

Human Rights and the Premature Infant

Introduction

Scientific and medical developments in fetal and neonatal medicine have enabled children who previously would have died to survive and lead healthy and fulfilling lives. These same developments have also created ethical, social and legal dilemmas for those families and health professionals who are faced with making complex and emotionally demanding decisions that may have lifelong consequences. The difficult questions that arise in fetal and neonatal medicine concern a number of recurring ethical issues. These include the nature and value of human life at different stages of development, distinctions between the active ending of life and death resulting from withholding or withdrawing treatment, and balancing the interests of affected children, their families and the needs of other social groups.¹ With ethical and moral complexities comes the inevitable discussion of the role in which human rights play in such an emotive subject.

It is acknowledged in the Cayman Islands Constitution's preamble that the Islands are a country that provides a comprehensive healthcare system. While not considered a developing Country in comparison to other countries in the Caribbean region, the Cayman Islands do not have the medical facilities to treat extremely premature (under 30 weeks) infants. Therefore almost all medical specialist care has to be referred overseas, generally to the United States. The specialist care comes at a high cost as is the norm in neonatal medical care.

The Ministry of Health, Sports, Youth and Culture has identified the need to draft a policy concerning the management of neonates. They have approached the Human Rights Commission for guidance and research regarding the inevitable human rights concerns regarding the rights of neonates. They have also asked for assistance in locating research sources which will assist with drafting the policy.

The following will:

- outline the primary legal instruments that may be applicable;
- discuss whether neonates qualify for these “rights” since their survival depends on extensive medical care and the decisions of others;
- note the rights and freedoms of others involved i.e. the parents;
- briefly discuss the role of the decision makers in determining the best interests of the child;
- discuss relevant case law;
- mention ascertaining “quality of life”;
- note the experts in the field;

¹ Critical care decisions in fetal and neonatal medicine : ethical issues, the Nuffield Council of Bioethics, Chapter 9 p. 154

- note a few of the nonprofit organisations dedicated to educating and campaigning for neonates;
- refer to the World Health Organisation’s guidelines; and
- conclude the human rights obligations that the Cayman Islands Government should acknowledge when making policy.

What are the rights, laws and obligations concerned?

Cayman Islands Constitution Order 2009

Bill of Rights Freedoms and Responsibilities

Section 2(2)

Right to life: No person shall be intentionally deprived of his or her life.

Section 3

Torture and inhuman treatment: No person shall be subjected to torture or inhuman or degrading treatment or punishment.

Section 17 (1)

Protection of children: In addition to the provisions of this Part which afford protection to children, the legislature shall enact laws to provide every child and young person under the age of eighteen with such facilities as would aid their growth and development, and to ensure every child has the right- (c) to basic nutrition, shelter basic health care services and social services.

Section 16—(1)

Non-discrimination: Subject to subsections (3), (4), (5) and (6), government shall not treat any person in a discriminatory manner in respect of the rights under this Part of the Constitution.

(2) In this section, “discriminatory” means affording different and unjustifiable treatment to different persons on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, age, mental or physical disability, property, birth or other status.

Children Law 2012

Section 3 - Welfare of the child*

(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 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, educational and emotional needs;
- (c) the likely effect on him of any change in his circumstances;
- (d) his age, sex, religious persuasion, background and any characteristic 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; and
- (g) the range of powers available to the court under this Law in the proceedings in question.

(4) The circumstances are that-

- (a) the court is considering whether to make, vary or discharge a section 10 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 an order under Part IV.

(5) Where a court is considering whether or not to make one or more orders under this Law 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.

*This legislation would only be applicable if the word “upbringing” refers to all things encompassing the child, i.e. nature vs nurture

International Convention Obligations

Convention on the Rights of the Child

Article 3

1. 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.

2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her, and, to this end, shall take all appropriate legislative and administrative measures.

3. States Parties shall ensure that the institutions, services and facilities responsible for the care or protection of children shall conform with the standards established by competent authorities, particularly in the areas of safety, health, in the number and suitability of their staff, as well as competent supervision.

Article 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.

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:
 - (a) To diminish infant and child mortality;
 - (b) To ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care;
 - (c) To combat disease and malnutrition, including within the framework of primary health care, through, inter alia, the application of readily available technology and through the provision of adequate nutritious foods and clean drinking-water, taking into consideration the dangers and risks of environmental pollution;
 - (d) To ensure appropriate pre-natal and post-natal health care for mothers;
 - (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents;
 - (f) To develop preventive health care, guidance for parents and family planning education and services.
3. States Parties shall take all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children.
4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries.

European Convention on Human Rights

Article 2

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 no 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.

Article 3

Prohibition of torture

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

Article 8

Right to respect for private and family life

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
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.

Article 14

Prohibition of discrimination

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.

Are infants born prematurely afforded these rights?

It would seem that in discussion the question comes down to whether or not a child born severely premature is considered a “person”. Obstetric and neonatal practice in the UK and US rests on the premise that when a fetus becomes viable they acquire the status of a person.² Viability is within the discretion of the attending physician.

There is no single law that defines the age of a child across the UK. The UN Convention on the Rights of the Child, ratified by the UK government in 1991, states that a child “means every human being below the age of eighteen years unless, under the law applicable to the child, majority is attained earlier”. The Cayman Islands’ Children Law 2012 defines a child as “a person under the age of 18”.

An important question that those involved in critical care decision making need to address concerns the value they place on the life of a fetus, or a newborn baby. There are several different views. For example, some believe that a newly formed embryo should have full moral status while others

² McCullough LB, Chervenak FA. Ethics in obstetrics and gynecology. Oxford: Oxford University Press, 1994:224–8.

consider that this is not acquired until a baby has a capacity for self-consciousness, which does not appear to develop until some months after birth. The Nuffield Council of Bioethics regards the moment of birth, which is straightforward to identify, as a significant threshold in potential viability and the significant moral and legal point of transition for judgments about preserving life. The law in England as elsewhere, and also indicated by the UN Convention recognises premature babies as persons, which is in line with the UN Convention on the Rights of the Child. The United Nations Convention on the Rights of the Child (1989), which is extended to the Cayman Islands, cannot be directly applied in UK courts, but ratification means that Governments undertake to honour the Convention and to report regularly to the United Nations on their progress in implementing children's rights. Therefore the definition may assist the courts.

The Cayman Islands are a self-proclaimed Christian nation adhering to “prolife” values. As such, abortion is illegal and it is safe to presume that the domestic court would consider a premature baby a person under the description of a child. Therefore the assumption will be put forward that premature babies are persons enjoying the full protection of the law and any other rights and obligations that exist, especially their right to life which should not be discriminated against with regards to nationality, age, mental or physical disability, birth or other status.

Rights and freedoms of other persons

A common caveat in human rights clauses is that deviations are permissible or taken into consideration once an individual's rights begin to impinge or react negatively with the “rights and freedoms of others”. The courts have to create a balancing act when determining which right is more important.

When dealing with neonates the rights of the parents come into question, essentially under the Right to Family and Private Life. In general, parents are considered to have the moral authority to make decisions in their child's best interests in all the circumstances of life. However, parents cannot make decisions on behalf of their children as if they owned them or were merely extensions of their own person³. The axiom regarding children is that all decisions must be in the best interests of the child. Therefore any “rights” the parents might have over the child are put aside when considering the best interest of the child.

Best Interests of the Child

When determining the best interests of the child parental wishes are taken into consideration, however medical opinion is of paramount importance. Healthcare professionals caring for the newborn child also have a responsibility to promote his or her best interests. Doctors are able to

³ Archard D (2004) *Children, Rights and Childhood*, 2nd Edition (London: Routledge), pp 141–4.

offer a prognosis based on their knowledge and experience. Nurses also have special knowledge and expertise, and are the professional group that spends the most time with parents and their baby. They are therefore well placed to provide additional insights into the best interests of both the child and his or her family.⁴

There are instances where medical opinion and parental wishes conflict. This is when the court will be called upon to make a decision. Case law shows that the courts find it difficult to go against healthcare provider's expert opinion. Below follows the development of case law regarding premature and or disabled babies, in addition to persuasive dicta.

Cases

'Baby Alexandra' [Re B 1981]⁵.

She was born a Down's Syndrome baby with an intestinal blockage. The Court of Appeal sanctioned surgery, which was thought to give her a life expectancy of 20 to 30 years (the normal life span of someone with Down's). The test applied was whether it could be said that Alexandra's life was demonstrably going to be so awful that she should be condemned to die, or whether it was so imponderable that she should be allowed to live⁶. The decision in Re B was only taken by a court because parents, the most obvious proxy choosers, preferred their daughter to die. This was a preference they later came to regret and they successfully requested the return of Alexandra to their custody when she was ten months old⁷. This illustrates both the difficulties of proxy choice and perhaps also the dangers of leaving such decisions with parents. Important dicta comes from Templeman L.J. who noted that "There may be cases...of severe proven damage where the future is so certain and where the life of the child is so bound to be full of pain and suffering that the court might be driven to a different conclusion."⁸

Re J [1990]⁹.

J was a baby born prematurely at 27 weeks gestation. At birth he weighed 1.1 kg; he was not breathing, was placed on a ventilator and given antibiotics by a drip to avoid infection. When taken off the ventilator at three months he suffered repetitive fits and cessations of breathing requiring resuscitation by ventilation. The prognosis was severe brain damage arising from prematurity. The most optimistic neonatologist thought that there would be serious spastic quadriplegia. It was likely that J would never be able to sit up or hold his head upright, he would probably be blind and deaf, and would be most unlikely to develop even the most limited intellectual abilities. On the other hand, there was evidence that he would be able to feel pain to the same extent as a normal baby. Life

⁴ Critical care decisions in fetal and neonatal medicine : ethical issues, the Nuffield Council of Bioethics, Chapter 2 p. 17

⁵ [1981] 1 WLR 1421

⁶ *Ibid.*, p. 1425

⁷ This was reported in The Observer, 5 December 1982. Retrieved from Michael Freeman, The Moral Status of Children, Essay on the Rights of the Child; Chapter 9

⁸ *Ibid.*, p. 1424

⁹ Re J [1990] 3 All E 930

expectancy at its highest was late teens, and probably would be considerably shorter. To the question what should be done if J suffered a further collapse, the first instance judge directed there should be no further ventilation, but the Court of Appeal ruled that, “it would not be in J’s best interest to re-ventilate him in the event of his stopping breathing unless to do so seems appropriate to the doctors caring for him given the prevailing clinical situation.”¹⁰

The Court made four significant points. First, whilst there is a strong presumption in favour of a course of action that will prolong life, the decision-maker must look at it from the perspective of the patient, which is to undertake a “substituted judgment.” Secondly, it was necessary to look at the quality of life, including pain, suffering and distress. Thirdly the court saw the decision-making as a co-operative effort between doctors and parents (or where the child, as commonly, had been warded, between the doctors and the court with the views of the parents being taken into consideration.) The decision was to be taken in the best interests of the child. And, fourthly, it was stressed, as it so often is in end of life decisions about children, that the debate was not about terminating life but about withholding treatment designed to prevent death from natural causes. Thus, Taylor L.J. stressed:

The court never sanctions steps to terminate life....There is no question of approving, even in a case of the most horrendous disability, a course aimed at terminating life or accelerating death. The court is concerned only with the circumstances in which steps should not be taken to pro-long life.¹¹

Essentially what Taylor L.J. said is that the court can never approve euthanasia or actions which will be the cause of death. The court only determines whether or not doctors should intervene with possibly natural causes of death.

Re J [1992]¹²

The facts of this case are irrelevant to neonatal policy however the dicta of Balcombe L.J. is important as it address the jurisdiction of the court verses the medical discretion of a doctor. The child was a 16 year old refusing treatment for anorexia nervosa. Balcombe L.J could conceive of “no situation where it would be a proper exercise of the jurisdiction of the court to order a doctor, whether directly or indirectly to treat a child in a manner contrary to his or her clinical judgment.”

Re C [1998]¹³

The parents were Orthodox Jews who believed that life should always be preserved. The 16 month old child had incurable spinal muscular atrophy but was conscious, able to recognize her parents and to smile. Parents and doctors disagreed as to what should happen if the child suffered a further respiratory relapse: the doctors did not want to re-ventilate her but the parents could not agree to

¹⁰ Ibid., 933

¹¹ Ibid., 943

¹² Re J [1992] 2 FLR 165.

¹³ Re C [1998] 1 FLR 384

this. To follow the parent's wishes would be tantamount to requiring the doctors to undertake a course of treatment which they are unwilling to do. The medical evidence was clear that muscular atrophy was a "no-chance situation¹⁴." The court gave leave to the hospital to withdraw treatment and not attempt resuscitation in the event of respiratory arrest. This was in C's best interests.

[A National Health Service Trust v D \[2000\]](#)¹⁵

This is the first reported case in which the European Convention on Human Rights was raised. The Applicant NHS trust sought a declaration from the Court that if D, a young child who suffered from chronic and irreversible lung disease along with heart, renal and liver problems, was to suffer a further episode of cardiac or respiratory failure, it should have permission to withhold artificial ventilation so as to prolong his life and simply provide palliative care to allow him to die peacefully and with dignity.

A strong body of medical opinion supported the view that such treatment would be in the child's best interests as artificial ventilation was a painful and intrusive process which would bring no lasting benefit. The application was opposed by his parents who regarded it as premature.

The interests of the patient were paramount in deciding whether medical treatment should be given or withheld. It was possible to apply this principle even in cases concerning the suitability of treatment in the future should a given set of circumstances arise. There was nothing in this approach that was incompatible with the rights of the individual as protected by the European Convention on Human Rights. In a case involving a young child, the Court's assessment of what was in his or her best interests would override that of the parents.

Quality of life

How is Quality of life to be measured? Should it be looked at objectively or focus on the experiences of the individual or should an attempt be made to combine the objective and subjective? Academic opinion of Robertson is quite thought provoking when ascertaining quality simply based on the probability of a disability, whether mild or severe, he argued:

One who has never known of the pleasures of mental operation, ambulation and social interaction surely does not suffer from the loss as much as one that has. While one who has known these capacities may prefer death to a life without them, we have no assurance that the handicapped person, with no point of comparison, would agree. Life and Life alone, whatever its limitation, might be of sufficient worth to him or her.¹⁶

¹⁴ See Royal College of Paediatrics and Child Health. (1998). Withholding or withdrawing lifesaving treatment in children: A framework for practice. London: Royal College of Paediatrics and Child Health.

¹⁵ NHS Trust v D (2000) Fam Div (Cazalet J) 12/7/2000

¹⁶ Robertson, J. A. (1974). Involuntary euthanasia of defective newborns: A legal analysis. *Standord Law Review*, 27(2), 213-269

In the case of *Re J*, Taylor L.J. attempted to combine the objective and subjective quantification of quality:

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.¹⁷

Nuffield Council of Bio Ethics recommendations

The [Nuffield Council on Bioethics](#) is an independent body that examines and reports on ethical issues in biology and medicine in the United Kingdom. It was established by the Trustees of the Nuffield Foundation in 1991, and since 1994 it has been funded jointly by the Foundation, the Wellcome Trust and the Medical Research Council.

The Council has achieved an international reputation for advising policy makers and stimulating debate in bioethics. They have a report titled ‘Critical care decisions in fetal and neonatal medicine: ethical issues’ which was published in 2006. With such an organized volume of research and information this report could prove to be extremely useful.

An extract from chapter nine “Conclusions and Recommendations” of the previously mentioned report is as follows:

‘Decisions to initiate life support are especially problematic where a baby is delivered before 24 weeks of gestation because there is a high probability that the baby will die or develop some level of disability, and great uncertainty about whether treatment is in the best interests of a baby should he or she survive. We consider that babies should not be subjected to intensive interventions that are not likely to have any benefit and which may cause suffering. We have given careful consideration to whether resuscitation and intensive care should be withheld from babies born below a stipulated number of weeks of gestation or a particular birth weight. Guidelines operating in the Netherlands recommend that babies of less than 25 weeks of gestation should not be resuscitated (see Box 8.1). We do not regard this as an appropriate matter for legislation in the UK. We consider any complete ban upon resuscitation and continuation of intensive care to be an unjustifiable infringement of the interests of both the child and the parents, and professional responsibilities. For similar reasons we reject any absolute limit below which resuscitation is not permitted, in view of the considerable variability in outcome for babies born at the same very early age of gestation, and the possibility of variation in estimates of gestational age by up to five days. However, we do believe that clearer guidance would be helpful to both parents and professionals. More clarity would assist parents in reaching a better understanding of the

¹⁷ *Re J* [1991] 1 FLR 366. 383-384

uncertainties about their baby's ability to survive, and subsequent state of health. It would also benefit less experienced doctors in labour wards and neonatal units when circumstances dictate that decisions on resuscitation have to be made in the absence of a senior doctor (see paragraph 8.26). It is our view that explicit guidelines will encourage more openness, greater consistency in practice and firmer expectations for parents.¹⁸

Guidelines on giving intensive care to extremely premature babies

■ **At 25 weeks and above**

Intensive care should be initiated and the baby admitted to a neonatal intensive care unit, unless he or she is known to be affected by some severe abnormality incompatible with any significant period of survival.

■ **Between 24 weeks, 0 days and 24 weeks, 6 days**

Normal practice should be that a baby will be offered full invasive intensive care and support from birth and admitted to a neonatal intensive care unit, unless the parents and the clinicians are agreed that in the light of the baby's condition it is not in his or her best interests to start intensive care.

■ **Between 23 weeks, 0 days and 23 weeks, 6 days**

It is very difficult to predict the future outcome for an individual baby. Precedence should be given to the wishes of the parents. However, where the condition of the baby indicates that he or she will not survive for long, clinicians should not be obliged to proceed with treatment wholly contrary to their clinical judgement, if they judge that treatment would be futile.

■ **Between 22 weeks, 0 days and 22 weeks, 6 days**

Standard practice should be not to resuscitate the baby. Resuscitation should only be attempted and intensive care offered if parents request resuscitation, and reiterate this request, after thorough discussion with an experienced paediatrician about the risks and long-term outcomes, and if the clinicians agree that it is in the baby's best interests.

■ **Before 22 weeks**

Any intervention at this stage is experimental. Attempts to resuscitate should only take place within a clinical research study that has been assessed and approved by a research ethics committee and with informed parental consent.

Royal College of Paediatrics and Child Health

Withholding or Withdrawing Life Sustaining Treatment in Children a Framework for Practice Second Edition May 2004¹⁹ - Foreword to the First Edition:

This important document provides a framework on which to construct a reasoned and compassionate approach towards withholding or withdrawing treatment from our patient. It represents the product of some two years' research and scholarship, framed within the existing law and upholding the rights of the child. It offers a perspective on this, our most difficult area of pediatric practice. I welcome it and commend it to you, in the best interest of the child.

- Professor David Baum, President, RCPCH, September 1997

¹⁸Critical care decisions in fetal and neonatal medicine : ethical issues, the Nuffield Council of Bioethics, Chapter 9 p. 154

¹⁹http://www.bapm.org/publications/documents/guidelines/Withholding&withdrawing_treatment.pdf

Charitable Organisations

Bliss

Bliss is the UK charity working to provide the best possible care and support for all premature and sick babies and their families.

We believe that:

- Babies should have the same rights as anyone else
- The voices of babies and families must be heard
- Driving quality and innovation in the NHS that will deliver improved care for premature and sick babies and their families
- We achieve more by working together with individuals and organisations
- We must always be able to demonstrate the difference we make to the lives of babies and their families

Bliss is active across England, Scotland, Wales and Northern Ireland, delivering a range of nationally available services.

March of Dimes

With its original goal of eliminating polio accomplished, the March of Dimes dedicated its resources to a new mission. In 1958, they launched its "Expanded Program" against birth defects, arthritis, and virus diseases, seeking to become a "flexible force" in the field of public health. In the mid-1960s, the organization focused its efforts on the prevention of birth defects and infant mortality, which became its mission thereafter. At this time, the cause of birth defects was unknown; only the effects were visible. In 1976, the organization changed its name to the March of Dimes Birth Defects Foundation. In 2005, reducing the toll of premature birth was added as a mission objective.

Awareness about preterm birth, which is associated with a variety of negative health outcomes, is an organizational goal. According to an editorial in the May 2004 issue of the *Journal of the National Medical Association*, the original goals of the campaign were to raise awareness of the problem from 35 percent to at least 60 percent and to decrease the rate of premature births by at least 15 percent (from 11.9 percent to 10.1 percent). In 2008, the Prematurity Campaign was extended by the Board of Trustees until 2020, and global targets were set for prematurity prevention. In 2008, the March of Dimes started its annual Premature Birth Report Card, which grades the nation and each individual state on preterm birth rates. In 2009 they released a white paper on preterm birth "The Global and Regional Toll" which was assisted by data from the World Health Organisation's Department of Reproductive Health and Research.

The March of Dimes also has an online Prematurity Prevention Resource Center (PPRC), which is cited as the most comprehensive source of information on prematurity and prematurity prevention. The site is targeted to professionals and includes the most current information on interventions, research, advocacy, professional education, global initiatives, teaching tools and resources to use with patients. It's also home for Healthy Babies are Worth the Wait® Program, the Prematurity Prevention Network and the 39+ Week toolkit and slide decks. It might be beneficial for policy writers to review the resources available via the link below:

<https://www.prematurityprevention.org/portal/server.pt>

World Health Organisation

The World Health Organisation in partnership with many other premature birth aids and advocates published the 'Born Too Soon Global Action report on preterm birth' in 2012. The following is an excerpt from the report's forwards by Mr. Ban Ki-moon the incumbent United Nations Secretary-General.

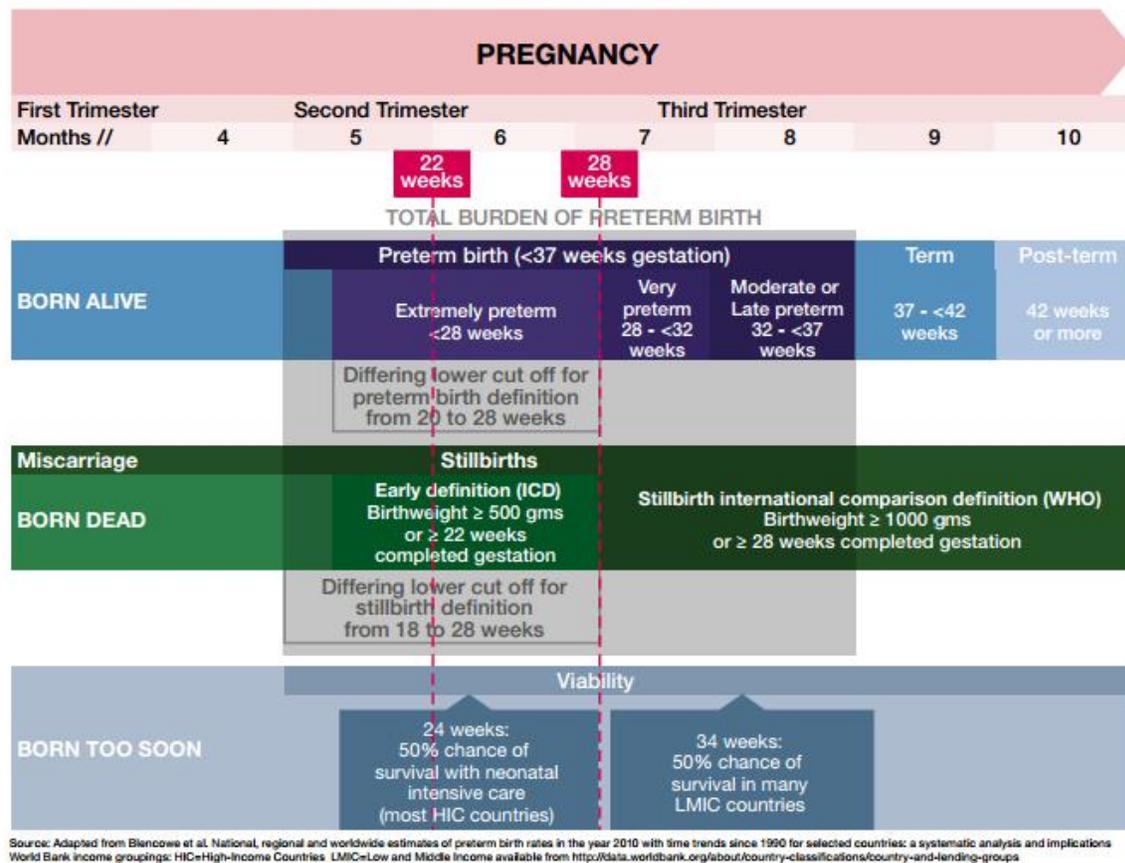
'Every year, about 15 million babies are born prematurely — more than one in 10 of all babies born around the world. All newborns are vulnerable, but preterm babies are acutely so. Many require special care simply to remain alive. Newborn deaths — those in the first month of life — account for 40 per cent of all deaths among children under five years of age. Prematurity is the world's single biggest cause of newborn death, and the second leading cause of all child deaths, after pneumonia. Many of the preterm babies who survive face a lifetime of disability.

These facts should be a call to action. Fortunately, solutions exist. Born Too Soon, produced by a global team of leading international organizations, academic institutions and United Nations agencies, highlights scientifically proven solutions to save preterm lives, provide care for preterm babies and reduce the high rates of death and disability.

Ensuring the survival of preterm babies and their mothers requires sustained and significant financial and practical support. The Commission on Information and Accountability for Women's and Children's Health, established as part of the *Every Woman Every Child* effort, has given us new tools with which to ensure that resources and results can be tracked. I hope this mechanism will instill confidence and lead even more donors and other partners to join in advancing this cause and accelerating this crucial aspect of our work to achieve the Millennium Development Goals by the agreed deadline of 2015.'

This should prove as another invaluable tool to assist policy makers. As a note attached is the WHO's viability chart.

Figure 2.2: Overview of definitions for preterm birth and related pregnancy outcomes



Bermuda

The Cayman Islands are a unique Caribbean island in that we have a higher standard of living in comparison to the majority of the countries within the region. Therefore it would be difficult to compare our situation to that of Haiti or Jamaica. It might be prudent to look at Bermuda as it is similar to our economic disposition.

Below is the extract from a news article in Bermuda.

‘Each year between 50 and 100 babies are born at King Edward VII Memorial Hospital prematurely. A hospital spokesperson said the prematurity rate is about eight percent. In the US it averages 20 percent. The low King Edward VII Memorial Hospital figure is positive and indicates that women in Bermuda receive a high standard of prenatal care.

While the Special Care Baby Unit offers intensive treatment and observation for babies Dr Outerbridge pointed out that it is not equipped to care for those younger than 34 weeks. Forty weeks is considered full term.

“If delivering less than 34 weeks, we try to transfer the mother to a centre overseas,” said Dr Outerbridge. “We feel that the outcome for the baby is better.”²⁰

While it does not discuss in depth details it is important to note that babies born less than 34 weeks gestation have to be sent elsewhere for medical care. It should be useful to approach health care practitioners in Bermuda for information on their policies, practices and procedures surrounding neonates.

Human Rights Considerations and Conclusions for the Cayman Islands

Premature babies qualify as persons with human rights therefore their right to life should be protected and not discriminated against. The Cayman Islands when drafting policy also need to consider the rights of these infants as stated in the Convention on the Rights of the Child. Case law shows that the question of quality of life and best interests of the child instead of economic liability has provoked more legal discussion. The main theme is that courts find it difficult to go against the expert medical opinion when deciding what is in the best interests of the child. Case law also shows that when reviewing their best interests, their right to a quality life, free from torture and inhumane treatment must be considered. However where the attending physician is of the opinion that there is a good chance they should act positively to preserve life. Where the chances appear slim they should be aware of the four criteria from Re J [1990] and proceed accordingly.

The Commission would be happy to review the policy once drafted. It is thought that it would be useful for the Ministry to review the resources used to assist this report and if hasn't already been done, consider approaching similar Caribbean islands for information. Once the policy is completed consideration should be given to educational and support resources for women at risk of delivering a premature child so they are fully aware of the hospital's resuscitation policies and procedures.

It should be noted that while this research is as comprehensive as possible the fact is that little comparison can be given to some of the information due to the jurisdictional issues which face the Cayman Islands. Unlike larger countries where the babies are transferred to another hospital which may only be a car ride away the Ministry has an added duty of considering cost implications which the research does not cover.

²⁰ <http://www.royalgazette.com/article/20120911/ISLAND05/709119995>

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The World Health Organization

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March of Dimes

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