Abortion and Babies with Anencephaly

What is anencephaly?

Anencephaly is the absence of a major portion of the brain and skull that occasionally occurs during the first month of fetal development in the womb.

It is a severe form of spina bifida where a failure of fusion of the neural rube in early pregnancy results in the baby developing without cerebral hemispheres, including the neocortex, which is responsible for cognition. The remaining brain tissue is often exposed - not covered by bone or skin.

Many pregnancies end in miscarriage and around half of babies with anencephaly do not survive birth. The rest almost all die in the first hours or days after birth although a very small number of cases have lived for a few years. There is no curative treatment available, only basic nursing care and symptom relief.

Isn't a baby with anencephaly, in effect, already dead?

Babies with anencephaly, although not conscious, and unable to feel pain, are not brain dead. Their brainstems are functioning at least in part which is why they can breathe without ventilators, often survive for several days and are not permitted to be used as organ donors.

How common is anencephaly?

Anencephaly is not uncommon, occurring in 1 out of 1,000 pregnancies, but only 1 out of 10,000 live births.1 208 babies with the condition were aborted in England and Wales in 2012.2

Anencephaly is usually diagnosed at the time of the 18 week anomaly scan so abortion is inevitably later than this, often after 20 weeks.

Surely abortion is the most compassionate and straightforward option for a pregnancy that is ‘medically futile’?

There are few things worse than losing a child and it is a major decision for a mother to carry a baby to term, knowing that her child will be born with a terrible deformity and die shortly afterwards. Abortion may appear to offer a more immediate and compassionate solution. However abortion is never a straightforward, easy answer and can compound an already traumatic situation. There are compassionate and positive alternatives (see later).

Many women do choose to have an abortion. Unfortunately, it tends to be the presumption of doctors that parents with disabled babies will choose to have them aborted. In some situations, this will be the case, but it should never be presumed.

The Bruce Inquiry in 2013 reported that after a discovery of fetal disability, the presumption of the medical profession was that parents would opt for abortion and this places a huge amount of subtle or direct coercive pressure on parents who have a much wanted pregnancy and are unsure of which path would be the more bearable choice.3

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3 Parliamentary Inquiry into Abortion on the Grounds of Disability. July 2013. p24: ‘When we were trying to make a decision in our own personal case we were told in no uncertain terms by a leading international obstetric team that our daughter would choke to death and suffer an unpleasant death and therefore we should consider a termination that evening.’ There is a growing literature of personal testimonies around this issue from women who were told they shouldn’t have babies because of perceived disability in themselves, or shouldn’t have babies because of some imperfection in the child. [http://www.amazon.co.uk/Defiant-Birth-Resist-Medical-Eugenics/dp/1876756594](http://www.amazon.co.uk/Defiant-Birth-Resist-Medical-Eugenics/dp/1876756594)
For women who do choose to have an abortion in England or Wales there must be counselling and support offered and available both before and after abortion. Counselling of women should be linked to high quality perinatal pathology services and clinical genetics with support for the mental health impact on the woman. These are particularly vulnerable women.

Isn’t forcing women to continue a ‘medically futile’ pregnancy to term cruel and lacking in compassion?

A diagnosis of anencephaly means that the parents' original wishes and dreams for their child's long life are already shattered. What she does next cannot change that. Women will usually suffer from bereavement like any other person who has lost a close relative.

However for many parents to compound this sense of bereavement by then intentionally ending their child's life is unthinkable. For them, choosing to continue the pregnancy is a parenting decision that honors the baby as well as the parents. It allows parents to give their baby - and themselves - the full measure of the baby's life and the gift of a peaceful, natural goodbye. Continuing the pregnancy is not about passively waiting for death. It is about actively embracing the brief, shining moment of this short life.

Aborting a baby should never be considered as being a compassionate response for either baby or mother. Research (see below) shows poor outcomes for many women post-abortion, and good outcomes for those using perinatal hospices.

A truly compassionate response is to offer genuine, positive alternatives to abortion, which is all too often presented as the only ‘choice’. In a British study, when parents were offered perinatal hospice as an alternative option, 40% percent chose to continue with their pregnancy. In a US study, when parents were given the option of perinatal hospice, the number rose to 75%.

Many women are not able to make an informed choice. They are not given information on palliative care, practical support nor enough time to consider their decision.

This is a far worse disability than, say, Down’s syndrome, so why should it not be treated differently?

Babies with anencephaly are just profoundly disabled people with special needs who should be treated the same as disabled people at any other age. Many other people suffer brain damage later in life, from tumours, stroke, trauma or dementia, that leaves them with similarly devastating brain damage. We should apply the same high standards of care for babies with anencephaly.

Babies with severe conditions like anencephaly are still human beings, worthy, like all human beings, of empathy, respect and protection. We all have a community responsibility to care for the weak and vulnerable babies in the womb, as well as their parents.

Some people who are pro-life support the right to abort terminally ill fetuses, such as anencephalic babies.

It is true that some Christians and pro-lifers support abortion in cases like this and this needs challenging as it implies that the dignity and worth of humans is contingent upon having a certain level of intellectual capacity and function, not on simply being human. It also involves the deliberate taking of the life of another person which is a rubicon we should not cross.

Isn't continuing a pregnancy in these circumstances harmful to the mother’s mental health?

5 Breeze et al, 2007
6 D’Almeida et al, 2006
Abortion may appear to offer an immediate and compassionate solution but the mother (and often father) will still be left to deal with the emotional trauma and unresolved grief of loss of what is almost always a wanted baby. Abortion in such situations is often highly traumatic. Moreover, abortion, particularly in the third trimester, is likely to engender deep feelings of guilt.

There is little research to support the popular assumption that terminating a pregnancy for fetal disability is easier on the mother psychologically.

The Bruce Inquiry heard that: ‘...the studies have all found that around 20% of women, between one and two years after an abortion for fetal anomaly, have a psychiatric condition, usually a complicated grief reaction, a depressive disorder or post-traumatic stress disorder.’

Other research suggests that women who terminate for fetal anomalies experience grief as intense as that of parents experiencing a spontaneous death of a baby (Zeanah 1993) and that aborting a baby with birth defects can be a ‘traumatic event ... which entails the risk of severe and complicated grieving.’ (Kersting 2004). Davies et al (2005) found that psychological morbidity following termination of pregnancy for fetal anomaly is prevalent and persistent. One long-term study found that ‘a substantial number...showed pathological scores for post-traumatic stress.’ (Korenromp et al, 2005). A recent follow up study found that 14 months after termination, nearly 17% of women were diagnosed with a psychiatric disorder such as post-traumatic stress, anxiety or depression (Kersting 2009).

Termination is not a shortcut through grief.

In contrast, parental responses to perinatal hospice are ‘overwhelmingly positive’.

What if the diagnosis is wrong?

In a small number of lethal abnormalities – including anencephaly - the outcome can be predicted with a high degree of certainty.

However prenatal diagnosis is not perfect and the Bruce Inquiry heard from one witness that of 32 post-mortems of late-term abortions he knew of two where the diagnosis had been ‘profoundly wrong’. Not all babies with anencephaly die immediately after birth, and a very small number have lived for a few years.

Isn’t abortion the most compassionate response for the baby?

It cannot be argued that abortion is out of compassion for the baby as with no cerebral hemispheres they are unconscious and do not have pain sensation. It is often more about protecting the parents and medical staff from having to deal with the perceived distress of continuing the pregnancy and having to look at a baby with significant deformities. However, if sensitively handled, allowing the parents to hold the baby after birth (with a skull cap on if necessary) facilitates saying good bye and healthier grieving and bereavement.

What right do we have to judge the actions of others, especially parents? It is their right to choose.

No man or woman is an island. We all value the opportunity of living in a free society but also recognise that personal autonomy has its limits. Rights need protection but they are not absolute. They must be balanced against responsibilities. We are not free to do things which undermine the reasonable freedoms of others. Those who claim to be for the protection of ‘choice’ are happy for choice to be restricted for others on other controversial issues eg. for smoking or for talking on mobiles while driving.

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7 Parliamentary Inquiry into Abortion on the Grounds of Disability. July 2013.p31
8 Parliamentary Inquiry into Abortion on the Grounds of Disability. July 2013. p31
10 Calhoun & Hoeldtke 2000
In human community abortion is not simply a matter between a woman and her doctor. There are others to consider: the father, any other citizens who may be affected by the decision (especially if there is a change in law) and, not least, the preborn baby herself.12

### What can be done for a baby that is carried to term, but who will then just die?

Babies with anencephaly are dying babies for whom no curative treatment is possible. The appropriate management in treating patients in this condition, as with any other person, is palliative care – food, water, warmth, human company and symptom relief.

With such care, the baby can be treated with dignity, loved and protected until death comes naturally. While the life expectancy of these babies is brief, they do have a life and are significant family members who will be valued, remembered and treasured.

Parents who have chosen perinatal hospice have said that this kind of care helped their hopes be fulfilled. Perinatal hospice is a way of caring for families whose babies' lives are expected to be brief. It can easily be incorporated into ordinary pregnancy and birth care just about anywhere. Support begins at the time of diagnosis, not just after the baby is born.

### Can we amend the law, or regulations, in Northern Ireland, to only cover these particularly severe cases?

About 40 abortions are performed in Northern Ireland each year although 905 women from the province had abortions in England Wales in 2012.13

Legislating for abortion for specific cases of disability is almost impossible:

First, there is little clinical and public consensus on the definition of 'serious'. Evaluating whether a life is worth living is beyond the expertise of the medical profession, and is hugely subjective, but is usually left with the medical profession to somehow interpret and advise.

Second, creating a list of conditions that meets certain criteria is subjective, fraught with difficulty and unworkable.14

Third, suggesting criteria for termination would create discrimination against a precisely defined group of people. The majority of the 299 oral and verbal submissions to the Bruce Inquiry 2013 viewed the operation of the Abortion Act 1967, which permits abortion for 'serious' fetal disability to birth, as discriminatory.

Fourth, in most cases, clinically, there are high levels of uncertainty about the outcomes for fetuses with disability. At birth, some babies' conditions are less or more severe than predicted. Sometimes the diagnosis is ambiguous all along. Occasionally a diagnosis can be wrong.15

Fifth, permitting abortion for a few cases would inevitably lead to incremental extension. Under the British Abortion Act 1967 babies have been aborted for cleft palate and club feet. Recent statistics showed that between 2002 and 2010 there were 17,983 abortions of disabled babies in Britain. The overwhelming majority of these were for conditions compatible with life outside the womb.

### What can we do?

**Show compassion**

In a society that values physical beauty, athletic prowess and intellectual capacity highly it is easy to see why babies with anencephaly are undervalued. They fall foul of our deep societal prejudice toward people who are ‘ugly to look at’, ‘unintelligent’ and ‘physically inept’. The only effective way of overcoming such
prejudices is to cultivate attitudes of compassion and care for people with severe disabilities in both families and communities. Being willing to shoulder this commitment for those most vulnerable helps to make us a more caring society.

If we are not in the forefront of providing support for parents struggling with the implications of a severely disabled baby, and defending the rights of the disabled and stigmatised within our community, our supposed commitment to the sanctity of human life is deeply suspect.

Draw attention to the fact that the BBC has interviewed a deeply traumatised grieving woman in front of a national audience just days before the most horrendous experience of her life – aborting her own baby.

**Use language sensitively and draw attention to when it is discriminatory**

These are babies living with anencephaly. They are not ‘anencephalics’, ‘dead babies’ or ‘non-persons’. These are dehumanising terms. Just as we would not accept the terms ‘spastic’, ‘moron’, ‘imbecile’ or ‘vegetable’ to describe human beings, neither should we accept these.

**Beware of media manipulation**

Why this case is coming to light and getting so much publicity? It is not the first time a baby with anencephaly has been born in NI. Media interest always focuses on ‘hard cases’ – the most difficult and unusual individual ethical dilemmas. These are presented in a polarised and often unhelpful way, but can really shape public debate and discussions about policy, leading to bad or unnecessary laws and professional guidelines.

**Warn against the use of ‘hard cases’**

Hard cases should not be the main factor that shapes the discussion and development of good medical practice especially when used by media presenters with a wider political agenda of liberalising abortion laws.

**Cite personal stories and experiences of women who have not chosen abortion**

The media coverage of this issue has prompted a number of women to share their own experiences of carrying a baby with anencephaly, or other life limiting condition, to term. More women are adding their own personal stories on a daily basis to a blog on this topic, as the issue generates increased media coverage.

‘Our first daughter had significant congenital abnormalities incompatible with life and we were offered termination as an option for her. We said that this was not something we would consider. To the credit of the doctors and midwives caring for us, it was never mentioned again and instead we were offered weekly viability scans to see if she was still alive. (She did die in utero.) We were treated with such compassion. We were never made to feel that we were wasting their time. Having faced that, I loved your paragraph about “Pregnancy is the most intimate form of hospitality.” It was a great comfort to us that, for however short her life was going to be, she was safe and warm in my womb where I could care for her…’

‘I am a mother who carried my third child full term, despite a fatal diagnosis with congenital heart disease. I can fully empathise with all the agonies this poor mother in Northern Ireland is going through. However, I do not regret not having an abortion, and I hope that if my husband and I were ever in the same situation again, we would make the same decisions. We gave our baby the best life we could and have so many happy memories of his three days with us.’

Thank you so much for this article. I am currently 37+ weeks pregnant with an anencephalic baby in the US where 98% of these babies are aborted. As I approach my due date your article gave me the peace and closure I have been seeking since I found out about his condition in June and decided to carry him. We had a friend in May who was left nearly brain dead from a fall this past spring. It was inevitable that he would die - ultimately he did after bring removed from life support. When the doctors initially discovered the damage was the option given to actually kill him due to his prognosis!? Of course not that would be murder! Why then in the case of babies should it be OK?

Thank you for writing this, I recently carried my baby girl, Sophia (diagnosed with anencephaly at 20 weeks) to term and we not only made it our aim to celebrate her life weekly as she grew in my womb, but to

16 [http://pjsaunders.blogspot.co.uk/2013/10/defending-indefensible-twenty-reasons.html](http://pjsaunders.blogspot.co.uk/2013/10/defending-indefensible-twenty-reasons.html)
celebrate with her when she was born. God gave us 10 precious hours with her alive after she was born. Though our hearts hurt now we have no regrets of the choices we made to carry our little girl! We have chronicled our story with her on my blog. I pray more and more women know they have another option, and the option to give life is so incredibly rewarding!

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