrician.
- The death was brought about in accordance with careful medical practice.
- The case was reported to the relevant authorities.

“Het hof komt tot de slotsom, dat de situatie waarin de verdachte zich geplaatst zag, naar wetenschappelijke verantwoord medisch ethiek geldende normen als een noodtoestand kan worden aangemerkt, waarin de door de verdachte gemaakte keuze als

gerechtvaardig is te beschouwen, zodat hij van alle rechtsvervolging dient te worden ontslagen."[80]

There are numerous similarities between the Prins[81] and Kadijk[82] cases. In both cases medical intervention would have been futile because of the severity of the malformations.[83] Both infants appeared to be suffering unbearable pain and there was no suitable medication available to relieve the pain.[84] After consultation with the parents the infants were given a lethal dose of medication which resulted in death.[85] The physicians in both cases faced criminal charges, more specifically murder and subsidiary homicide.[86] Both physicians were acquitted on the ground of necessity in terms of Article 40 of the Dutch Penal Code.[87] The argument was that the responsible doctor "had been confronted with a conflict of duties between the two ethical imperatives that characterise the medical profession; saving life and relieving suffering".[88] In both cases the objective opinions of other physicians who were consulted

80 *Tijdschrift voor Gezondheidrecht* Nr 5/1996:290.
81 Prins. Court of Alkmaar, 26 April 1995, TGR 1995/41 and Court of Appeal of Amsterdam, the Netherlands. 7 November 1995, TGR 1996/1.
82 *Tijdschrift voor Gezondheidsrecht,* No 5/1996:284-291.
83 Dorscheidt 2005:805.
84 Dorscheidt 2005:805; Moratti 2010:483; Verhagen and Sauer 2005b:738.
85 Dorscheidt 2005:805.
86 Dorscheidt 2005:805.
87 Article 40 of the *Wetboek van Strafrecht* reads as follows: "Niet strafbaar is hij die een feit begaat waartoe hij door overmacht is gedrongen." Moratti 2010:483.
88 De Leeuw ea 1996:664; Moratti 2010:483. See also Jochemsen 1998:448.

were also considered and they agreed that in these cases medical treatment would have been futile.[89]

"The *Prins* and *Kadijk* cases clarified that the rules applicable to deliberate ending of life are essentially those laid down in the Report of the Association of Paediatrics."[90]

7.3.5 Professional guidelines regarding resuscitation

It is standard practice in the Netherlands not to initiate neonatal intensive care in the case of extremely preterm neonates and intensive care is withdrawn once it becomes clear that it will be futile.[91] A decision was taken at the University Medical Centre in Leiden that preterm infants of less than twenty-five weeks' gestational age were not to be actively treated, except in cases where parents insisted and doctors regarded the infant as having an exceptional chance of survival.[92] The reason for this decision was that from 1996 to 1997 the mortality rate was 66% of those born between 23 and 24 weeks' gestational age and, if they survived, they were severely mentally and physically handicapped.[93]

89 Dorscheidt 2005:806.
90 See par 7.3.3 for a discussion of this aspect.
91 Walther 2005:971.
92 Brazier and Cave 2007:380; Miller 2007:23.
93 Miller 2007:23.

From twenty-five weeks' gestational age, a neonate is resuscitated at birth if he or she seems to be viable. If not, he or she receives only palliative care.[94] After twenty-six weeks' gestational age, the neonate receives full resuscitation and intensive care, except when it is clear that he or she also suffers from other "lethal congenital abnormalities".[95]

According to the Dutch Medical Association and the Dutch Paediatric Association, withholding or withdrawing life-sustaining treatment is justifiable medical practice in neonates with a poor prognosis.[96]

7.4 The Groningen Protocol, 2002

7.4.1 Background to the drafting of the Groningen Protocol

After fifteen years of discussions between the medical profession and the public, and with the guidance of legal precedents, the Groningen Protocol was developed.[97] The following incident led paediatricians to take action: In 2001 at the University Medical Centre in Groningen, the paediatricians dealt with a baby girl suffering from epidermolysis[98] bullosa, a lethal skin disease which caused her skin to come off

94 Walther 2005:971.
95 Walther 2005:971.
96 Walther 2005:971.
97 Verhagen and Sauer 2008:4.
98 *Dorland's* 1985:451*:* "a loosened state of the epidermis".

whenever she was touched.[99] She was experiencing unbearable pain and no medication seemed to relieve her pain effectively, not even heavy sedation.[100] Since she was not dependent on life-sustaining treatment, withholding treatment from her was not an option.[101] Her parents requested the doctors to deliberately terminate her life, but the doctors refused and instead transferred her to a smaller hospital, where she died a few months later.[102]

In 2002 the Groningen Protocol was drafted with the assistance of the local prosecutor to provide guidelines to doctors regarding the deliberate termination of the life of infants who are terminally ill and deemed to be in a state of unbearable pain.[103]

The Groningen Protocol was officially adopted by the Association of Paediatrics in July 2005 for use throughout the Netherlands.[104]

99 Moratti 2010:485; Verhagen and Sauer 2008:4.
100 Moratti 2010:485; Verhagen and Sauer 2008:4.
101 Moratti 2010:485-486.
102 Moratti 2010:486.
103 Manninen 2006:643; Moratti 2010:486.
104 Manninen 2006:643; Moratti 2010:488; Verhagen and Sauer 2005b:738; Verhagen and Sauer 2008:5.

7.4.2 The content of the Groningen Protocol

The Groningen Protocol was developed so that a doctor can end the life of a baby in exceptional circumstances and if certain strict criteria are met to prevent prosecution.[105] In essence the Protocol allows neonatal euthanasia, although this does not formally form part of Dutch law.[106]

According to the Groningen Protocol, neonates in respect of whom end-of-life decisions might be made, can be categorised into three groups:[107]

- First category: "no chance of survival" (Physiologic Futility).[108] For neonates who fall into this category death is imminent, and they will not survive despite receiving sophisticated medical treatment.[109] They often suffer from conditions such as anencephaly,[110] and lung and kidney hypoplasia.[111] In this case medical treatment would be futile and consequently it is considered acceptable medical practice to withhold or withdraw treatment.[112] Verhagen and Sauer[113] are of the opinion that

105 Brazier and Cave 2007:378; Verhagen and Sauer 2005a:960.
106 Brazier and Cave 2007:378.
107 Verhagen and Sauer 2005a:959; Verhagen and Sauer 2005b:737. See also Centre for Ethics and Health 2007:26.
108 Verhagen and Sauer 2005b:737.
109 Verhagen and Sauer 2005a:959; Verhagen and Sauer 2005b:736.
110 See chapter 3 par 3.3.1 fn 49 and par 3.3.1.1 for an explanation of this term.
111 Moratti 2010:486; Verhagen and Sauer 2005a:960. For an explanation of this term, see chapter 3 fn 82.
112 Verhagen and Sauer 2005b:737.
113 Verhagen and Sauer 2005b:737.

"there are no ethical or legal dilemmas in withholding or withdrawing treatment from this group of patients".

- Second category: "poor prognosis" (Intensive Care Treatment with a Very Poor Prognosis).[114] These neonates may survive on life-preserving treatment, but their prognosis is bleak.[115] They can be kept alive in a neonatal intensive care unit, but there are concerns about the quality of life of these neonates who will be severally mentally and physically handicapped despite the best treatment.[116] Should they survive, they will experience a poor quality of life.[117] These infants often experience abnormalities of the brain or extensive damage to their organs as a result of hypoxemia.[118] Verhagen and Sauer[119] recognise that the best interests of these infants are paramount and decisions whether to withhold or withdraw treatment should be based on the best interests of the child. If the parents want to continue with life-preserving treatment, this should be done. If parents and health care professionals agree that it would be in the best interests of the child to withhold or

114 Verhagen and Sauer 2005b:737.
115 Moratti 2010:487; Verhagen and Sauer 2005a:959.
116 Moratti 2010:487; Verhagen and Sauer 2005b:736.
117 Verhagen and Sauer 2005a:960.
118 *Dorland's* 1995:644. Hypoxemia: "deficient oxygenation of the blood". Verhagen and Sauer 2005a:959.
119 Verhagen and Sauer 2005b:737.

withdraw treatment, then this should be the course of action to be followed.[120] However, agreement between parents and health care professionals is critical in these instances.[121]

- Third category: "hopeless prognosis" (Stable Infants with a Hopeless Prognosis).[122] Neonates who fall into this category, such as those suffering from severe forms of spina bifida, suffer unbearable pain.[123] They are not dependent on intensive care for survival, but their quality of life is poor, despite surgical intervention.[124] This is the most problematic group for paediatricians to deal with and if a decision were taken to let "nature take its course", the neonate would eventually die of insufficient hydration and nutrition.[125] The suffering of these babies may be prolonged if a decision is not taken to deliberately end their lives.[126] The baby in the Prins[127] case falls into this category.

In the case of the first group of infants ("no chance of survival") it is considered good practice to withhold or withdraw life-preserving

120 Verhagen and Sauer 2005b:737.
121 Verhagen and Sauer 2005b:737.
122 Verhagen and Sauer 2005:737.
123 Moratti 2010:487; Verhagen and Sauer 2005a:960
124 Verhagen and Sauer 2005b:736-737.
125 Verhagen and Sauer 2005b:737.
126 Verhagen and Sauer 2005b:737.
127 Prins. Court of Alkmaar, 26 April 1995, TGR 1995/41 and Court of Appeal of Amsterdam, the Netherlands. 7 November 1995, TGR 1996/1. Discussed in par 7.3.4.

treatment, in other words neonates who fall into this group are not treated.[128] These neonates will die immediately after life-sustaining treatment is withdrawn.[129]

In the case of the second group ("poor prognosis"), it is regarded as acceptable medical practice for neonatologists to withhold or withdraw treatment on condition that both the health care professionals and the parents agree that this is in the best interests of the child.[130]

The third and last category ("hopeless prognosis") is the most difficult. It is essential that the position is discussed with the parents and that they are given an accurate assessment of the prognosis of their child.[131] They must agree that death is more acceptable than protracted suffering.[132] Verhagen and Sauer[133] are of the opinion that termination of life may be justified in these cases if it is strictly controlled:

- The parents must consent after the condition and the prognosis have been explained to them.

128 Moratti 2010:486.
129 Verhagen and Sauer 2005:960.
130 Moratti 2010:487; Verhagen and Sauer 2005:960.
131 Verhagen and Sauer 2005:960.
132 Moratti 2010:487; Verhagen and Sauer 2005:960.
133 Verhagen and Sauer 2005:960.

- An independent physician, who was not directly involved in the treatment of the baby, must confirm that the condition is untreatable and that the baby's suffering is unbearable.[134]

After discussion with the parents and after their approval has been obtained, high doses of opiates such as morphine are used to induce the death of the baby gently over one or two days.[135] Immediate lethal injections such as potassium chloride injections are not used.[136] After the baby's death, it is obligatory that the matter be reported to the coroner, and thereafter a committee of five members, including an ethicist and a lawyer, scrutinise the decision to ensure that treatment of the baby met the conditions set out in the Protocol.[137]

Dorscheidt[138] analyses a study that was undertaken by Verhagen and others. This study focused on the Group II infants, namely those with a poor prognosis where there were concerns about their quality of life.[139] The study did not include the first category of infants, as this group is regarded as unproblematic. It was not expected that there would be conflicting opinions about this group, since because of the severity of

134 McHaffie 1999:443; Verhagen and Sauer 2005:960.
135 Brazier and Cave 2007:378-379; Verhagen and Sauer 1995:960.
136 Brazier and Cave 2007:378-379.
137 Brazier and Cave 2007:378-379; Verhagen and Sauer 2005:961.
138 Dorscheidt ea 2011:4.
139 Dorscheidt ea 2011:4.

their abnormalities there was no hope that Group I infants would survive, not even with the best medical treatment.[140] The study revealed that a difference of opinion mostly involved "the decision to continue or to withdraw intensive treatment. The main consequence of such a difference of opinion is that the treatment decision is postponed, while in the end both parties always reached consensus as to the discontinuation of the child's treatment."[141]

Infants who belong to the second category have a chance of survival, if treated, but with concerns regarding their future quality of life.[142] However, if the principle of legal equality is applied, an infant who falls into this category should be considered equal to an infant who is not suffering from a disability, and should be entitled to the same medical treatment as a healthy infant.[143]

In the Netherlands persons older than sixteen years may request euthanasia, but parents as proxy decision makers for their children may not ask for the termination of the life of their child.[144] The deliberate "killing" of an infant remains a criminal offence and will be subject to

140 Dorscheidt ea 2011:4.
141 Dorscheidt ea 2011:5,8,10.
142 Dorscheidt ea 2011:10.
143 Dorscheidt ea 2011:10-11.
144 Verhagen and Sauer 2005:959. See also *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding* quoted above.

judicial examination, but if a physician acts in accordance with the requirements of careful practice as set out in the Protocol, he will not be prosecuted.[145] The requirements for careful medical practice are set out below:

- "There is a high degree of certainty over the diagnosis and the prognosis.
- The baby is suffering unbearably and without prospects of improvement, and there are no medically responsible means to relieve the suffering.
- The condition of the baby is so severe that life-prolonging treatment would be deemed "futile" according to the criteria for abstention on grounds of "medical futility" laid down in the 1992 Report of the Association of Paediatrics.
- The doctor informs both parents extensively about the diagnosis and the prognosis and both parents agree that there is no acceptable solution for relieving the baby's suffering.
- At least one independent doctor or multidisciplinary team is consulted, examines the baby in person, and agrees with findings of the doctor who treats the baby.

145 Brazier and Cave 2007:378-379; Moratti 2010:486; Van der Heide and Van der Maas 1997:254.

- Deliberate ending of life is performed in accordance with state-of-the-art medical standards."[146]

There are thus five essential requirements that have to be met before a baby is eligible for euthanasia under the Protocol:

- Intolerable suffering. "The suffering must be so severe that the infant has no prospects for a future."[147]
- No viable alternatives. "There is no possibility that the infant can be cured or alleviated of her affliction with medication or surgery."[148]
- Parental consent.[149]
- Team discussion and independent consultation. "A second opinion must be provided by an independent doctor who has not been involved with the child's treatment."[150]
- Responsible practice.[151]

If a patient dies of natural causes, a doctor would issue a medical certificate, but when a patient has been euthanised a particular

146 Moratti 2010:487.
147 Manninen 2006:644.
148 Manninen2006:644.
149 Manninen 2006:644.
150 Manninen 2006:644.
151 Manninen 2006:644; McHaffie 1999:444; Verhagen and Sauer 2005:961.

procedure must be followed:[152]

- The doctor must inform the coroner, who in turn must inspect the body.
- The coroner would then inform the District Attorney.
- The Office of the District Attorney reviews each case in the light of the relevant legislation or jurisprudence.
- The District Attorney then presents each case together with his own opinion on the case to the College of Attorneys-General.
- The four members of the College of Attorneys-General decide whether to prosecute.
- The final decision whether to prosecute is made by the Minister of Justice.

An important aspect of the Groningen Protocol is the obligatory reporting of neonatal euthanasia "to prevent uncontrolled and unjustified euthanasia".[153] However, even if the correct procedure is followed by a physician when performing neonatal euthanasia, there is no guarantee that he will not be prosecuted, although to date no doctor has been prosecuted after following the correct procedure.[154]

152 Verhagen and Sauer 2005a:960; Verhagen and Sauer 2005b:738. See also Centre for Ethics and Health 2007:16.
153 Verhagen and Sauer 2005:961.
154 Verhagen and Sauer 2005:961.

7.4.3 Criticism of the Groningen Protocol

According to Manninen,[155] the Groningen Protocol has been the subject of criticism, among other things because it would permit the termination of the life of disabled or unwanted infants. Manninen[156] defends the Protocol and points out that the five requirements that have to be met prevent a baby from being euthanised for a minor defect. She points out that the first requirement does not make a quality of life assessment, but determines that the infant must be terminally ill.[157] It is not the intention of the Protocol that the life of all disabled infants should be ended.[158] She uses the example of Baby Doe[159] to illustrate that not all handicapped children in the Netherlands would have been considered suitable candidates for end-of-life decisions in the Netherlands, in terms of the Groningen Protocol.[160] The decision not to operate on Baby Doe, but rather to leave him to die, did not meet the second criterion, namely "viable alternative".[161] In his case surgery would have been a viable alternative and consequently the medical principle of non-maleficence was not adhered to by the health care professionals in whose care he

155 Manninen 2006:643.
156 Manninen 2006:643.
157 Manninen 2006:644.
158 Manninen 2006:644.
159 The case of Baby Doe is discussed in chapter 6 par 6.2.5.5 fn 109.
160 Manninen 2006:644.
161 Manninen 2006:645.

was.[162] Moreover, by allowing him to die while corrective surgery was an option, his welfare interest was violated.[163]

The Groningen Protocol was also criticised by Chervenak, McCullough and Arabin[164] for its use of imprecise phrases such as “hopeless and unbearable suffering”, “best interests of the patient”, “medical-ethical values” and “severe spina bifida”. They are of the opinion that these phrases are not sufficiently defined in the document, which leaves them open to different interpretations.[165] A similar criticism of the Protocol is expressed by Kompanje, de Jong, Arts and Rotteveel.[166] According to them the term *“uitzichtloosheid en ondraaglijk lijden”* is too vague in the case of neonates suffering from spina bifida.[167]

7.5 International human rights instruments

An individual’s right to life is protected by various human rights instruments, which the Netherlands has ratified.[168] Article 6 of the International Covenant on Civil and Political Rights, 1966[169] (hereafter ICCPR) and article 2 of the European Convention for the Protection of

162 Manninen 2006:645.
163 Manninen 2006:645.
164 Chervenak ea 2008:6.
165 Chervenak ea 2008:6.
166 Kompanje ea 2005:2067-2069.
167 Kompanje ea 2005:2067-2069.
168 Dorscheidt 2011:12.
169 “Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.”

Human Rights and Fundamental Freedoms, 1950[170] (hereafter ECHR) both protect the individual's right to life. The right to life is an inalienable right and therefore cannot be transferred to another person, not even the parents of a defective neonate.[171] "In consequence parents are not entitled to renounce their infant's legal protection of this fundamental right."[172]

The Netherlands ratified the ECHR in August 1954.[173] Article 2 has a direct impact on withholding and withdrawing treatment and above all on euthanasia ("end of life" in the case of neonates). However, Dorscheidt[174] mentions that this provision is not absolute and can in certain instances be limited, for example where a non-viable fetus is aborted. Article 2(2)[175] mentions three situations in which the right may be limited.[176] The stance of the Dutch government on neonatal end of life is that since a neonate does not have the capacity to decide whether it

170 "Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law."
171 Dorscheidt ea 2011:13.
172 Dorscheidt ea 2011:13.
173 Dorscheidt 2005:320.
174 Dorscheidt 2005:813-814.
175 Deprivation of life shall not be regarded as inflicted in contravention of this article when it results from the use of force which is not more than absolutely necessary:
(a) in defence of any person from unlawful violence;
(b) in order to effect a lawful arrest or to prevent the escape of a person lawfully detained;
(c) in action lawfully taken for the purpose of quelling a riot or insurrection.
176 Dorscheidt 2005:813.

would be in his or her best interests to waive his right to life, the right to life is an inalienable right in the case of neonates.[177]

The Dutch government also ratified the United Nations Convention on the Rights of the Child 1989 on 26 January 1990 and thereby committed itself to bring its legislation pertaining to children into line with the rights embodied in the Convention.[178] Thus, at first glance end-of-life decisions with regard to neonates seem to be incompatible with the above-mentioned international human rights instruments. However, Dorscheidt[179] presents an argument on how end-of-life decisions can be reconciled with the provisions in favour of the right to life in international human rights instruments. Dorscheidt[180] argues that the child's right to life is an inalienable right and that a neonate is in no position to waive this right and no parent has the right to transfer this right to another person. This means that end-of-life decisions made by parents on behalf of their children would be incompatible with Dutch law and international human rights instruments.[181] He continues as follows:[182]

> "We therefore believe that it is not the inalienable character of the right to life that stands in the way of (regulating) the deliberate

177 Dorscheidt 2005:816-817.
178 Dorscheidt 1999:303,305.
179 Dorscheidt ea 2011:13-15.
180 Dorscheidt 2011:13.
181 Dorscheidt 2011:13.
182 Dorscheidt 2011:15.

ending of the life of a hopeless and unbearable suffering neonate, but the fact that this child is incapable of divesting its right to life of its inalienable nature. What follows, is a situation of legal inequality between the unbearable suffering competent person and the equally unbearable suffering incompetent newborn child regarding the possibility to prevent the exercise of one's right to life contrary to one's personal interest in avoiding a life of hopeless and unbearable suffering. In real neonatal practice situations occur in which it is unsound to hold on unconditionally to the idea of the inalienable right to life of a newborn child. To do this would mean to make a newborn child a prisoner of its inalienable right to life. This, we believe, distorts the fundamental aim of this elementary right."

According to Dutch civil law, once a person is born alive (or is a viable unborn) he or she is considered a person and acquires all the rights conferred by law on a citizen.[183] That means that a neonate also acquires all the rights conferred on him or her by international human rights instruments, such as the ECHR and the CRC.

183 Dorscheidt 1999:304.

Dorscheidt[184] mentions that the inalienability doctrine "when interpreting the right to life in the context of end-of-life decisions in neonatology is, yet, under debate. Whether a certain withdrawal or withholding of life-sustaining treatment, a particular medical regime or even medical neonaticide constitutes a violation of this inherency and/or inalienability isn't easy to establish, due to a lacking manifest and univocal standard for legal interpretation of these concepts." Parents often contravene the right to life of their children when making decisions regarding the medical care of their children.[185] However, according to the Groningen Protocol, it is considered to be "careful practice" when parents have consented to the administering of drugs that will hasten the death of a neonate.[186]

In terms of the Termination of Life on Request and Assisted Suicide Act,[187] which came into force in 2002, an incompetent person cannot consent to euthanasia, which means that a neonate's right to life is inalienable.[188] "Be this as it may, in our view at least it seems rather unjust that a neonate cannot have a reasonable interest in abandoning his right to life, especially when the exercise of this right is accompanied

184 Dorscheidt ea 2011:13.
185 Dorscheidt ea 2011:14.
186 Dorscheidt ea 2011:14.
187 *Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding.*
188 Dorscheidt ea 2011:14.

by hopeless, unbearable and incurable pain and suffering."[189] It sometimes happens in NICU that it would not be sound medical practice to keep a neonate alive, where this would be accompanied by unbearable suffering. If one were to rely on the inalienability of his or her right to life and the fact that this right cannot be transferred to his or her parents, it would mean that the suffering neonate would be "a prisoner of its inalienable right to life".[190] There seems to be an anomaly here: On the one hand there is the inalienability of the right to life, but on the other hand, when parents agree with the physician that it would be in the child's best interests to terminate the life of a severely defective and suffering neonate, it is regarded as "careful practice".[191]

7.6 Conclusion

In the Netherlands end-of-life decisions were dealt with from a criminal point of view rather than from the point of view of the best interests of the child standard. Various guidelines were drafted regarding end-of-life decisions in the Netherlands, culminating in the important Groningen Protocol.

189 Dorscheidt ea 2011:14.
190 Dorscheidt ea 2011:15.
191 Dorscheidt ea 2011:16.

Unlike in England and Wales, in the Netherlands only a few cases regarding end-of-life decisions have reached the courts. The reason for this could be that guidelines formulated by paediatricians, such as the Groningen Protocol and the guidelines framed by the *Nederlandse Vereniging voor Kindergeneeskunde* (namely, *Doen of Laten? Grenzen van het Medisch Handelen in de Neonatologie* (Utrecht 1992)) and the Health Council of the Netherlands are followed. This would eliminate the need for a court to step in and rule on an end-of-life decision. One of the guidelines in these reports is that parental consent is essential before any end-of-life decision can be made. If parental consent is not obtained, the doctors must continue with life-sustaining treatment.

An interesting aspect regarding the court cases that were discussed is that although the Netherlands ratified the Convention on the Rights of the Child in 1990, in which the best interests standard was established,[192] this standard was not mentioned in either the Prins[193] or the Kadjik cases. These cases were heard after the ratification of the CRC by the Dutch government. The emphasis was placed instead on the deliberate termination of the life of a nonviable neonate.

192 Article 3(1) reads as follows: "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration."

193 Prins. Court of Alkmaar, 26 April 1995, TGR 1995/41 and Court of Appeal of Amsterdam, the Netherlands. 7 November 1995, TGR 1996/1.

In *Burgerlijk Wetboek, Boek 1, Personen- en Familierecht*, no article deals exclusively with the best interests of the child standard. In fact there is no article that can be compared to section 28(2) of the Constitution of the Republic of South Africa, 1996[194] or section 9 of the Children's Act 38 of 2005.[195] In England and Wales the same standard is to be found in section 1(1) of the Children Act, 1989,[196] although different terminology is used.

The approach in the Netherlands regarding end-of-life decisions in neonatal intensive care appears irreconcilable with the legislation applicable in South Africa and England and Wales, since in both these jurisdictions it would amount to murder to actively end the life of a neonate, no matter how ill or disabled he or she might be. In South Africa and England and Wales the emphasis is rather on the best interests of the child.

194 "A child's best interests are of paramount importance in every matter concerning the child."

195 "In all matters concerning the care, protection and well-being of a child the standard that the child's best interest is of paramount importance, must be applied."

196 (1) When a court determines any question with respect to—
(a) the upbringing of a child; or
(b) the administration of a child's property or the application of any income arising from it, the child's welfare shall be the court's paramount consideration.

CHAPTER 8

CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

Society has come a long way since Antiquity, when neonates enjoyed no protection. Malformed or unwanted neonates could be killed at the whim of the head of the household. If the infant was lucky he was exposed and could possibly be rescued and raised by someone else.[1] Attitudes changed noticeably during the Middle Ages and by this time infanticide had come to be considered a crime.[2] The Roman-Dutch authors wrote that a malformed baby (or monster) could be killed with impunity, but a healthy child could not be killed.[3] Among certain indigenous South African cultures it was customary to kill malformed neonates or one of a pair of twins. This custom was largely based on superstition.[4]

It should be noted that in our day children suffering from conditions such as spina bifida and Down's syndrome are not regarded as monsters,

1 For a discussion see chapter 2 paras 2.2.4, 2.3 and 2.4.
2 For a discussion see chapter 2 par 2.4.
3 Kahn in Kahn (ed) 1984:27. For a discussion see chapter 2 par 2.6.
4 For a discussion, see chapter 2 par 2.9.1.

because they still have a human form.[5] According to South African law anyone born from human descent is regarded as a human being no matter how severely deformed he or she might be.[6] In English law, Acts like the Infanticide Act 1922 and the Infanticide Act 1938 were promulgated to protect neonates.[7]

In South Africa, as in England and Wales, a fetus does not have any rights, but as soon as the fetus is born alive, he or she enjoys all the rights that are assigned to a human being.[8] South Africa, England and Wales and the Netherlands have ratified the CRC, which means that children in all three of these countries enjoy the rights enunciated in this document, of which the two most significant rights are the best interests of the child and the right to health care.

To date no cases where there was disagreement between the health care professionals and parents regarding withholding or withdrawing of treatment in the case of neonates have been reported in South Africa,

5 Kahn in Kahn (ed) 1984:27.
6 Heaton 2008:5.
7 See chapter 2 par 2.7 for a discussion.
8 Heaton 2008:4,5.

save for *Hay v B*.[9] There are various possible reasons for this. A few suggested reasons are the following:

- Parents do not challenge the decisions of health care professionals regarding the treatment of their offspring.
- Agreement between health care professionals and parents is reached privately.
- Litigation costs discourage people from embarking on court action.
- Cases are settled out of court.
- This is an emotional issue and people might not feel that a court is the correct forum in which to settle it.
- Public hospitals do not have the financial resources to engage in litigation in the event of a disagreement between parents and health care professionals, unlike the NHS Trust in England and Wales, which has been a party in several court cases.

It is suggested that as parents become better informed, cases in which there is disagreement between health care professionals and parents will be subjected to judicial scrutiny. There are, however,

9 The question of blood transfusions is now contained in section 129(10) of the Children's Act. See chapter 4 par 4.3.1 and chapter 5 par 5.4.7 for a discussion.

several cases where delictual claims have been instituted against health care professionals and hospitals for damages following alleged negligence by either the physician or the hospital.[10]

8.2 The position in South Africa

8.2.1 Strong points of the South African legal position

South Africa has ratified various human rights instruments[11] and effect has been given to the provisions of these human rights instruments in the Constitution of the Republic of South Africa, 1996, and legislation such as the Children's Act 38 of 2005 and the National Health Act 61 of 2003. The provisions that are of particular importance are those relating to the best interests of the child in Article 3 of the CRC and the right to health care in Article 24 of the CRC. Both these rights are entrenched in the Constitution, in sections 27 and 28(2), and in sections 7, 8 and 9 of the Children's Act 38 of 2005, as well as in sections 4 and 5 of the National Health Act 61 of 2005.[12] In terms of the National Health Act 61

10 Examples of such cases are: *Hughes v Laubscher* [1999] JOL 5833 (E); *Wright v Medi-Clinic Ltd* 2007 SA 327 (C). The cases concerning "wrongful life" and "wrongful birth" which were discussed in chapter 4 par 4.4.1 are also relevant.

11 See chapter 5 par 5.2 for a discussion.

12 For a discussion, see chapter 5 par 5.2.

of 2003, a child, including a neonate, is entitled to free health services.[13] This is in line with Millennium Development Goal 4, which aims to reduce the infant mortality rate.[14]

There is also a disparity in the quality of care in state and private hospitals. Even in the public sector, the quality of care can range from the worst to the best. Baragwanath hospital could be used as an example of care at the lower end of the scale, since it is not always possible to offer mechanical ventilation where necessary.[15] Lack of resources also contribute to infections which in turn also lead to deaths.[16] Tygerberg hospital in the Western Cape is an example of a public hospital where the quality of care is at the top end of the scale.[17] Here a significant improvement has been made in the overall survival rate of very low birth rate neonates.[18]

13 See chapter 5 par 5.5.1 for a discussion.
14 See chapter 5 par 5.3 for a discussion.
15 Velaphi and Van Kwawegen "Diagnosis on admission and causes (Pathological and systemic) of deaths among neonates who were admitted to a high care nursery)"
16 Velaphi and Van Kwawegen "Diagnosis on admission and causes (Pathological and systemic) of deaths among neonates who were admitted to a high care nursery)."
17 Madide and Kirsten "Premature loss: can we reduce extreme low birth weight neonatal mortality?"
18 Velaphi and Van Kwawegen "Diagnosis on admission and causes (Pathological and systemic) of deaths among neonates who were admitted to a high care nursery." (

According to Dr Carin Maree[19] the following scenarios illustrate what happens when there is a shortage of facilities in NICUs (neonatal intensive care units) in the public health care sector:

- Unrelated neonates are placed together in incubators. This secures some form of treatment for all neonates in need of specialised treatment, albeit with the accompanying risk of cross-infection.
- The strongest neonates are transferred from the NICU to a high care unit, although they do not meet the criteria for transferral. These infants would normally only have been transferred to a high care unit at a later stage.
- Neonates are referred to other hospitals with sufficient facilities, although these might be a long distance away.
- Neonates who are actually in need of specialised care receive only palliative care.

Extensive provision is made in the Children's Act for consent to medical treatment.[20] Under normal circumstances the parent or guardian would consent to treatment, but the Children's Act makes provision for other

19 Senior lecturer, Department of Nursing Science, University of Pretoria. This was mentioned during a personal interview with her.
20 See chapter 5 par 5.5.2.1 for a discussion.

interested parties to consent to life-saving treatment when the parents refuse to give consent or are unable to consent. In terms of section 129(4) a caregiver can also consent to medical treatment, other than surgery. A “welcome clarification” is introduced by section 129(10) of the Children’s Act, which affords special protection to children. It provides that parents, guardians or care-givers may not refuse to give consent to the medical treatment of their children by reason of religious or other beliefs, unless they can prove that there is a medically accepted alternative to the proposed treatment.[21] It is commendable that section 11 of the Children’s Act provides for the protection of children with disabilities and chronic illnesses to ensure that they are part of a family and the community, in addition to participating in therapeutic programmes.[22]

In Antiquity and among primitive cultures a premature neonate, severely malformed baby or critically-ill neonate would not have survived for even a short while owing to the lack of medical expertise and appropriate technology. These days active measures can be and are taken to keep premature and critically-ill babies alive, but sometimes at a tremendous

21 Sloth–Nielsen in Davel and Skelton (eds) 2007:7-36.
22 See chapter 5 par 5.5.2.2 for a discussion. See also Davel in Davel and Skelton 2007:2-15.

cost to the individual and his or her family, both medically and socially, not to mention the financial implications.

Neonates are not completely without legal protection under South African law, but protection is to be found in different sections of different Acts pertaining to children and health care in general.

8.2.2 Weak points of the South African legal and medical position

No guidelines regarding the route to be followed in critical care decisions similar to guidelines in other parts of the world, such as those published by the Royal College of Paediatrics and the Nuffield Council on Bioethics in the United Kingdom, and the Groningen Protocol in the Netherlands, exist in South Africa. This is problematic since there are currently two hospital systems in operation. On the one hand there are private hospitals and on the other hand, there are public hospitals.[23] The public health system renders services to the greater part of the population while the private health care system mainly renders services to those who belong to medical aid funds and those who are wealthy enough to

23 Carstens and Pearmain 2007:229. In a reported case, although it does not specifically pertain to neonates, a patient died of septicaemia allegedly because of lack of proper care in the Tembisa hospital, which is a public hospital. This also points to the fact that the standard of health care in public hospitals is often below par. See *S v Tembani* 2007 (2) SA 291 (SCA).

pay for medical services rendered themselves.[24] The fact that there are no guidelines available at the moment means that the same approach regarding critical care decisions is not necessarily followed by health care professionals in the different hospitals, whether private or public. This creates inconsistency in borderline cases, such as neonates with a very low birth weight, low gestational age and congenital abnormalities.[25]

8.3 The position in England and Wales

8.3.1 Strong points of the legal position in England and Wales

Although there is no separate document dealing with the health care of children, the right to health care has been enacted in legislation in England and Wales. In terms of section 1(1) and (2) of the Children and Young Persons Act, it is a criminal offence if a person who has parental responsibility for a child fails to provide appropriate health care.[26] The Children Act 1989 provides that consent should be given by persons with parental authority; however, in the event of an emergency this consent can be extended to provide for consent from a person in whose

24 Carstens and Pearmain 2007:229.
25 According to Dr Carin Maree, senior lecturer, Department of Nursing Science, University of Pretoria, during a personal interview.
26 See chapter 6 paras 6.2.1 and 6.2.2 for a discussion of the provisions in this Act.

care a child is left.[27] Where there is disagreement between parents, the court can be approached to issue a specific issue order in terms of section 8 of the Children Act.[28] Moreover, the High Court can be approached to give permission to continue with life-saving medical treatment in the absence of the required form of consent in an emergency.

In the event of disagreement between health care professionals and parents there are various options: the court can be approached for a special issue order in terms of section 8 of the Children Act or a local authority can approach the High Court in terms of section 100(3), (4) and (5) for an order sanctioning treatment without the necessary consent.[29] The legal approach followed by the courts regarding critical care decisions can best be learnt from judgments in cases where the court was asked to intervene. In all the cases the decisions of the courts were based on the best interests of the child or the welfare principle after a balancing exercise had been performed. In cases where it was in the best interests of the child to continue with emergency medical treatment despite parental objection (for example in the case of religious

27 See chapter 6 par 6.2.2 for a discussion of parental responsibility.
28 See chapter 6 par 6.2.4 for a discussion of this section.
29 See chapter 6 par 6.2.4 for a discussion of this section in the Children Act.

objections to a blood transfusion), the court was willing to overrule parental authority and ordered that the medical team proceeded with lifesaving treatment.[30] In the case of the conjoined twins, Jodie and Mary, the court also weighed the best interests of the two babies and came to the conclusion that it would be in Jodie's best interests that the surgical operation be performed even though it would mean that Mary would not survive the operation.[31]

8.3.1.1 Guidelines regarding treatment of critically-ill neonates

In 2003 a Green Paper entitled *Every Child Matters* was drafted; this made provision for the fulfilment of the potential of children and the safeguarding of vulnerable children against neglect or abuse.[32] Through a consultation process five goals were formulated, one of which is "being healthy".[33] This goal is given effect in legislation and in the various documents that will be discussed below.

In the United Kingdom various documents containing guidelines regarding the treatment of neonates have been published by the Royal College of Paediatrics and Child Health. Although these are not legally

30 See chapter 6 paras 6.2.4.1 and 6.2.5 for a discussion of this aspect.
31 This case is discussed in more detail in chapter 6 par 6.2.4.2.
32 Bridgeman 2007:46,63.
33 Bridgeman 2007:63.

binding, they are worth taking note of. In December 2000 “Guidelines for Good Practice: *Management of Neonatal Distress Syndrome”* was published. This document contained recommendations regarding resuscitation, treatment with surfactant and CPAP (Continuous Positive Air Pressure). In 2004 *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice* was published.[34]

The most important document regarding the treatment or withholding of treatment in the United Kingdom is the report that was published in November 2006 by the Nuffield Council on Bioethics.[35] This is a comprehensive study that was undertaken by a multidisciplinary team in which recommendations were made regarding all aspects pertaining to the treatment of premature and critically-ill neonates. The Working Party that compiled the recommendations consisted of experts from different fields, namely neonatologists, an obstetrician, a professor of paediatric nursing, philosophers, social scientists, lawyers, health economists and people working with the families of premature and disabled children.[36] The report deals with various aspects pertaining to critical care in neonatal medicine. The report contains a detailed discussion of ethical

34 Bridgeman 2007:159.
35 This document is discussed in detail in chapter 6 par 6.3.
36 For a discussion, see chapter 6 par 6.3.

issues, medical issues and legal issues, including withdrawal of treatment, which have an impact on decision making in neonatal care. The most significant of the recommendations is probably that a neonate of 25 weeks and above should be admitted to a neonatal intensive care unit, and between 24 weeks and 24 weeks 6 days the neonate should be admitted to a neonatal intensive care unit, unless the parents and health care professionals agree that such treatment would be futile. Between 23 weeks and 23 weeks 6 days, health care professionals should not proceed with treatment which, in their clinical opinion appears to be futile, unless the parents insist on treatment. Between 22 weeks and 22 weeks 6 days a neonate should not be resuscitated unless the parents request resuscitation. Neonates born before 22 weeks should not be resuscitated. The Working Party is opposed to the deliberate termination of a neonate's life as this would amount to a violation of the duty to protect life. This is in direct contrast to the approach in the Netherlands, as will be seen below.[37]

8.3.2 Weak points of the legal position in England and Wales

The best interests standard is currently the only standard available to the courts, although it is not without problems: Apart from the fact that this

37 See also chapter 6 par 6.3.3 for a detailed discussion of these recommendations.

standard is indeterminate, to date the best interests of other siblings have not been considered in court cases. The Children Act 1989 uses the term "welfare principle" and not the best interests standard enunciated in the CRC. It is uncertain whether the best interests standard forms part of the welfare principle or vice versa or whether these two terms are interchangeable. It is suggested that the courts use these terms interchangeably in medical law cases. The welfare principle is also the term employed by the Children (Northern Ireland) Order 1995 and the Children (Scotland) Act.[38]

A balancing exercise should be performed to determine the best interests of a particular child. However, when doing the balancing exercise, the best interests of the child in question are not the only consideration, although they do carry the most weight. It is also necessary to attach some weight to what the parents feel they are capable of coping with, not only financially but also emotionally. The position in England and Wales became clear from cases that were discussed in chapter 6. It is clear that no weight is attached by the courts to the question whether the parents feel that they can cope with a

38 See chapter 6 paras 6.2.5.1 and 6.3.2 for a detailed discussion of the best interests standard and the welfare principle, as well as the relationship between the two terms.

critically-ill neonate. At the same time the opinion of the health care professionals should also be valued and considered when arriving at a decision. It is no mean feat to balance all these matters when making a decision.

8.4 The position in the Netherlands

8.4.1 Strong points of the legal position in the Netherlands

As in other jurisdictions, consent is required to proceed with medical treatment. In the case of neonates, consent is needed from someone with parental authority, usually a parent.[39] But in cases where this cannot be obtained, a *kinderrechter* may give consent instead.[40] The law of the Netherlands also makes provision for a child to be temporarily removed from the custody of his or her parents where parents refuse to consent to treatment, and medical treatment would be in the best interests of the child.[41]

Various documents containing guidelines concerning end-of-life decisions were drafted. The first one was compiled in the mid 1980s by

39 This is discussed in chapter 7 par 7.2.1.
40 See chapter 7 par 7.2.1.
41 See chapter 7 par 7.2.2.

the Dutch Association of Paediatrics (*Nederlandse Vereniging voor Kindergeneeskunde*). This document sets out the criteria for ascertaining medical futility. The active role of parents in the decision-making process is also emphasised. A report by the Dutch Paediatric Association followed in 1992 and in 1997 the Royal Dutch Medical Association issued a report containing guidelines on the circumstances in which life-sustaining treatment may be withdrawn.[42]

The most important and comprehensive document concerning end-of-life decisions on neonates is undoubtedly the Groningen Protocol, which was drafted in 2002 and was adopted by the Association of Paediatrics in July 2005 for use throughout the Netherlands.[43] The purpose of the Groningen Protocol is to enable a doctor to actively end the life of a neonate in certain cases if strict criteria are met while avoiding prosecution. The criteria are set out in the Protocol. This document was drafted by paediatricians with the assistance of the local prosecutor.[44] A point of criticism that could be raised against the way this document was drafted is that it was not drafted by a multidisciplinary team, unlike the report by the Nuffield Council on Bioethics. The document could also be

42 See chapter 7 par 7.3.3.
43 See chapter 7 par 7.4 for a discussion of the Groningen Protocol.
44 See chapter 7 par 7.4.1.

criticised for the fact that it is not a comprehensive study, but deals only with the cases where the life of a neonate can be actively ended. The Groningen Protocol sets out the criteria for when this can be done with impunity and thereby effectively legalises euthanasia for neonates.[45]

Certain positive aspects also emerged from the document, such as the importance of parental involvement in the decision-making process. Health care professionals may not deliberately end the life of a neonate without the consent of his or her parents. In those cases where parents insist on aggressive treatment for their critically-ill offspring, in accordance with the Groningen Protocol their wishes must be respected and treatment must be given.[46]

Only three cases could be found which turned on end-of-life decisions concerning neonates in the Netherlands.[47] The legal principles that were laid down were incorporated in the guidelines that were drafted by the professional organisations. It is possible that so few cases reached the courts of the Netherlands because of the certainty created by the different guidelines, especially the Groningen Protocol. Another aspect

45 See chapter 7 par 7.4.2.
46 See chapter 7 par 7.4.2.
47 See chapter 7 par 7.3.4 for a discussion of the baby Ross, Prins and Kadijk cases.

that could have an influence on the paucity of cases is the fact that parental consent is necessary to withhold or withdraw treatment in end-of-life decisions. It is a requirement that parents are well informed about the proposed treatment or course of action, so that they can make a well-informed decision. A consultation process is necessary, which includes consultation with an independent doctor and the health care team, which includes nurses.[48]

8.4.2 Weak points of the legal position in the Netherlands

The Netherlands ratified the CRC in 1990 and the best interests of the child standard is laid down in Article 3, but it seems as if insufficient emphasis is placed on this standard. In none of the three cases discussed was any mention made of the best interests standard. The case of baby Ross was reported in 1990. It is possible that it was heard before the CRC was ratified, which would explain the absence of references to this standard. The Prins case was reported in 1995 and the Kadijk case in 1996,[49] in other words after ratification of the CRC, and still the best interests of the child were not considered by the courts in question. However, reference is made to the best interests of the child

48 See chapter 7 par 7.3.1.
49 See chapter 7 par 7.3.3 fn 61 and fn 62.

in some of the Articles of the *Burgerlijk Wetboek*, for example Articles 266,[50] 269[51] and 327.[52] One would expect more emphasis on the best interests standard in both legislation and case law, in view of the fact that the Netherlands also ratified the CRC.

8.5 Recommendations for legal reform in South Africa

8.5.1 Introduction

The ideal way in which to make critical decisions regarding the treatment of an infant (i.e. regarding the aggressiveness of treatment or whether to forego life-saving treatment) would be after consultation or discussion

50 "Mits het belang van die kinderen zich daar niet tegen verzet, kan de rechtbank een ouder van het gezag over een of meer van zijn kinderen ontheffen, op grond dat hij ongeschikt of onmachtig is zijn plicht tot verzorging en opvoeding te vervullen."

51 "Indien de rechtbank dit in het belang van de kinderen noodzakelijk oordeelt, kan zij een ouder van het gezag over een of meer van zijn kinderen ontzetten, op grond van:
- a misbruik van het gezag, of grove verwaarlosing van de verzorging of opvoeding van een of meer kinderen;
- b slecht levensgedrag;
- c onherroepelijke veroordeling:
  - 1 wegens opzettelijke deelneming aan enig misdrijf met een onder zijn gezag staande minderjarige;
  - 2 wegens het pleging tegen de minderjarige van een van de misdrijven, omschreven in de titels XIII-XV en XVIII-XX van het tweede boek van het Wetboek van Strafrecht;
  - 3 tot een vrijheidstraf van twee jaar of langer;
- d het in ernstige mate verontachtzamen van de aanwijzingen van de stichting, bedoeld in artikel 1, onder f, van de Wet op de jeugdzorg of belemmering van een uithuisplaatsing krachtens het bepaalde in artikel 261;
- e het bestaan van gegronde vrees voor verwaarlozing van de belangen van het kind, doordat de ouder het kind terugeist of terugneemt van anderen, die diens verzorging en opvoeding op zich hebben genomen."

52 "Indien de rechtbank dit in het belang van die minderjarigen noodzakelijk oordeelt, kan zij een voogd ten aanzien van een of meer tot een zelfde voogdij behorende minderjarigen ontzetten …"

between parents and health care professionals.[53] Consultation is important, since on the one hand, doctors and health care professionals have expert knowledge, skills and expertise, although the outcome of treatment might be uncertain.[54] On the other hand, parents are emotionally involved in the health care of their children; most parents would like to pursue a course of action that would be in the best interests of their children and they know whether they would be able to cope with a particular outcome of treatment, not only as parents, but also as a family.

When the court is requested to intervene where there is a difference of opinion between parents and health care professionals regarding treatment or withholding of treatment of a critically-ill neonate, a distinction should be made between those infants who will be severely mentally and physically handicapped despite life-saving treatment and those who will be healthy and normal infants after treatment. In the case of the former it might not be in the best interests of the neonate if his or her life were saved, but he or she then had to be institutionalised. This would place an unnecessary financial and emotional burden on the

53 Miller 2007:34.
54 Miller 2007:34.

parents and also a financial burden on the state coffers. A classic case where the court should be able to overrule the parents' wishes (and has indeed done so) is where a child needs a life-saving blood transfusion, but the parents refuse to give permission on the grounds of their religious beliefs, as in the case of *Hay v B*.[55] In such a case it would be in the best interests of a child if the courts overruled the parents' wishes and disregarded their right to religious freedom.

8.5.2 Mediation

Another option that has not yet been explored in South African law is mediation as a form of alternative dispute resolution. In the Wyatt case brief mention is made of mediation: "Only a tiny proportion of consent to treatment cases which come to lawyers for advice end up before court. The vast majority were resolved when additional experts were brought into the case (on either side); when mediators were used, and when the prospects of proceedings focused everyone's minds. All this would be lost if cases could only be brought at the last minute."[56] The inference that can be drawn from this quotation is that mediation is used in England and Wales in cases where there is disagreement between

55 For a discussion, see chapter 5 par 5.4.7.

56 *Portsmouth Hospitals NHS Trust v Wyatt* [2005] 1 WLR:4027. This case is discussed in chapter 6 par 6.2.5.6.

parents and health care professionals regarding the course of treatment that should be followed in the case of a critically-ill neonate. The Nuffield Council on Bioethics also recommends that critical care decisions be referred for mediation.[57]

It is recommended that in the event of disagreement between parents and health care professionals or disagreement between parents regarding the course of treatment, the matter should be referred to mediation.[58] During the mediation process an impartial mediator helps the parties to reach an agreement that is acceptable to both parties. It is essential that the mediator should be a trained mediator and skilled in the mediation process. Mediation as an option has various advantages over going to court: The mediation process is an informal process, while a court case is a very formal process and an adversarial procedure. The fact that mediation is informal can be advantageous during the mediation process in critical care decisions, since such decisions are highly emotional and sensitive issues.

57 NCOB 2006:147,163. See also chapter 6 par 6.3.4.

58 The author of this thesis is also a qualified mediator and does mediation for FAMSA, Pretoria as community service. What follows comes from the experience of the author during mediation. For mediation in divorce cases, see De Jong 2010:515-531.

Co-mediation is the ideal model to be followed in the mediation process. During the co-mediation process there are two mediators, one of whom is a lawyer and the other a psychologist or social worker who deals with emotional issues.[59] The mediation process is not as expensive as litigation. If parties cooperate with the mediators and each other the mediation process can also be quicker than the court process. Mediation can improve communication between parties, because parties are encouraged to voice their opinion on the matter. Poor communications can lead to misunderstanding, which in turn can lead to disputes.[60] An important aspect mentioned by the NCOB is that mediators should be available to assist parties with follow-up, whether mediation succeeds or not.[61] It is submitted that this is not applicable in the South African context, since mediators are not usually involved in any further process if mediation has failed. It is recommended that parties should rather be referred to counselling[62] when mediation has failed.

59 The co-mediation model is the model preferred and utilised by FAMSA (Family South Africa).
60 NCOB 2006:163.
61 NCOB 2006:163.
62 Mediation and counselling are two concepts that are often confused. These two processes are not mutually exclusive, but mediation is done by trained mediators, while clinical psychologists and social workers do counselling. When the need arises parties are often referred for counselling during mediation . The aspect of counselling, therefore does not fall within the scope of this thesis.

After agreement has been reached between the parties during the mediation process, a “memorandum of understanding” or settlement agreement is drafted.[63] Since the High Court is the upper guardian of all minors in South Africa, such a “memorandum of understanding” should be made an order of court. It is recommended that the Children’s Act be amended to provide for compulsory mediation when disputes in critical care decisions arise as it has many advantages over a court action, as mentioned above.

Mediation has successfully been employed to settle disputes in divorce issues before going to court, but the process can easily be adapted to make it suitable in critical care decisions.

8.5.3 Guidelines

In South African health care pertaining to neonates no guidelines have so far been drafted which could assist health care professionals in critical care decisions, apart from a document drafted by the Health Professions Council of South Africa (HPCSA).[64] This document is very general in nature and is not applicable to the treatment of neonates only,

63 FAMSA prefers to draft a “memorandum of understanding” and not a settlement agreement.

64 Guidelines for the Withholding and Withdrawing of Treatment (2nd edition) Booklet 13 (2007).

although certain aspects covered in this document are also relevant to the treatment of neonates. This document is, however, not nearly as comprehensive as the one drafted by the NCOB, and is consequently inadequate when it comes to the treatment of neonates. As was mentioned previously, two health care systems are in operation in the country, namely private and public health care systems and different practices exist in private and public hospitals. It is recommended that guidelines be drafted that will be accepted throughout the country. It is further recommended that the guidelines of the Nuffield Council on Bioethics be used as an example and not the Groningen Protocol, which is used in the Netherlands. The guidelines on critical care decisions by the Nuffield Council on Bioethics were drafted by a multidisciplinary team, and moreover they are very comprehensive and would be more in line with the Constitution of the Republic of South African and legislation such as the Children's Act. The primary objective of the Groningen Protocol is to allow doctors to actively end the life of critically-ill neonates under certain circumstances without being prosecuted. Under South African law, euthanasia is illegal and actively killing a neonate, no matter how disabled he or she is, would lead to criminal prosecution.[65] It is

65 In *S v De Bellocq* 1975 (3) SA 538 (T) which concerned a mother who drowned her baby when she realised that he was suffering from toxoplasmosis and that his

suggested that the life of a neonate, even in a hopeless case, should not be actively ended, but that palliative care be provided in such cases.

An organisation, namely the South African Neonatal Infant and Toddler Association (hereinafter SANITSA), has been established to support the parents of critically-ill neonates, including premature babies. It is a multidisciplinary organisation that consists of people who have an interest in neonatal care, such as paediatricians, nurses who specialise in neonatal intensive care, psychologists, speech therapists, occupational therapists, lawyers and the parents of premature babies or children who need additional support. It is suggested that this organisation be tasked with drafting comprehensive guidelines on critical care decisions. It is further suggested that SANITSA should invite people from the different fields of interest pertaining to neonatal care to participate and to collaborate with other neonatal interest groups and that a Working Party be convened that will operate under the auspices of SANITSA. Guidelines drafted by a multidisciplinary team made up of people working in the field, for the benefit of people working in the field, should be recognised and accepted throughout the country.

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prognosis was very poor, the court per De Wet J made the following remark on p 539: "The law does not allow any person to be killed whether that person is an imbecile or very ill. The killing of such a person is an unlawful act and it amounts to murder in law."

Aspects pertaining to neonatal care, such as when to resuscitate a neonate or when to withdraw or withhold treatment, should be contained in guidelines rather than legislation. The reason for this recommendation is that when a child is born either prematurely or with a life-threatening disease, the parents have to face a very emotional and sensitive issue that should be dealt with by way of guidelines and mediators rather than legislation and litigation.

8.5.4 Court intervention

As was mentioned earlier, the court has never yet been asked to intervene in a case where there was disagreement between parents and health care professionals regarding the course of treatment, for example whether a neonate should be resuscitated, or whether life-saving treatment should be withdrawn or withheld. It is suggested that as parents become more informed they will take a keen interest in the treatment of their offspring and eventually cases similar to those in England and Wales will reach the South African courts. It is suggested that when adjudicating such cases the courts should follow the precedent set by the courts of England and Wales. In these cases the best interests of the child should be considered even though this

standard is indeterminate. However, when the best interests of the child standard is employed, the interests of the neonate in question, as well as those of the other siblings (if there are any) and the parents should be balanced in reaching a decision. In *Hay v B*[66] the court showed its willingness to overrule parents' constitutional rights in favour of the best interests of their child. This judgment proves that the courts considered the child's best interests to carry more weight than the parents' constitutional right to freedom of religion.

8.6 Concluding remarks

The idea that the court should be asked to intervene in critical care decisions is a relatively new one and the only cases of this nature that can serve as an example were tried in England and Wales. In the Netherlands, the court has only intervened in cases where the life of a neonate was ended and the physician was criminally charged.

Regrettably neonates, and in particular premature babies and critically-ill neonates, have not received the necessary attention and legal protection

66 See chapter par 5.4.7 for a discussion of this case.

in South Africa, unlike in England and Wales. The author is a member of SANITSA and hopes to be instrumental in drafting suitable guidelines on neonatal care in South Africa, following the example of the Nuffield Council on Bioethics.

ADDENDUM: CERTAIN SECTIONS PERTAINING TO CHAPTER 6

For ease of reference certain sections referred to in chapter 6 are cited below.

ENGLISH AND WELSH LEGISLATION:

Children Act 1989

Section 1: Welfare of the child.

(1) When a court determines any question with respect to—

(a) the upbringing of a child; or

(b) the administration of a child's property or the application of any income arising from it, the child's welfare shall be the court's paramount consideration.

(2) In any proceedings in which any question with respect to the upbringing of a child arises, the court shall have regard to the general principle that any delay in determining the question is likely to prejudice the welfare of the child.

(3) In the circumstances mentioned in subsection (4), a court shall have regard in particular to—

(a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);

(b) his physical, emotional and educational needs;

(c) the likely effect on him of any change in his circumstances;

(d) his age, sex, background and any characteristics of his which the court considers relevant;

(e) any harm which he has suffered or is at risk of suffering;

(f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs;

(g) the range of powers available to the court under this Act in the proceedings in question.

(4) The circumstances are that—

(a) the court is considering whether to make, vary or discharge a section 8 order, and the making, variation or discharge of the order is opposed by any party to the proceedings; or

(b) the court is considering whether to make, vary or discharge a special guardianship order or an order under Part IV.

(5) Where a court is considering whether or not to make one or more orders under this Act with respect to a child, it shall not make the order or any of the orders unless it considers that doing so would be better for the child than making no order at all.

Section 2: Parental responsibility for children.

(1) Where a child's father and mother were married to each other at the time of his birth, they shall each have parental responsibility for the child.

Where a child—

(a) has a parent by virtue of section 42 of the Human Fertilisation and Embryology Act 2008; or

(b) has a parent by virtue of section 43 of that Act and is a person to whom section 1(3) of the Family Law Reform Act 1987 applies, the child's mother and the other parent shall each have parental responsibility for the child.

(2) Where a child's father and mother were not married to each other at the time of his birth—

(a) the mother shall have parental responsibility for the child;

(b) the father shall have parental responsibility for the child if he has acquired it (and has not ceased to have it) in accordance with the provisions of this Act.

(2A) Where a child has a parent by virtue of section 43 of the Human Fertilisation and Embryology Act 2008 and is not a person to whom section 1(3) of the Family Law Reform Act 1987 applies—

(a) the mother shall have parental responsibility for the child;

(b) the other parent shall have parental responsibility for the child if she has acquired it (and has not ceased to have it) in accordance with the provisions of this Act

(3) References in this Act to a child whose father and mother were, or (as the case may be) were not, married to each other at the time of his birth must be read with section 1 of the M1Family Law Reform Act 1987 (which extends their meaning).

(4) The rule of law that a father is the natural guardian of his legitimate child is abolished.

(5) More than one person may have parental responsibility for the same child at the same time.

(6) A person who has parental responsibility for a child at any time shall not cease to have that responsibility solely because some other person subsequently acquires parental responsibility for the child.

(7) Where more than one person has parental responsibility for a child, each of them may act alone and without the other (or others) in meeting that responsibility; but nothing in this Part shall be taken to affect the operation of any enactment which requires the consent of more than one person in a matter affecting the child.

(8) The fact that a person has parental responsibility for a child shall not entitle him to act in any way which would be incompatible with any order made with respect to the child under this Act.

(9) A person who has parental responsibility for a child may not surrender or transfer any part of that responsibility to another but may arrange for some or all of it to be met by one or more persons acting on his behalf.

(10) The person with whom any such arrangement is made may himself be a person who already has parental responsibility for the child concerned.

(11) The making of any such arrangement shall not affect any liability of the person making it which may arise from any failure to meet any part of his parental responsibility for the child concerned.

Section 3: Meaning of parental responsibility

Section 3(5):

A person who—

(a) does not have parental responsibility for a particular child; but

(b) has care of the child, may (subject to the provisions of this Act) do what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare.

Section 4: Acquisition of parental responsibility by father.

(1) Where a child's father and mother were not married to each other at the time of his birth, the father shall acquire parental responsibility for the child if—

(a) he becomes registered as the child's father under any of the enactments specified in subsection (1A);

(b) he and the child's mother make an agreement (a "parental responsibility agreement") providing for him to have parental responsibility for the child; or

(c) the court, on his application, orders that he shall have parental responsibility for the child.

(1A) The enactments referred to in subsection (1)(a) are—

(a) paragraphs (a), (b) and (c) of section 10(1) and of section 10A(1) of the Births and Deaths Registration Act 1953;

(b) paragraphs (a), (b)(i) and (c) of section 18(1), and sections 18(2)(b) and 20(1)(a) of the Registration of Births, Deaths and Marriages (Scotland) Act 1965; and

(c) sub-paragraphs (a), (b) and (c) of Article 14(3) of the Births and Deaths Registration (Northern Ireland) Order 1976.

(1B) The Secretary of State may by order amend subsection (1A) so as to add further enactments to the list in that subsection.

(2) No parental responsibility agreement shall have effect for the purposes of this Act unless—

(a) it is made in the form prescribed by regulations made by the Lord Chancellor; and

(b) where regulations are made by the Lord Chancellor prescribing the manner in which such agreements must be recorded, it is recorded in the prescribed manner.

(2A) A person who has acquired parental responsibility under subsection (1) shall cease to have that responsibility only if the court so orders.

(3) The court may make an order under subsection (2A) on the application—

(a) of any person who has parental responsibility for the child; or

(b) with the leave of the court, of the child himself, subject, in the case of parental responsibility acquired under subsection (1)(c), to section 12(4).

(4) The court may only grant leave under subsection (3)(b) if it is satisfied that the child has sufficient understanding to make the proposed application.

4ZA Acquisition of parental responsibility by second female parent

(1) Where a child has a parent by virtue of section 43 of the Human Fertilisation and Embryology Act 2008 and is not a person to whom section 1(3) of the Family Law Reform Act 1987 applies, that parent shall acquire parental responsibility for the child

if—

(a) she becomes registered as a parent of the child under any of the enactments specified in subsection (2);

(b) she and the child's mother make an agreement providing for her to have parental responsibility for the child; or

(c) the court, on her application, orders that she shall have parental responsibility for the child.

(2) The enactments referred to in subsection (1)(a) are—

(a) paragraphs (a), (b) and (c) of section 10(1B) and of section 10A(1B) of the Births and Deaths Registration Act 1953;

(b) paragraphs (a), (b) and (d) of section 18B(1) and sections 18B(3)(a) and 20(1)(a) of the Registration of Births, Deaths and Marriages (Scotland) Act 1965; and

(c) sub-paragraphs (a), (b) and (c) of Article 14ZA(3) of the Births and Deaths Registration (Northern Ireland) Order 1976.

(3) The Secretary of State may by order amend subsection (2) so as to add further enactments to the list in that subsection.

(4) An agreement under subsection (1)(b) is also a "parental responsibility agreement", and section 4(2) applies in relation to such an agreement as it applies in relation to parental responsibility agreements under section 4.

(5) A person who has acquired parental responsibility under subsection (1) shall cease to have that responsibility only if the court so orders.

(6) The court may make an order under subsection (5) on the application—

(a) of any person who has parental responsibility for the child; or

(b) with the leave of the court, of the child himself, subject, in the case of parental responsibility acquired under subsection (1)(c), to section 12(4).

(7) The court may only grant leave under subsection (6)(b) if it is satisfied that the child has sufficient understanding to make the proposed application.

4A Acquisition of parental responsibility by step-parent

(1) Where a child's parent ("parent A") who has parental responsibility for the child is married to, or a civil partner of, a person who is not the child's parent ("the stepparent")—

(a) parent A or, if the other parent of the child also has parental responsibility for the child, both parents may by agreement with

the step-parent provide for the step-parent to have parental responsibility for the child; or

(b) the court may, on the application of the step-parent, order that the step-parent shall have parental responsibility for the child.

(2) An agreement under subsection (1)(a) is also a "parental responsibility agreement", and section 4(2) applies in relation to such agreements as it applies in relation to parental responsibility agreements under section 4.

(3) A parental responsibility agreement under subsection (1)(a), or an order under subsection (1)(b), may only be brought to an end by an order of the court made on the application—

(a) of any person who has parental responsibility for the child; or

(b) with the leave of the court, of the child himself.

(4) The court may only grant leave under subsection (3)(b) if it is satisfied that the child has sufficient understanding to make the proposed application.

Section 8: Residence, contact and other orders with respect to children.

(1) In this Act —

"a contact order" means an order requiring the person with whom a child lives, or is to live, to allow the child to visit or stay with the

person named in the order, or for that person and the child otherwise to have contact with each other; “a prohibited steps order” means an order that no step which could be taken by a parent in meeting his parental responsibility for a child, and which is of a kind specified in the order, shall be taken by any person without the consent of the court;

“a residence order” means an order settling the arrangements to be made as to the person with whom a child is to live; and

“a specific issue order” means an order giving directions for the purpose of determining a specific question which has arisen, or which may arise, in connection with any aspect of parental responsibility for a child.

(2) In this Act “a section 8 order” means any of the orders mentioned in subsection (1) and any order varying or discharging such an order.

(3) For the purposes of this Act “family proceedings” means any proceedings—

(a) under the inherent jurisdiction of the High Court in relation to children; and

(b) under the enactments mentioned in subsection (4), but does not include proceedings on an application for leave under section 100(3).

Section 100: Restrictions on use of wardship jurisdiction.

(3) No application for any exercise of the court's inherent jurisdiction with respect to children may be made by a local authority unless the authority have obtained the leave of the court.

(4) The court may only grant leave if it is satisfied that—

(a) the result which the authority wish to achieve could not be achieved through the making of any order of a kind to which subsection (5) applies; and

(b) there is reasonable cause to believe that if the court's inherent jurisdiction is not exercised with respect to the child he is likely to suffer significant harm.

(5) This subsection applies to any order—

(a) made otherwise than in the exercise of the court's inherent jurisdiction; and

(b) which the local authority is entitled to apply for (assuming, in the case of any application which may only be made with leave, that leave is granted).

Children and Young Persons Act 1933

Section 1: Cruelty to persons under sixteen.

(1) If any person who has attained the age of sixteen years and has responsibility for any child or young person under that age, wilfully

assaults, ill-treats, neglects, abandons, or exposes him, or causes or procures him to be assaulted, ill-treated, neglected, abandoned, or exposed, in a manner likely to cause him unnecessary suffering or injury to health (including injury to or loss of sight, or hearing, or limb, or organ of the body, and any mental derangement), that person shall be guilty of a misdemeanor, and shall be liable—

(a) on conviction on indictment, to a fine or alternatively, or in addition thereto, to imprisonment for any term not exceeding ten years;

(b) on summary conviction, to a fine not exceeding £400 pounds, or alternatively, or in addition thereto, to imprisonment for any term not exceeding six months.

(2) For the purposes of this section—

(a) a parent or other person legally liable to maintain a child or young person, or the legal guardian of a child or young person, shall be deemed to have neglected him in a manner likely to cause injury to his health if he has failed to provide adequate food, clothing, medical aid or lodging for him, or if, having been unable otherwise to provide such food, clothing, medical aid or lodging, he has failed to take steps to procure it to be provided under the enactments applicable in that behalf;

(b) where it is proved that the death of an infant under three years of age was caused by suffocation (not being suffocation caused by disease or the presence of any foreign body in the throat or air passages of the infant) while the infant was in bed with some other person who has attained the age of sixteen years, that other person shall, if he was, when he went to bed, under the influence of drink, be deemed to have neglected the infant in a manner likely to cause injury to its health.

(3) A person may be convicted of an offence under this section—

(a) notwithstanding that actual suffering or injury to health, or the likelihood of actual suffering or injury to health, was obviated by the action of another person;

(b) notwithstanding the death of the child or young person in question.

Human Rights Act 1998

Section 3: Interpretation of legislation

(1) So far as it is possible to do so, primary legislation and subordinate legislation must be read and given effect in a way which is compatible with the Convention rights.

(2) This section –

(a) applies to primary legislation and subordinate legislation whenever enacted;

(b) does not affect the validity, continuing operation or enforcement of any incompatible primary legislation; and

(c) does not affect the validity, continuing operation or enforcement of any incompatible subordinate legislation if (disregarding any possibility of revocation) primary legislation prevents removal of the incompatibility.

SCOTTISH LEGISLATION

Children (Scotland) Act 1995
Section 1: Parental responsibilities.

(1) Subject to section 3(1)(b) and (3) of this Act, a parent has in relation to his child the responsibility—

(a) to safeguard and promote the child's health, development and welfare;

(b) to provide, in a manner appropriate to the stage of development of the child—

(i) direction;

(ii) guidance, to the child;

(c) if the child is not living with the parent, to maintain personal relations and direct contact with the child on a regular basis; and

(d) to act as the child's legal representative, but only in so far as compliance with this section is practicable and in the interests of the child.

(2) "Child" means for the purposes of—

(a) paragraphs (a), (b)(i), (c) and (d) of subsection (1) above, a person under the age of sixteen years;

(b) paragraph (b)(ii) of that subsection, a person under the age of eighteen years.

(3) The responsibilities mentioned in paragraphs (a) to (d) of subsection (1) above are in this Act referred to as "parental responsibilities"; and the child, or any person acting on his behalf, shall have title to sue, or to defend, in any proceedings as respects those responsibilities.

(4) The parental responsibilities supersede any analogous duties imposed on a parent at common law; but this section is without prejudice to any other duty so imposed on him or to any duty imposed on him by, under or by virtue of any other provision of this Act or of any other enactment.

Section 4: Acquisition of parental rights and responsibilities by natural father.

(1) Where a child's mother has not been deprived of some or all of the parental responsibilities and parental rights in relation to him and, by virtue of subsection (1)(b) of this Act, his father has no parental responsibilities or parental rights in relation to him, the father and mother, whatever age they may be, may by agreement provide that, as from the appropriate date, the father shall have the parental responsibilities and parental rights (in the absence of any order under section 11 of this Act affecting those responsibilities and rights) he would have if married to the mother.

(2) No agreement under subsection (1) above shall have effect unless –

(a) in a form prescribed by the Secretary of State; and

(b) registered in the Books of Council and Session while the mother still has the parental responsibilities and parental rights which she had when the agreement was made.

(3) The date on which such registration as is mentioned in subsection (2)(b) above takes place shall be the "appropriate date" for the purposes of subsection (1) above.

(4) An agreement which has effect by virtue of subsection (2) above shall, subject only to section 11(11) of this Act, be irrevocable.

Section 5: Care or control of child by person without parental responsibilities or parental rights.

(1) Subject to subsection (2) below, it shall be the responsibility of a person who has attained the age of sixteen years and who has care or control of a child under that age, but in relation to him either has no parental responsibilities or parental rights or does not have the parental responsibility mentioned in section 1(1)(a) of this Act, to do what is reasonable in all the circumstances to safeguard the child's health, development and welfare; and in fulfilling his responsibility under this section the person may in particular, even though he does not have the parental right mentioned in section 2(1)(d) of this Act, give consent to any surgical, medical or dental treatment or procedure where—

(a) the child is not able to give such consent on his own behalf; and

(b) it is not within the knowledge of the person that a parent of the child would refuse to give the consent in question.

(2) Nothing in this section shall apply to a person in so far as he has care or control of a child in a school ("school" having the meaning given by section 135(1) of the Education (Scotland) Act 1980).

Section11: 11 Court orders relating to parental responsibilities etc.

Section 11(2)(e)

an order regulating any specific question which has arisen, or may arise, in connection with any of the matters mentioned in paragraphs (a) to (d) of subsection (1) of this section (any such order being known as a "specific issue order")

Section 11(7)(a)

(7) Subject to subsection (8) below, in considering whether or not to make an order under subsection (1) above and what order to make, the court—

(a) shall regard the welfare of the child concerned as its paramount consideration and shall not make any such order unless it considers that it would be better for the child that the order be made than that none should be made at all;

Section 12: Cruelty to persons under sixteen.

(1) If any person who has attained the age of sixteen years and who has parental responsibilities in relation to a child or to a young person under that age or has charge or care of a child or such a young person, wilfully assaults, ill-treats, neglects, abandons, or exposes him, or causes or procures him to be assaulted, ill-treated,

neglected, abandoned, or exposed, in a manner likely to cause him unnecessary suffering or injury to health (including injury to or loss of sight, or hearing, or limb, or organ of the body, and any mental derangement), that person shall be guilty of an offence, and shall be liable—

(a) on conviction on indictment, to a fine, or alternatively, or in default of payment of such a fine, or in addition thereto, to imprisonment for any term not exceeding ten years;

(b) on summary conviction, to a fine not exceeding £400, or alternatively, or in default of payment of such a fine, or in addition thereto, to imprisonment for any term not exceeding six months.

(2) For the purposes of this section—

(a) a parent or other person legally liable to maintain a child or young person or the legal guardian of a child or young person shall be deemed to have neglected him in a manner likely to cause injury to his health if he has failed to provide adequate food, clothing, medical aid or lodging for him, or if, having been unable otherwise to provide such food, clothing, medical aid or lodging, he has failed to take steps to procure it to be provided under the enactments applicable in that behalf;

(b) where it is proved that the death of a child under three years of age was caused by suffocation (not being suffocation caused by disease or the presence of any foreign body in the throat or air passages of the child) while the child was in bed with some other person who has attained the age of sixteen years, that other person shall, if he was, when he went to bed, under the influence of drink, be deemed to have neglected the child in a manner likely to cause injury to his health.

(3) A person may be convicted of an offence under this section—

(a) notwithstanding that actual suffering or injury to health, or the likelihood of actual suffering or injury to health, was obviated by the action of another person;

(b) notwithstanding the death of the child or young person in question.

(4) Where any person who has attained the age of sixteen years is tried on indictment for the culpable homicide of a child or young person under the age of sixteen years and he had parental responsibilities in relation to, or charge or care of, that child or young person, it shall be lawful for the jury, if they are satisfied that he is guilty of an offence under this section, to find him guilty of that offence.

Section 16: Welfare of child and consideration of his views.

(1) Where under or by virtue of this Part of this Act, a children's hearing decide, or a court determines, any matter with respect to a child the welfare of that child throughout his childhood shall be their or its paramount consideration.

Children and Young Persons (Scotland) Act

Section 12: Cruelty to persons under sixteen.

(1) If any person who has attained the age of sixteen years and who has parental responsibilities in relation to a child or to a young person under that age or has charge or care of a child or such a young person, wilfully assaults, ill-treats, neglects, abandons, or exposes him, or causes or procures him to be assaulted, ill-treated, neglected, abandoned, or exposed, in a manner likely to cause him unnecessary suffering or injury to health (including injury to or loss of sight, or hearing, or limb, or organ of the body, and any mental derangement), that person shall be guilty of an offence, and shall be liable—

(a) on conviction on indictment, to a fine, or alternatively, or in default of payment of such a fine, or in addition thereto, to imprisonment for any term not exceeding ten years;

(b) on summary conviction, to a fine not exceeding £400, or alternatively, or in default of payment of such a fine, or in addition thereto, to imprisonment for any term not exceeding six months.

(2) For the purposes of this section—

(a) a parent or other person legally liable to maintain a child or young person or the legal guardian of a child or young person shall be deemed to have neglected him in a manner likely to cause injury to his health if he has failed to provide adequate food, clothing, medical aid or lodging for him, or if, having been unable otherwise to provide such food, clothing, medical aid or lodging, he has failed to take steps to procure it to be provided under the enactments applicable in that behalf;

(b) where it is proved that the death of a child under three years of age was caused by suffocation (not being suffocation caused by disease or the presence of any foreign body in the throat or air passages of the child) while the child was in bed with some other person who has attained the age of sixteen years, that other person shall, if he was, when he went to bed, under the influence of drink, be deemed to have neglected the child in a manner likely to cause injury to his health.

(3) A person may be convicted of an offence under this section—

(a) notwithstanding that actual suffering or injury to health, or the likelihood of actual suffering or injury to health, was obviated by the action of another person;

(b) notwithstanding the death of the child or young person in question.

(4) Where any person who has attained the age of sixteen years is tried on indictment for the culpable homicide of a child or young person under the age of sixteen years and he had parental responsibilities in relation to, or charge or care of, that child or young person, it shall be lawful for the jury, if they are satisfied that he is guilty of an offence under this section, to find him guilty of that offence.

NORTHERN IRISH LEGISLATION

Children (Northern Ireland) Order 1995

Article 3: Child's welfare to be paramount consideration

(1) Where a court determines any question with respect to—

(a) the upbringing of a child; or

(b) the administration of a child's property or the application of any income arising from it, the child's welfare shall be the court's paramount consideration.

(2) In any proceedings in which any question with respect to the upbringing of a child arises, the court shall have regard to the general principle that any delay in determining the question is likely to prejudice the welfare of the child.

(3) In the circumstances mentioned in paragraph (4), a court shall have regard in particular to—

(a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);

(b) his physical, emotional and educational needs;

(c) the likely effect on him of any change in his circumstances;

(d) his age, sex, background and any characteristics of his which the court considers relevant;

(e) any harm which he has suffered or is at risk of suffering;

(f) how capable of meeting his needs is each of his parents and any other person in relation to whom the court considers the question to be relevant;

(g) the range of powers available to the court under this Order in the proceedings in question.

(4) The circumstances are that—

(a) the court is considering whether to make, vary or discharge an Article 8 order, and the making, variation or discharge of the order is opposed by any party to the proceedings; or (aa) the

court is considering whether to make an order under Article 7; or

(b) the court is considering whether to make, vary or discharge an order under Part V.

(5) Where a court is considering whether or not to make one or more orders under this Order with respect to a child, it shall not make the order or any of the orders unless it considers that doing so would be better for the child than making no order at all.

Article 5:Parental responsibility for children.

(1) Where a child's father and mother were married to each other at the time of his birth, they shall each have parental responsibility for the child.

(2) Where a child's father and mother were not married to each other at the time of his birth—

(a) the mother shall have parental responsibility for the child;

(b) the father shall have parental responsibility for the child if he has acquired it (and has not ceased to have it) in accordance with the provisions of this Order.

(3) The rule of law that a father is the natural guardian of his legitimate child is abolished.

(4) More than one person may have parental responsibility for the same child at the same time.

(5) A person who has parental responsibility for a child at any time shall not cease to have that responsibility solely because some other person subsequently acquires parental responsibility for the child.

(6) Where more than one person has parental responsibility for a child, each of them may act alone and without the other (or others) in meeting that responsibility; but nothing in this Part shall be taken to affect the operation of any statutory provision which requires the consent of more than one person in a matter affecting the child.

(7) The fact that a person has parental responsibility for a child shall not entitle him to act in any way which would be incompatible with any order made with respect to the child under this Order.

(8) A person who has parental responsibility for a child may not surrender or transfer any part of that responsibility to another but may arrange for some or all of it to be met by one or more persons acting on his behalf.

(9) The person with whom any such arrangement is made may himself be a person who already has parental responsibility for the child concerned.

(10) The making of any such arrangement shall not affect any liability of the person making it which may arise from any failure to meet any part of his parental responsibility for the child concerned.

Article 6: Meaning of "parental responsibility"

(1) In this Order "parental responsibility" means all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property.

(2) It also includes the rights, powers and duties which a guardian of the child's fortune or estate (appointed, before the commencement of Part XV (guardians), to act generally) would have had in relation to the child and his property.

(3) The rights referred to in paragraph (2) include, in particular, the right of the guardian to receive or recover in his own name, for the benefit of the child, property of whatever description and wherever situated which the child is entitled to receive or recover.

(4) The fact that a person has, or does not have, parental responsibility for a child shall not affect—

(a) any obligation which he may have in relation to the child (such as a statutory duty to maintain the child); or

(b) any rights which, in the event of the child's death, he (or any other person) may have in relation to the child's property.

(5) A person who—

(a) does not have parental responsibility for a particular child; but

(b) has care of the child, may (subject to the provisions of this Order) do what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare.

Article 8: Residence, contact and other orders with respect to children.

(1) In this Order—

"contact order" means an order requiring the person with whom a child lives, or is to live, to allow the child to visit or stay with the person named in the order, or for that person and the child otherwise to have contact with each other;

"prohibited steps order" means an order that no step which could be taken by a parent in meeting his parental responsibility for a child, and which is of a kind specified in the order, shall be taken by any person without the consent of the court;

"residence order" means an order settling the arrangements to be made as to the person with whom a child is to live; and

"specific issue order" means an order giving directions for the purpose of determining a specific question which has arisen, or

which may arise, in connection with any aspect of parental responsibility for a child.

(2) In this Order “Article 8 order” means any of the orders mentioned in paragraph (1) and any order varying or discharging such an order.

(3) For the purposes of this Order “family proceedings” means any proceedings—

(a) under the inherent jurisdiction of the High Court in relation to children; and

(b) under the provisions mentioned in paragraph (4), but does not include proceedings on an application for leave under Article 173(2) (restriction on use of wardship jurisdiction).

SUMMARY

Until relatively recently extremely premature babies and critically-ill neonates would not have survived because medical science was insufficiently advanced to save them. Infanticide was a common practice among the Greeks and Romans as a form of birth control and a means of disposing of malformed offspring. Certain indigenous South African tribes also committed infanticide to rid society of deformed infants. Gradually the law came to take a stricter view of infanticide, and with the rise of Christianity it was regarded as murder.

The advancement in medical technology, skills and expertise increased the need to take account of biomedical ethics, since this is the framework within which critical care decisions should be made. The principal ethical theories, namely deontology, utilitarianism and virtue ethics, are discussed, as well as the principles of biomedical ethics, namely beneficence, non-maleficence, autonomy and justice. Since actions for wrongful life and wrongful birth also touch on the sanctity of life and quality of life principle, these aspects are briefly discussed.

Various international human rights instruments not only guarantee the right to life, but also prescribe a high standard of health care to member states.

The right of access to health care, the right to emergency medical treatment and the best interests of the child are entrenched in the Constitution of the Republic of South Africa, 1996. The best interests of the child are of paramount importance in all matters concerning the child and this concept runs like a golden thread through all cases in which children's rights are considered. In terms of the National Health Act 61 of 2003, free health services are offered to children below the age of six years. Section 129 of the Children's Act 38 of 2005 specifically deals with medical treatment of children, while section 11 deals with children with disabilities and chronic illnesses.

A legal comparative study was undertaken in which the legal position in England and Wales, as well as that of the Netherlands, was considered in order to formulate a framework of legislation for the protection of premature babies and critically-ill neonates. The position in England and Wales can best be determined by studying the judgments delivered in court cases.

A comprehensive report, “Critical care decisions in fetal and neonatal medicine: ethical issues”, was compiled by the Nuffield Council on Bioethics. This report was drafted by a multi-disciplinary working party and provides guidelines regarding the medical treatment of neonates.

In the Netherlands euthanasia is legal, but then the person requesting it must be above the age of sixteen years. Since neonates cannot request euthanasia, the preferred term is “end-of-life decisions”. The Groningen Protocol was drafted by paediatricians assisted by the public prosecutor coroner to prevent a physician from being criminally prosecuted if the guidelines in the Protocol are adhered to in the case of end-of-life decisions.

In the thesis three recommendations are made:

- Guidelines that would be suitable for South African conditions should be drafted by a multidisciplinary team along the lines of the Nuffield Council on Bioethics.
- When cases concerning whether treatment should be withheld or withdrawn reach a South African court, it is recommended that the cases adjudicated in England and Wales be used as a precedent.

- It is recommended that mediation be considered as an option when there is disagreement regarding the treatment of critically-ill neonates between health care professionals and parents, or between parents. Since the High Court is the upper guardian of all minors, the outcome of the mediation should be made an order of court.

Key words: best interests of the child; consent to medical treatment; critical care decisions; guidelines; health care professionals; infanticide; international human rights instruments; neonates; quality of life; sanctity of life.

OPSOMMING

Tot redelik onlangs sou uiters premature babas en kritiek-siek neonate nie kon oorleef nie, weens ’n gebrek aan mediese kennis. Kindermoord was ’n algemene praktyk onder die Grieke en Romeine. Dit is gedoen as ’n vorm van geboortebeperking en om die samelewing van wanskape kinders te verlos. Om dieselfde rede het sekere inheemse Suid-Afrikaanse stamme ook kindermoord gepleeg Die reg het geleidelik meer onsimpatiek teenoor kindermoord geword, en met die opkoms van die Christendom, is dit as moord beskou.

Die tegnologiese vooruitgang op mediese gebied, noodsaak die oorweging van biomediese etiek, aangesien dit die raamwerk waarbinne kritiese sorg-besluite geneem moet word, voorsien. Die vernaamste etiese teorieë, naamlik, reëlgebaseerde etiek, utilisme en deugetiek word bespreek, sowel as die beginsels van biomediese etiek, naamlik om goed te doen, om nie skade te doen nie, outonomie en regverdigheid. Aangesien aksies vir “ongeoorloofde lewe” en “ongeoorloofde geboorte” raakpunte met die “heiligheid van lewe” en “kwaliteit van lewe” beginsels het, word hierdie aksies ook kortliks bespreek.

Verskeie internasionale menseregte handveste waarborg nie alleen die reg op lewe nie, maar skryf ook ’n hoë standaard van gesondheidsorg aan lidlande voor. Dit is opgeneem in die Millennium Ontwikkelingsdoelwitte nommer 4, wat die afname in die getal kindersterftes as doelwit het.

Die reg van toegang tot gesondheidsorg, die reg op geneeskundige noodbehandeling en die beste belang van die kind word beskerm in die Grondwet van die Republiek van Suid-Afrika, 1996. Die beste belang van die kind is van die uiterste belang in alle sake rakende die kind en

dit loop soos ’n goue draad deur sake waarin kinderregte ter sprake is. Ingevolge die *National Health Act* 61 van 2003 moet gratis mediese behandeling aan kinders onder die ouderdom van ses jaar verskaf word. Artikel 129 van die *Children’s Act* behandel die mediese behandeling van kinders, terwyl artikel 11 handel oor gestremde kinders, asook kinders wat aan chroniese siektes ly.

’n Regsvergelykende studie is onderneem waarin daar oorweging geskenk is aan die regsposisie in Engeland en Wallis, sowel as die regsposisie in Nederland, sodat ’n raamwerk vir die beskerming van premature babas en kritiek-siek neonate voorgestel kan word. Die regsposisie in Engeland en Wallis blyk uit hofbeslissings oor die onderwerp. Die Nuffield Council on Bioethics het ’n baie omvattende verslag getiteld, “Critical care decisions in fetal and neonatal medicine: ethical issues” opgestel. Hierdie verslag is deur ’n multidissiplinêre komitee saamgestel en verskaf riglyne oor die mediese behandeling van neonate.

In Nederland is eutanasie wettig, op voorwaarde dat die persoon wat dit versoek, ouer as sestien jaar moet wees. Dit beteken dat neonate nie kan kwalifiseer vir eutanasie nie, maar die term wat in hulle geval

gebruik word, is einde-van-lewe besluite. Die Groningen Protokol is deur pediaters, in samewerking met die staatsaanklaer opgestel. Die oogmerk van hierdie Protokol is om te verhoed dat ’n dokter strafregtelik vervolg word, in die geval van einde-van-lewe besluite indien daar aan die riglyne in die Protokol voldoen word.

In die tesis word drie aanbevelings gemaak:

- Daar behoort riglyne deur ’n multidissiplinêre komitee opgestel word. Die voorbeeld van die Nuffield Council on Bioethics behoort gebruik te word, maar die riglyne moet spesifiek toepaslik vir Suid-Afrikaanse omstandighede wees.
- Daar word aanbeveel dat indien sake of mediese behandeling weerhou of gestaak moet word, die sake wat in Engeland en Wallis beslis is, as presedent gebruik word.
- Mediasie moet oorweeg word in gevalle waar daar ’n dispuut tussen mediese praktisyns en ouers, of tussen ouers is, rakende die mediese behandeling van neonate. Aangesien die hoë hof die oppervoog van alle minderjariges in Suid-Afrika is, moet die uiteinde van die mediasie ’n bevel van die hof gemaak word.

BIBLIOGRAPHY

BOOKS

ASHWORTH A

2006. *Principles of Criminal Law.* 5th ed. Oxford:Oxford University Press.

BAINHAM A, SCLATER SD AND RICHARDS M (eds)

2002. *Body lore and laws.* Oxford:Hart Publishing.

BAINHAM A

2009. *Is anything now left of Parental Rights?* Probert, Gilmore and Herring (eds) 2009:23-42.

BEAUCHAMP TL AND CHILDRESS JF

1979. *Principles of Biomedical Ethics.* New York:Oxford University Press.

BEACHAMP TL AND CHILDRESS JF

2009. *Principles of Biomedical Ethics.* New York:Oxford University Press.

BEAUCHAMP TL AND McCULLOUGH LB

1984. *Medical Ethics. The Moral Responsibilities of Physicians.* Englewood Cliffs, New Jersey:Prentice-Hall.

BELLINGHAM D

1989. *An Introduction to Greek Mythology*: London:The Apple Press.

BöESEKEN AJ

1977. *Slaves and Free Blacks at the Cape 1658-1700*. Cape Town:Tafelberg.

BOEZAART T (ed)

2009. *Child Law in South Africa.* Claremont:Juta.

BOONZAAIER E, MALHERBE C, SMITH A AND BERENS P

1996. *The Cape Herders: A History of the Khoikhoi of Southern Africa*. Cape Town:David Philip.

BOSWELL J

1988. *The Kindness of Strangers: The Abandonment of Children in Western Europe from Late Antiquity to the Renaissance.* New York:Pantheon Books.

BRAZIER M

1995. *11B Government regulations in the United Kingdom: commentary.* Goldworth 1995:328-340.

BRAZIER M AND CAVE E

2007. *Medicine, Patients and the Law.* 4th ed. London:Penquin Books.

BRIDGE C

2002. *Religion, Culture and the Body of the Child.* Bainham 2002:265-287.

BRIDGEMAN J

1998. *'Because we care? The medical treatment of children?'* Sheldon 1998:97-114.

2006. *Caring for children with severe disabilities: boundaried and relational rights.* Freeman 2006:99-119.

2007. *Parental Responsibility, Young Children and Health Law.* Cambridge:Cambridge University Press.

2009. *Parental Responsibility, Relational Responsibility.* Probert, Gilmore and Herring (eds) 2009:255-269.

2010. *Children with exceptional needs.* Wallbank, Choudhry and Herring (eds) 2010:239-256.

BROWNLIE I AND GOODWIN-GILL GS

2010. *Brownlie's Documents on Human Rights*. 6th ed. Oxford:Oxford University Press.

BRYANT J, BAGGOTT LA VELLE L AND SEARLE J

2005. *Introduction to Bioethics.* West Sussex:John Wiley.

BUCHANAN A

1996. *Health-care delivery and Resource Allocation.* Veatch (ed) 1996:321-362.

BUCKLAND WW (3rd edition revised by Stein P)

1975. *A Text-Book of Roman Law from Augustus to Justinian.* Cambridge:University Press.

BULFINCH T

1981. *Myths of Greece and Rome*. Middlesex:Penguin Books.

BURCHELL J AND MILTON J

2006. *Principles of Criminal Law.* 3rd ed. Lansdowne:Juta.

CAMPBELL A, GILLET G AND JONES G

2005. *Medical Ethics*. 4th ed. South Melbourne:Oxford University Press.

CAMPBELL AGM

1995. *Goverment regulations in the United Kingdom.* Goldworth 1995:307-325.

CARD R

2006. *Card, Cross and Jones Criminal Law.* 17th ed. Oxford:Oxford University Press.

CARSTENS P AND PEARMAIN D

2007. *Foundational Principles of South African Medical Law.* Durban: LexisNexis.

CHILDRESS JF

2007. *Methods in bioethics.* Steinbock (ed) 2007:15-45.

CHOUDHRY S, HERRING J AND WALLBANK J

2010. *Welfare, rights, care and gender in family law.* Wallbank, Choudhry and Herring (eds) 2010:1-25.

COHEN LG

1990. *Before Their Time: Fetuses and Infants at Risk.* Washington DC: American Association on Mental Retardation.

COTTERELL A
2000. *Illustrated Encyclopedia: Classical Mythology.* 3rd ed. London:Lorenz Books.

CURRIE I AND DE WAAL J
2005. *The Bill of Rights Handbook.* Wetton:Juta.

DAVEL CJ AND SKELTON AM
2007. *Commentary on the Children's Act.* Cape Town: Juta

DAVEL T
2007. *General principles.* Davel and Skelton (eds) 2007:2.1-2.27.

DE KOCK V
1950. *Those in Bondage: An Account of the Life of the Slave at the Cape in the Days of the Dutch East India Company.* Cape Town: Howard B. Timmins.

DE VOS W
1992. *Regsgeskiedenis. Met 'n Kort Algemene Inleiding tot die Regstudie.* Kaapstad:Juta.

DE WET JC
1985. *De Wet en Swanepoel Strafreg.* 4de uitg. Durban:Butterworths.

DHAI A AND ETHERIDGE H
2011. *Codes for Healthcare ethics.* Dhai and McQuoid-Mason (eds) 2011:16-34.

DHAI A AND McQUOID-MASON D (eds)
2011. *Bioethics, Human Rights and Health Law. Principles and Practice.* Claremont:Juta.

DONNELLY M
2010. *Healthcare Decision-Making and the Law. Autonomy, Capacity and the Limits of Liberalism.* Cambridge:Cambridge University Press.

DORNAN SS
1975. *Pygmies & Bushmen of the Kalahari.* Cape Town:C Struik.

DU PLESSIS P
2010. *Borkowski's Textbook on Roman Law*. 4th ed. Oxford:Oxford University Press.

DUPRÉ B (ed)
1999. *The Oxford Children's Encycopedia of History* Oxford:Oxford University Press.

DURANT W
1944. *Caesar and Christ*. New York:Simon and Schuster.

ELLISTON S
2005. *Treating the preterm infant.* Norman and Greer (eds) 2005:364-396.

ELPHICK R
1985. *Khoikhoi and the Founding of White South Africa*. Johannesburg:Ravan Press.

EVANS RJ
1991. *Rome – 'n Historiese Oorsig.* Kaapstad:Maskew Miller Longman.

FEATHERSTONE B
2010. *Gender, responsibilities and social policy.* Wallbank, Choudhry and Herring (eds) 2010:26-42.

FLETCHER N, HOLT J, BRAZIER M AND HARRIS J
1995. *Ethics, Law and Nursing*. Manchester:Manchester University Press.

FORTIN J
2009. *Children's Rights and the Developing Law*. 3rd ed. Cambridge:Cambridge University Press.

FREEMAN M (ed)
2006. *Children's Health and Children's Rights*. Leiden/Boston:Martinus Nijhoff.

GOLDWORTH A, SILVERMAN W, STEVENSON DK, AND YOUNG EWD AND RIVERS R(eds)
1995. *Ethics and Perinatology*. New York: Oxford University Press.

GUPTA R AND WEINDLING M

2005. *Management of the preterm neonate.* Norman and Greer (eds) 2005:260-306.

HADLEY J

1904. *Introduction to Roman Law: In Twelve Academical Lectures* New York:D. Appleton.

HAGGER L

2009. *Parental Responsibility and Children's Health: care treatment.* Probert, Gilmore and Herring (eds) 2009:185-199.

2009. *The Child as Vulnerable Patient. Protection and Empowerment*. Surrey:Ashgate.

HARPER RS

1999. *Medical Treatment and the Law. The Protection of Adults and Minors in the Family Division.* Bristol:Jordan.

HEATON J

2008. *The South African Law of Persons.* 3rd ed by Jaqueline Heaton. Durban:LexisNexis.

HERRING J

2006. *Medical Law and Ethics.* Oxford:University Press.

HOLLAND S

2003. *Bioethics. A Philosphical Introduction.* Cambridge:Polity Press.

HOSTEN WJ, EDWARDS AB, BOSMAN F AND CHURCH J

1998. *Introduction to South African Law and Legal Theory.* Durban:Butterworths.

HUNT PMA AND MILTON JRL

1990. *South African Criminal Law and Procedure. (Formerly Gardiner and Landsdown) Volume II (Common-law Crimes)*. 2nd ed. Cape Town:Juta.

JACKSON M (ed)

2002. *Infanticide. Historical Perspectives on Child Murder and Concealment, 1550-2000.* Aldershot:Ashgate.

JOHNSTON GB
1998. *The Newborn Child*. 8th ed. New York:Churchill Livingston.

JOST TS
2007. *Readings in Comparative Health Law and Bioethics.* 2nd ed. Durham:Carolina Academic Press.

KAHN E (ed)
1984. *Murder as a fine art.* Kahn (ed)1984:24-29.

1984. *The Sanctity of Human Life*. Senate Special Lectures. Johannesburg:WITS.

KASER M (translated by Dannenbring R)
1984. *Roman Private Law*. Durban:Butterworths.

KASSAN D AND MAHERY P
2009. *Special Child Protective Measures in the Children's Act.* Boezaart (ed) 2009:185-224.

KATZEN M
1984. *Should the severely handicapped newborn be saved: Spina bifida as an example of the dilemma.* Kahn 1984:21-29.

KENNEDY I AND GRUBB A
2000. *Medical Law*. 3rd ed. London:Butterworths.

KLIEGMAN RM, BEHRMAN RE, JENSON HB AND STANTON BF (eds)
2007. *Nelson Textbook of Pediatrics*. Philadelphia:Saunders Elsevier.

KLING S AND KRUGER M
2011. *Paediatrics Ethics.* Moodley (ed) 2011:183-202.

KOPELMAN LM
2008. *The best interest of the child: Standard and parental and guardian's consent.* Perkin ea (eds) 2008:42.

KRIGE EJ
1965. *The Social System of the Zulus.* 2nd ed. Pietermaritzburg:Shuter & Shooter.

KRIGE EJ AND KRIGE JD

1947. *The Realm of a Rain-Queen.* London:Oxford University Press.

KRUGER H AND SKELTON A (eds)

2010. *The Law of Persons in South Africa.* Cape Town:Oxford University Press.

KUHSE H AND SINGER P

1985. *Should the Baby Live? The Problem of Handicapped Infants.* Oxford:Oxford University Press.

LEENEN HJJ, GEVERS JKM AND PINET G

1993. *The Rights of Patients in Europe. A Comparative Study.* Deventer:Kluwer Law.

LEVENE M AND MIALL L

2005. *Fetal outcome following preterm delivery.* Norman and Greer 2005:109-132.

LEIBBRANDT HCV

1901. *Precis of the Archives of the Cape of Good Hope. Journal, 1662-1670*. Cape Town:W.A. Richards.

LIEBENBERG S

2010. *Socio-Economic Rights. Adjudication under a Transformative Constitution.* Claremont:Juta.

LLOYD A

2001. *Consent, Rights and Choices in Health Care for Children and Young People.* London:BMJ Books.

LUBBE W

2008. *Prematurity. Adjusting your Dream*. Pretoria:Little Steps.

MALHERBE R

2009. *The Impact of Constitutional Rights on Education.* Boezaart (ed) 2009:420-455.

MASON JK AND LAURIE GT

2011. *Mason and McCall Smith's Law and Medical Ethics*. 8th ed. Oxford:Oxford University Press.

MCCLEAN S AND ELLISTON S
2005. *The management of pregnancy and labour.* Norman and Greer (eds) 2005:329-363.

MCDONAGH J
2003. *Child Murder and British Culture 1720-1900.* Cambridge:Cambridge University Press.

MCLEAN S
1999. *Old Law, New Medicine; Medical Ethics and Human Rights.* London:Pandora.

MCQUOID-MASON D AND DADA M
2011. *A-Z of Medical Law.* Claremont:Juta.

MCQUOID-MASON D AND DHAI A
2011. *Consent.* Dhai and McQuoid-Mason 2011:69-85

MERENSTEIN GB AND GARDNER SL
2006. *Handbook of Neonatal Intensive Care*. 6th ed. Missouri: Mosby Elsevier.

MILLER G
2007. *Extreme Prematurity: Practices*, Bioethics, and the Law. Cambridge:Cambridge University Press.

MITCHELL J
2006. *Children Act Private Law Proceedings: A Handbook*. 2nd ed. Bristol:Jordan Publishing Limited.

MOODLEY K (ed)
2011. *Medical Ethics, Law and Human Rights. A South African Perspective.* Pretoria:Van Schaik.

2011. *Respect for patient autonomy.* Moodley (ed) 2011:41-56.

MORGAN D
2001. *Issues in Medical Law and Ethics*. London:Cavendish.

MYBURGH AC
1985. *Papers on Indigenous Law in Southern Africa*. Pretoria:Van Schaik.

NIAZI T AND WALKER ML
2008. *Myelomeningocele and Medical Ethics*. Özek ea (eds) 2008: 67-71.

NIEUWENHUIS JH, STOLKER CJJM AND VALK WL
2003. *Burrgerlijk Wetboek: boeken 1, 2, 3 en 4: Tekst & Commentaar.* Deventer:Kluwer.

NORMAN J AND GREER I (eds)
2005. *Preterm Labour: Managing Risk in Clinical Practice.* Cambridge:Cambridge University Press.

ORMEROD D
2005. *Smith & Hogan: Criminal Law.* 11th ed. Oxford:Oxford University Press.

ÖZEK MM, CINALLI G AND MAIXNER W (eds)
2008. *Spina Bifida: Management and Outcome.* New York:Springer.

PERKIN RM, SWIFT JD, NEWTON DA AND ANAS NG
2008. *Pediatric Hospital Medicine.* Philadelphia:Wolters Kluwer.

POST AH
1887. *Afrikanische Jurisprudenz*. *Ethnologisch-juristische Beiträge zur Kenntniss der einheimischen Rechte Afrikas.* Oldenburg: Schulzesche Hof-Buchandlung und Hof-Buchdruckerei.

PRINSLOO MW (met die medewerking van Myburgh AC)
1983. *Inheemse Publiekreg in Lebowa*. Pretoria:J.Lvan Schaik.

PRINSLOO MW
1978. *Die inheemse strafreg van die Noord-Sotho.* Johannesburg: *Randse Afrikaanse Universiteit.*

PROBERT R, GILMORE S AND HERRING J (eds)
2009. *Responsible Parents and Parental Responsibility*. Oxford:Hart.

PROUDLOCK P
2009. *Children's Socio-economic Rights.* Boezaart (ed) 2009:291-308.

RAWSON B (ed)
1986. *The Family in Ancient Rome: New Perspectives.* London:Croom Helm.

REDSHAW ME, RIVERS RPA AND ROSENBALTT DB
1985. *Born too Early. Special Care for your Preterm Baby*. Oxford:Oxford University Press.

SCHäFER L
2011. *Child Law in South Africa. Domestic and InternatIonal Perspectives.* Durban:LexisNexis.

SCHAPERA I
1965. *The Khoisan Peoples of South Africa*. London:Routledge & Kegan Paul.

1970. *A Handbook of Tswana Law and Custom*. London:Frank Cass.

SCHERPE JM
2009. *Establishing and Ending Parental Responsibility.* Probert, Gilmore and Herring (eds) 2009:43-62.

SCHWARTZ LL AND IZZER NK
2007. *Child Homicide: Parents Who Kill.* Boca Raton:Taylor and Francis.

SHELDON S AND THOMSON M (eds)
1998. *Feminist perspectives on Health Care Law*. London:Cavendish.

SKELTON A
2009. *Protection of Children's Rights.* Boezaart (ed) 2009:265-290.

SLOTH-NIELSEN J
2007. *Protection of children.* Davel and Skelton (eds) 2007:7.1-7.60.

SNYMAN CR
2008. *Criminal Law.* 5th ed. Durban:LexisNexis.

STEINBOCK B (ed)
2007. *The Oxford Handbook of Bioethics.* Oxford: Oxford University Press.

STOFFBERG DP
1982. *Inleiding tot die Volkekunde*. Johannesburg:Macmilllan.

STRAUSS SA
1991. *Doctor, Patient and the Law. A Selection of Practical Issues.* 3rd ed. Pretoria:J.L. van Schaik.

THOMAS JAC
1976. *Textbook of Roman Law*. Amsterdam:North-Holland.

TYLER J
1971. *Forty Years among the Zulus*. Cape Town:Struik.

VAN NIEKERK AA
2011. *Ethics theories and the principalist approach in bioethics.* Moodley (ed) 2011:19-40.

VAN ZYL DH
1983. *History and Principles of Roman Private Law.* Durban:LexisNexis.

VEATCH RM (ed)
1996. *Medical Ethics.* 2nd ed. Sudbury, Massachusetts:Jones and Bartlett.

VENTER F, VAN DER WALT CFC, VAN DER WALT AJ, PIENAAR GJ, OLIVIER NJJ EN DU PLESSIS LM
1990. *Regsnavorsing. Metode en Publikasie.* Kaapstad:Juta.

VERKLAN MT AND WALDEN M (eds)
2004. *Core Curriculum for Neonatal Intensive Care Nursing.* 3rd ed. St. Louis, Missouri:Elsevier Saunders.

WALLBANK J, CHOUDHRY S AND HERRING J (eds)
2010. *Rights, Gender and Family Law*. Abingdon:Routledge.

WEIR RF
1984. *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine.* New York:Oxford University Press.

WESSELS JW

1908. *History of the Roman-Dutch Law.* Grahamstown:African Book.

WILLIAMS G

1958. *The Sanctity of Life and the Criminal Law.* London:Faber & Faber.

JOURNALS

ALDERSON P; HAWTHORNE J; KILLEN

2005. The participation rights of premature babies. *The International Journal of Children's Rights* 13:31-50.

BARTON B

1998. When murdering hands rock the cradle: An overview of America's incoherent treatment of infanticidal mothers. *Southern Methodist University Law Review*. 51:591-619.

BENNETT H

1923. The exposure of infants in ancient Rome. *The Classical Journal* 18(6) March:341-351.

BRAZIER M

1996. Euthanasia and the law. *British Medical Bulletin.* 52(2): 317-325.

BRIDGEMAN J

2005. Caring for children with severe disabilities: Boundaries and relational rights. *The International Journal of Children's Rights.* 13:99-119.

BÜCHNER-EVELEIGH M AND NIENABER A

2012. Gesondheidsorg vir kinders: Voldoen Suid-Afrikaanse wetgewing aan die land se verpligtinge ingevolge die Konvensie oor die Regte van die Kind en die Grondwet? *Potchefstroomse Elektroniese Regstydskrif.* 15(1):103-146.

CHÜRR C

2009. A delictual claim based on "wrongful life": Is it possible? Stewart v Botha 2007 6 SA 247 (C). *Tydskrif vir Hedendaagse Romeins-Hollandse Reg*. 72(1):2009:168-174.

CLARK B

2001. My right to refuse or consent: the meaning of consent in relation to children and medical treatment. *Tydskrif vir Hedendaagse Romeins-Hollandse Reg.* 64(4):605-618.

CRAIG M

2004. Perinatal risk factors for neonaticide and infant homicide: can we identify those at risk? *Journal of the Royal Society of Medicine*. 97:57-61.

DAVEL T

2002. The African Charter on the rights and welfare of the child, family law and children's rights. *De Jure*. 35(2):281-291.

DEACON H

1998. Midwives and medical men in the Cape Colony before 1860. *The Journal of African History*. 39:271-292.

DE JONG M

2010. A pragmatic look at mediation as an alternative to divorce litigation. *Tydskrif vir die Suid-Afrikaanse Reg.* 2010(3):515-531.

DE VOS P

1995. The economic and social rights of children and South Africa's transitional Constitution. *South African Public Law.* 10(1):233-259.

DE WACHTER MAM

1992. Euthanasia in the Netherlands. *The Hastings Center Report.* 22(2):23-30.

DORSCHEIDT JHHM

2005. Assessment procedures regarding end-of-life decisions in neonatology in the Netherlands. *Medicine and Law*. 24:803-829.

DORSCHEIDT JHHM

1999. The unborn child and the UN Convention on Children's Rights: the Dutch perspective as a guideline. *The International Journal of Children's Rights* 7:303-347.

DORSCHEIDT JHHM; VERHAGEN E; SAUER PJJ AND HUBBEN JH
2011. Parental involvement in end-of-life decisions in neonatology: legal considerations with regard to Dutch medical practice. *Medical Law International*. 11:1-22.

DRESCHER-BURKE K; KRALL J; AND PENICK A
2004. Discarded infants and neonaticide: A review of the literature. *National Abandoned Infants Assistance Resource Center, University of California at Berkeley. National Resource Center. A service of the Children's Bureau.* September 2004:1-13.

EEKELAAR J
2002. Beyond the welfare principle. *Child and Family Law Quarterly.* 14(3):237-249.

ELMALIK K AND WHEELER RA
2007. Consent: luck or law? *Annual Royal College of Surgeons of England.* 89:627-630.

FABER S
1976. Infanticide, especially in eighteenth-century Amsterdam; with some references to Van der Keessel. *Acta Juridica* 253-267.

FREEMAN MDA
1983. Freedom and the welfare state: child-rearing, parental autonomy and state intervention. *Journal of Social Welfare Law*. 70-91.

FREEMAN M
1997. The best interests of the child? Is *the best interests of the child* in the best interests of children? *International Journal of Law, Policy and the Family.* 11:360-388.

GIESEN I
2009. Of wrongful birth, wrongful life, comparative law and the politics of tort law systems. *Tydskrif vir Hedendaagse Romeins-Hollandse Reg*. 72(2):257-273.

GOLDEN M
1981. Demography and the exposure of girls at Athens. *Phoenix.* 35(4):316-331.

GOSTIN L

1985. A moment in human development: legal protection, ethical standards and social policy on the selective non-treatment of handicapped neonates. *American Journal of Law and Medicine*. 11(1):31-78.

HEATON J

1990. Some general remarks on the concept “best interests” of the child. *Tydskrif vir Hedendaagse Romeins-Hollandse Reg.* 35(3):272-291.

HERRING J

1999. The Human Rights Act and the welfare principle in family law – conflicting or complementary? *Child and Family Law Quarterly*. 11(3):223-235.

HUMAN S AND MILLS L

2010. The immeasurable wrongfulness of being: the denial of the claim for wrongful life. *Stellenbosch Law Review.* 21(1):67-89.

JOCHEMSEN H

1998. Dutch court decisions on nonvoluntary euthanasia critically reviewed. *Issues in Law & Medicine.* 13(4):447-458.

KOMPANJE EJO; DE JONG THR; ARTS WFM AND ROTTEVEEL JJ

2005. Problematische basis voor ‘uitzichtloosheid en ondraaglijk lijden’ als criterium voor actieve levensbeëindiging bij pasgeborenen met spina bifida. *Nederlands Tijdschrift voor Geneeskunde.* 149(37):2067-2069.

KLING S

2006. Children’s rights and health care in South Africa. *South African Paediatric Review.* 3(3):42-46.

KLITSCH M

1983. Mercy or murder? Ethical dilemmas in newborn care. *Family Planning Perspectives*. 15(3):143-146.

KRUUSE, H.J.

2009. Fetal “rights”? The need for a unified approach to the fetus in the context of feticide. *Tydskrif vir Hedendaagse Romeins-Hollandse Reg. 72(1):*126-136.

LABUSCHAGNE, J.M.T.

1996. Aktiewe eutanasie van 'n swaar gestremde baba: 'n Nederlandse hof herstel die *ius vitae necisque* in 'n medemenslike gewaad. *South African Law Journal.* 113(1):216-218.

LANGER W.L.

1974. Infanticide: A historical survey. *History of Childhood Quarterly.* 1:353-366.

LA RUE VAN HOOK

1920. The exposure of infants at Athens. *Transactions and Proceedings of the American Philological Association.* 51:134-145.

LIND C

1992. Wrongful-birth and wrongful-life actions. *South African Law Journal*. 109:428-446.

MADANAMOOTHOO A

2011. Saviour-sibling and the psychological, ethical and judicial issues that it creates: Should English and French legislators close the Pandora's box? *European Journal of Health Law* 18:293-303.

MANNINEN BA

2006. A case for justified non-voluntary active euthanasia: exploring the ethics of the Groningen Protocol. *Journal of Medical Ethics.* Vol 32, No 11 (Nov. 2006):643-651.

McCLAREN T

2005. The best interests of the child: a right or a principle? *Responsa Meridiana* 119-135.

McHAFFIE HE, CUTTINI M, BRöLZ-VOIT G, RANDAG L, MOUSTY R, DUGUET A-M, WENNERGREN B, BENCIOLINI P

1999. Withholding/withdrawing treatment from neonates: legislation and official guidelines across Europe. *Journal of Medical Ethics*. 25(6):440-446.

McQUOID-MASON D AND LOTZ L

2005. Religious beliefs and the refusal of blood transfusions for children: what should doctors do? *Tydskrif vir Hedendaagse Romeins-Hollandse Reg*. 68:315-321.

MEYERS DW
2005. *Wyatt* and *Winston-Jones*: Who decides to treat or let die seriously ill babies? *Edinburgh Law Review.* 9(2):307-316.

MORATTI S
2010. End-of-life decisions in Dutch neonatology. *Medical Law Review.* 18:471-496.

MORATTI S
2010. Non-treatment decisions on grounds of "medical futility" and "quality of life": interviews with fourteen Dutch neonatologists. *Issues in Law & Medicine.* 26(1):4-11.

MOSELEY KL
1986. The history of infanticide in western society. *Issues in Law and Medicine.* 1(5):345-361.

MUBANGIZI JC
2002. Public health, the South African Bill of Rights and the socio-economic polemic. *Tydskrif vir die Suid-Afrikaanse Reg.* 2:343-352.

NEETHLING J
2005. Personality Rights: a comparative overview. *Comparative and International Law Journal of Southern Africa.* 38(2):211-245.

NGWENA C
2000. Access to health care as a fundamental right: the scope and limits of Section 27 of the Constitution. *Journal for Juridical Science* 25(1):1-32.

NADASEN S
1997. "Suffer the little children…" – Euthanasia and the best interests of the child. *Tydskrif vir Hedendaagse Romeins-Hollandse Reg.* 60(1):124-131.

NICHOLSON C; POLITIS A
2001. The life and death lottery: tipping the scales in favour of the child's best interests. *De Jure*. 34(3):594-604.

OOSTHUIZEN H AND VERSCHOOR T
2008. Ethical principles becoming statutory requirements. *South African Family Practice.* 50(5):36-40.

PIEPER CH AND HESSELING PB

2007. The changing face of neonatal intensive care in South Africa. *South African Journal of Child Health.* 1(2):58-62.

PIETERSE M

2003. Reconstructing the private/public dichotomy? The enforcement of children's constitutional social rights and care entitlements. *Tydskrif vir die Suid-Afrikaanse Reg*. 1-19.

PRINSLOO WM

2007. Posisie van tweelinge in die inheemse reg en kultuur: 'n regsantropologiese aantekening. *Tydskrif vir die Suid-Afrikaanse Reg.* 735-740.

REID R

1977. Spina bifida: The fate of the untreated. *The Hastings Center Report*. 7(4):16-19.

ROBINSON JA

2002. An introduction to the international law on the rights of the child relating to the parent-child relationship. *Stellenbosch Law Review*. 13(2):309-320.

SCULLY P

1996. Narratives of infanticide in the aftermath of slave emancipation in the nineteenth-century Cape Colony, South Africa. *Canadian Journal of African Studies*. 30(1):88-105.

SILVERMAN WA

1981. Mismatched attitudes about neonatal death. *The Hastings Center Report.* 11(6):12-16.

SLABBERT M

2010. Ethics, justice and the sale of kidneys for transplantation purposes. *Potchefstroomse Elektroniese Regstydskrif.* 13(2);77-105.

SLOTH-NIELSEN J

1995. Ratification of the United Nations Convention on the Rights of the Child: some implications for South African law. *South African Journal on Human Rights.* 11(3):401-420.

STRAUSS SA

1987. Ethics and the law in South Africa. *South African Journal of Medical Education.* 5:21-26.

STRAUSS SA

1995. First South African case on wrongful life: child cannot sue doctor for disablement if he has failed to advise mother to terminate pregnancy. *SA Practice Management.* 16(2):12-13.

TRIPP J AND McGREGOR D

2006. Withholding and withdrawing of life sustaining treatment in the newborn. *Archives of Disease in Childhood: Fetal & Neonatal.* 9(1):F67-F71.

VAN DER HEIDE A; VAN DER MAAS PJ; VAN DER WAL G; DE GRAAFF CLM; KESTER JGC KOLLéE LAA DE LEEUW R AND HOLL RA

1997. Medical end-of-life decisions made for neonates and infants in the Netherlands. *Lancet*. 350(9073):251-257.

VAN NIEKERK GJ

2005. Criminal Justice at the Cape of Good Hope in the seventeenth century: Narratives of infanticide and suicide. *Fundamina.* 11(2):135-154.

VERHAGEN E AND SAUER PJJ

2005. The Groningen Protocol – euthanasia in severely ill newborns. *The New England Journal of Medicine*. 352(10):959-962.

VERHAGEN E AND SAUER PJJ

2005. End-of-life decisions in newborns: an approach from the Netherlands. *Pediatrics*. 116(3):736-739.

VERHAGEN EAA; VAN DER HOEVEN MAH; VAN MEERVELD RC; AND SAUER PJJ

2007. Physician medical decision-making at the end of life in newborns: insight into implementation at 2 Dutch centers. *Pediatrics.* 120(1):e20-e28.

VERHAGEN EAA; SAUER PJ; CALLAHAN D AND CHERVENAK FA

2008. “Are their babies different from ours?” Dutch culture and the Groningen Protocol. *Hastings Center Report.* 38(4):4-8.

VERHAGEN EAA; DE VOS M; DORSCHEDIT JHMM; ENGELS B HUBBEN JH AND SAUER PJ

2009. Conflicts about end-of-life decisions in NICUs in the Netherlands. *Pediatrics*. 124(1):e112-e119.

VERHAGEN EAA; DORSCHEIDT JD; ENGELS B, HUBBEN JH AND SAUER PJ

2009. End-of-Life decisions in Dutch neonatal intensive care units. *Archives of Pediatrics and Adolescent Medicine*. 163(10):895-901.

VILJOEN, F.

1999. Why South Africa should ratify the African Charter on the rights and welfare of the child. *South African Law Journal.* 116(3):660-664.

VOIROL M

2002. Hush little baby; don't say a word: saving babies through the no questions asked policy of "Dumpster Baby Statutes". *Thomas M. Cooley Journal of Practical and Clinical Law.* 5(1):115-137.

WALTHER FJ

2005. Withholding treatment, withdrawing treatment, and palliative care in the neonatal intensive care unit. *Early Human Development* 81:965-972.

WELLS JC

1998. Eva’s men: gender and power in the establishment of the Cape of Good Hope, 1652-74. *Journal of African History.* 39(3):417-437.

WEN CHEN WU M

2003. Culture is no defense for infanticide. *American University Journal of Gender, Social Policy and the Law*. 11(2):975-1021.

WILKINSON LP

1978. Classical approaches to population and family planning. *Population and Development Review.* 4(3):439-455.

REGISTER OF LEGISLATION

South African legislation

Children's Act 38 of 2005

Choice on Termination of Pregnancy Act 92 of 1992

Constitution of the Republic of South Africa, 1996

Health Professions Act 56 of 1974

National Health Act 61 of 2003

Ordinance 10 of 1845 (C)

FOREIGN LEGISLATION

England and Wales, Scotland and Northern Ireland

Children Act 1989

Children (Scotland) Act 1995

Children and Young Persons Act 1933

Children and Young Persons (Scotland) Act 1937

Human Fertilization and Embryology Act 2008

Human Rights Act 1998

Infanticide Act 1922 (12 & 13 Geo 5 c 18)

Infant Life Protection Act 1872 (35 & 36 Vict c 38)

Infant Life (Preservation) Act 1929 (19 & 20 Geo 5 c 34)

Infanticide Act 1938 (1 & 2 Geo. 6 c. 36)

Malicious Shooting or Stabbing Act (Lord Ellenborough's Act) (43 Geo 3 c 58)

Offences Against the Person Act 1828 (9 Geo 4 c 31)

Offences Against the Person Act 1861 (24 &25 Vict c 100)

Scotland Act 1998

The Children (Northern Ireland) Order 1995

The Netherlands

Algemene Kinderbijslagwet, April 1962

Burgerlijk Wetboek Boek 1, Personen-en familierecht

Dutch Constitution

Wetboek van Strafrecht

Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding

REGISTER OF CASE LAW

South African case law

AD v DW (Centre for Child Law as Amicus Curiae; Department for Social Development as Intervening Party) 2008 (3) SA 183 (CC)

Castell v De Greeff 1994 (4) SA 408

Centre for Child Law v Minister of Home Affairs 2005 (6) SA 50 (TPD)

Clarke v Hurst 1992 (4) SA 630 (D)

Christian Lawyers Association of South Africa v The Minister of Health 1998 (11) BCLR 1434 (T), 1998 (4) SA 1113 (T)

Christian Lawyers' Association v Minister of Health 2004 (10) BCLR 1086 (T)

De Reuck v Director of Public Prosecutions, WLD 2004 (1) SA 406 (CC)

Edouard v Administrator, Natal 1989 (2) SA 368 (D & CLD)

Fletcher v Fletcher 1948 (1) SA 130 (A)

Friedman v Glicksman 1996 (1) SA 1134 (WLD)

Government of the Republic of South Africa v Grootboom 2001 (1) SA 46 (CC)

Hay v B 2003 (3) SA 492 (W)

Khosa v Minister of Social Development; Mahlaule v Minister of Social Development 2004 (6) SA 505 (CC)

Laerskool Middelburg v Departementshoof, Mpumalanga 2003 (4) SA 160 (TPA)
Minister of Health v Treatment Action Campaign 2002 (5) SA 703 (CC)

Minister of Welfare and Population Development v Fitzpatrick 2000 (3) SA 422 (CC)

Minister van Polisie v Ewels 1975 (3) SA 590 (A)

Mukheiber v Raath 1999 (3) SA 1065 (SCA)

R v Adams (1903) 20 SC 556

R v Arends 1913 CPD 194

R v Oliphant 1950 1 SA 48 (O)

R v Verrooi 1913 CPD 864

S v Bengu 1965 (1) SA 298 (N)

S v De Bellocq 1975 (3) SA 538 (T)

S v M (Centre for Child Law as Amicus Curiae) 2008 (3) SA 232 (CC)

S v Makwanyane 1995 (3) SA 391 (CC)

S v Tembani 2007 (2) SA 291 (SCA)

Soobramoney v Minister of Health, KwaZulu-Natal 1998 (1) SA 765 (CC)

Stewart v Botha 2007 (6) SA 247 (C)

Stoffberg v Elliott 1923 CPD 148

English and Welsh case law

Airedale NHS Trust v Bland [1993] AC 789

An NHS Trust v MB [2006] EWHC 507 (Fam)

Finlayson, applicant, sub nom Finlayson v 1989 SCLR 601

Glass v United Kingdom [2004] 1 FLR 1019
In re A (Children) (Conjoined Twins: Surgical Separation) [2001] 2 WLR 480 (CA)

In re B (a Minor) (Wardship: Medical Treatment) [1981] 1 WLR 1421 (CA)

In re C (a Minor) (Wardship: Medical Treatment) [1989] 3 WLR 240 (CA)

In re J (a Minor) (Child in Care: Medical Treatment) [1992] 3 WLR 507 (CA)

In re J (Wardship: Medical Treatment) [1991] 2 WLR 140 (CA)

In re O (a Minor) (Medical Treatment) [1993] 2 FLR 149 (CA)

In re T (a Minor) (Wardship: Medical Treatment) [1997] 1 WLR 242 (CA)

NHS Trust A v NHS; Trust B v H [2001] 2 WLR Fam 942

Portsmouth Hospitals NHS Trust v Wyatt [2005] EWCA Civ 1181 1 WLR 3995

R (On the Application of Josephine Quintavalle on Behalf of CORE v HFEA [2005] UKHL 28)

R v Arthur [1981] Crim L.R. 298, 111 SJ 435

Re A (Male Sterilisation) [2000] 1 FLR 549.

Re C (a Baby) [1996] 2 FLR 43

The NHS Trust v A and another [2007] EWHC 1696 (Fam)

Dutch case law

Nr. 46. Hoge Raad (Strafkamer) DD89.398. *Nederlandse Jurisprudentie. Uitspraken in burgerlijke en strafzaken* 1990:200. (Baby Ross)

Nr 602. ARR.-RECHTBANK ALKMAAR (Strafkamer) 26 April 1995. Nederlandse Jurisprudentie 1995:2876-2877

Prins. Court of Alkmaar, 26 April 1995. TGR 1995/41 and Court of Appeal of Amsterdam, the Netherlands, 7 Novemver 1995, TGR 1996/1

Nr 113. Hof Amsterdam (Strafkamer) 7 November 1995. *Nederlandse Jurisprudentie* 1996:554-555. [This case is reported in *Tijdschrift voor Gezondheidsrecht,* 1996(5):284-291.] (Kadijk)

ACADEMIC THESES

BREYTENBACH WJ

1971. *Die Familiereg van die Usuthu-Zulu van Nongoma*. Unpublished dissertation for Master of Arts: University of Pretoria.

BÜCHNER-EVELEIGH M

2009. *'n Kritiese Evaluering van Wetgewing wat die Gesondheid van Kinders Beïnvloed.* Unpublished doctoral thesis (LLD): University of South Africa.

DE BEER FC

1986. *Groepsgebondenheid in die Familie-, Opvolgings- en Erfreg van die Noord-Ndebele*. Unpublished doctoral thesis (D. Phil): University of Pretoria.

GREY DJR

2008. *Discourses of Infanticide in England, 1880-1922.* Unpublished doctoral thesis (PhD): School of Arts, Roehampton University, University of Surrey.

NEL JP

1996. *Regsvrae rondom die Geneeskundige behandeling van ernstig gestremde pasgeborenes.* Unpublished master's dissertation (LLM): University of South Africa.

NGOBESE WRM

2003. *The Continuity of Life in African Religion with reference to Marriage and Death among the Zulu People.* Unpublished dissertation for Master of Theology: University of South Africa.

VAN DEN HEEVER JA

1984. *'n Sistematiek vir die Inheemse Deliktereg van die Swartman.* Unpublished LLD thesis: University of Pretoria.

REPORTS

A guide to the Children's Act for health professionals. 2010. Children's Institute, University of Cape Town.

Considerations pertaining to neonatal life termination. Health Council of the Netherlands.Ethics and health monitoring report 2007. Centre for Ethics and Health.

Critical care decisions in fetal and neonatal medicine: ethical issues. November 2006: Nuffield Council on Bioethics.

Guidelines for Good Practice: *Management of Neonatal Respiratory Distress Syndrome.* December 2000: Royal College of Paediatrics and Child Health.

Guidelines for the Withholding and Withdrawing of Treatment (2nd edition) Booklet 13. (29 May 2007). Health Professions Council of South Africa.

National Health Insurance in South Africa. Policy Paper. 2011. Department: Health, Republic of South Africa.

Report 83 (1997) – Partial Defences to Murder: Provocation and Infanticide Law Reform Commission, New South Wales [http://www.lawlink.nsw.gov.au/lrc.nsf/pages/R83CHP3]

SANITSA August 2008: "Motivation for recognition of postbasic specialisation in neonatal nursing science by SANC."

South Africa. Millennium Development Goals. Mid-term Country Report. September 2007.

Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice. (2nd ed.) May 2004: Royal College of Paediatrics and Child Health.

PAPERS DELIVERED AT CONFERENCES

Madide A and Kirsten GF

"Premature loss: Can we reduce extreme low birth weight neonatal mortality?" The 30th Conference on Priorities in Perinatal Care in South Africa (2011).

Velaphi S and Van Kwawegen A

"Diagnosis on admission, and causes (pathological and systemic) of deaths among neonates who were admitted to a high care nursery." The 30th Conference on Priorities in Perinatal Care in South Africa (2011).

MEDIA

Newspaper articles

Anon.

"Boetie 'ontwerp' om siek suster se lewe te red" *Beeld* 5 October 2000.

Elsabé Brits

"Aborsie na geboorte? Ja, sê 2 navorsers" *Beeld* 6 Maart 2012.

Cornelia du Plooy

"Baby given blood after court ruling 'doing well' *Pretoria News* 26 Oktober 2005.

Pieter du Toit

"Bloedoortapping op baba gedoen al sê Jehova-ma nee" *Beeld* 29 October 2005.

Bongani Mthethwa

"Court rules against religious beliefs" *Sunday Times* 23 September 2007.

Ingrid Oellerman

"Judge orders blood transfusion for critically ill baby", *Witness* 6 November 2008.

Kanina Ross
"Court order saves Jehova's Witness girl's life: *Star* 20 February 2009.

Zelda Venter
"Doctors get blood for baby in court" *Pretoria News* 25 October 2005.

Gareth Wilson
"Judge orders baby to be given blood transfusion" *The Herald* 9 July 2008.

Elsabé Brits
Beeld 21 September 2011.

Thandi Sakde
Pretoria News 29 September 2011.

Electronic media

AFTER-BIRTH ABORTION:WHY SHOULD THE BABY LIVE?,
See http://www.stormfront.org/forum/t869752/
[accessed on 2012/03/26].

Aish HaTorah,
see http://www.aish.com/seminars/**worldperfect**/wp03n11.htm
[accessed on 2007/05/27].

Anon.
http://www.un.org/millenniumgoals/bkgd.shtml
[accessed on 2011/12/13].

EDELSTEIN L,
See http://www.pbs.org/wghb/nova/doctors/oath_classical.html
[accessed on 2010/05/27]

HIPPOCRATIC OATH,
See http://www.nlm.nih.gov/hmd/greek/greek_oath
[accessed 2010/05/27]. (Translated by Michael North, National Library of Medicine, 2002.

FURDON SA,
see http://www.emedicine.com/ped/topic1889.htm
[accessed on 2008/10/18]

MORAN DR,
See http://www.deathreference.co./Ho-Ka/Infanticide.html
[accessed on 2008/03/13]

PRICE C,
see
*h*ttp://www.christiancadre.org/member_contrib/cp_infanticide.php
[accessed on 2007/06/14].

INTERNATIONAL HUMAN RIGHTS INSTRUMENTS

African Charter on Human and Peoples' Rights 1981

African Charter on the Rights and Welfare of the Child 1990

Convention on the Elimination of all Forms of Discrimination against Women 1979

(United Nations) Convention on the Rights of the Child 1989

Declaration on the Rights of the Child 1954

International Covenant on Economic, Social and Cultural Rights 1966

International Covenant on Civil and Political Rights 1966

The European Convention for the Protection of Human Rights and Fundamental Freedoms 1950

Universal Declaration of Human Rights 1948

DICTIONARY

AUDI R (ed)
1999. *The Cambridge Dictionary of Philosophy*. Cambridge: Cambridge University Press.

1985. *Dorland's Illustrated Medical Dictionary*. Twenty-sixth Edition. Philadelphia: W.B. Saunders Company.

PRIMARY SOURCES

ARISTOTLE (with and English translation by H. Rackham)
1959. *Politics.* London:William Heinemann.

CICERO (with an English translation by N.H. Watts)
1955. *De Domo Sua*. (*The Speeches*). London:William Heinemann. [*Pro Archia Poeta; Post Reditum in Senatum; Post Reditum ad Quirites; De Domo Sua; De Haruspicu Responsis; Pro Plancio*]

CICERO (with and English translation by C.W. Keyes)
1961. *De Legibus.* London:William Heinemann. [*De Republica; De Legibus*]

CODEX THEODOSIAUNUS IACOBI GOTHOFREDI TOMUS TERTIUS.
1738. lipsiae: Maur. Georgii Weidmanni.

CORPUS IURIS CANONICI EMENDATUM ET NOTIS ILLUSTRATUM.
1661. Coloniae Munatianae.

DIONYSIUS OF HALICARNASSUS (with and English translation by E. Cary on the basis of the version of E. Spelman)
1948. *The Roman Antiquities of Dionysius of Halicarnassus*. In seven volumes. (Vol I) Cambridge:Harvard University Press.

EURIPIDES (with an English translation by Way AS)
1962. *The Phoenician Maidens.* Volume 3. London: William Heinemann.

EURIPIDES (with an English translation by Arthur S Way)
1958. *Ion, Hippolytys, Medea, Alcestis.* In four volumes; Vol IV.Cambridge: Harvard University Press.

DE GROOT, HUGO (GROTIUS)
1939. *Inleidinge tot de Hollandsche Rechts-Geleerdheid* (Met aanteekeningen van Mr S.J. Fockema Andreae. Vierde, herziene en vermeerderde uitgave door Mr L.J. van Apeldoorn). Arnhem: S.Gouda Quint.

GAIUS
1958. *The Institutes of Gaius (text with critical notes and translation by Francis de Zulueta).* Oxford:Clarendon Press.

HERODOTUS (with and English translation by A.D. Godley)
1960. In four volumes. Volume I, Book I and II. London:William Heinemann.

HUBER, ULRICH
1939. *The Jurisprudence of my Time (Heedensdaegse Rechtsgeleertheyt)*. Volume II translated from the fifth edition by Percival Gane Durban: Butterworth.

JUSTINIANUS
1985. *The Digest of Justinian. (*Latin text edited by Theodor Mommsen with the aid of Paul Krueger. English translations edited by Alan Watson*)*. Vol II and IV. Philadelphia: University of Philadelphia Press.

JUSTINIANUS
1962. *The Institutes of Justinian* (with English introduction, translation and notes by TC Sandars). London: Longmans.

LIVY (with and English translation by F.G. Moore).
1958. *From the founding of the city.* (*Ab Urbe Condita*). Fourteen volumes. Volume VII. London:William Heinemann.

LUCIUS APULEIUS (with and English translation by W. Adlington (1566) revised by S.Gaselee).
1858. *The Golden Ass being the Metamorphoses*. London:William Heinemann.

MOORMAN J
1764. *Verhandelinge over de misdaden en der selver straffen*. Arnhem:Nyhof.

MATTHAEUS A (TRANSLATED INTO ENGLISH BY HEWETT M AND STOOP BC (ed)
1987. *De Criminibus. On Crimes: A Commentary on Books XLVII and XLVIII of the Digest. Vol 2.* Cape Town:Juta.

PLATO (with an English translation by H.N. Fowler)
1961. *Theaetetus and Sophist.* London:William Heinemann.

PLATO (with and English translation by P. Shorey)
1956. *The Republic.* In two volumes. Vol II, books VI – X. London: William Heinemann.

POLYBIUS (with an English translation by W.R. Paton)
1954. *Histories.* In six volumes. Vol VI. London:William Heinemann.

SENECA (with an English translation by J.W. Basore.
1958. *Moral Essays. (De Ira).* In three volumes. Vol I. London: William Heinemann.

TACITUS (with an English translation by M. Hutton revised by R.M. Ogilvie)
1953. Tacitus *Germania.* In five volumes. Vol I. Cambridge: Harvard University Press.

TACITUS (with an English translation by C.H. Moore)
1951. *Historiae/Histories.* Cambridge: Harvard University Press.

VAN DER KEESSEL DG (Dionysius Godefridus)
1961. *Praelectiones Iuris Hoderni ad Hugonis Grotii Introductionem ad Iurisprudentiam Hollandicam. Voorlesinge oor die Hedendaagse Reg na aanleiding van de Groot se "Inleiding tot de Hollandse Rechtsgeleerdheyd.* (Translated into Afrikaans by H.L. Gonin) Volumen Primum/Eerste Band. Amsterdam : A.A. Balkema.

VAN LEEUWEN, SIMON
1923. *Simon van Leeuwen's Commentaries on Roman-Dutch Law (Roomsch Hollandsch Recht*) revised and edited with notes in two volumes by C.W. Decker (translated by Sir John G. Kotzé 1923) London: Maxwell.

VAN DER LINDEN, JOHANNES
1806. *Regtsgeleerd, Practicaal, en Koopmans Handboek; ten dienste van regters, practizijns, kooplieden, en allen, die een algemeen overzicht van regskennis verlangen*. Amsterdam: Johannes Allart.

VOET, JOHANNES
1955. *The Selective Voet being the Commentary on the Pandects (Commentarius ad Pandectas)* (and the supplement to that work by Johannes van der Linden; translated with explanatory notes and notes of all South African reported cases by Percival Gane). Volume I. Durban: Butterworth.