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Continuing the Pregnancy When the Unborn Child has a Life-Limiting Condition

When an unborn child is diagnosed with a life-limiting or life-threatening condition, many people now believe that the best solution is to immediately terminate the pregnancy. This article explores the option of continuing the pregnancy with the support of perinatal palliative care. Many parents have found this alternative fits better with their values, and better honours both their unborn child and their situation as the loving parents of this child. The article also explores the information and support which parents need in order to make a truly informed choice between termination and continuing the pregnancy.

Through prenatal screening and diagnosis, an unborn child may be diagnosed nowadays with a life-limiting or life-threatening condition as early as the first or second trimester of pregnancy. Such conditions include anencephaly, Trisomy 13 (Patau syndrome), Trisomy 18 (Edwards syndrome), and a host of others. This article argues that parents in this situation are often not given the support and information that they need to make a truly informed decision about what to do, and indeed that sometimes they are almost coerced into immediate termination of these pregnancies. It continues by detailing the information and support which parents should be offered at this time.

The remainder of this article explores perinatal palliative care as an alternative to termination. It looks at the pioneering insights of Byron Calhoun and his colleagues, a resource book for parents titled *A Gift of Time*, and the significant contributions of Amy Kuebelbeck. It also illustrates the burgeoning development of perinatal palliative care around the world by more briefly reviewing quite a number of peer -reviewed articles and guidelines about this form of care. The article concludes by calling for the ongoing development of perinatal palliative care services throughout Australia.

Challenging Current Practice

What does happen nowadays when a woman is pregnant and her child is diagnosed before birth with a life-limiting or life-threatening condition? A true story gives us insight into what is unfortunately so often the current practice. It also reveals the harm that this current practice can cause:

At a Melbourne hospital in 2001, Natalie Withers and her husband were told after a 19-week ultrasound that their little girl had a rare congenital heart condition which also affected her stomach, liver and spleen. While the doctors "didn't know how badly affected she would be," they "immediately suggested terminating [the] pregnancy." Natalie reports that she and her husband "felt pressured into that course of action." She insists that "no one explored any alternatives with us."

The couple were also given very little information about what such a termination involves. Indeed, these practical matters were "only discussed with [them] on the day labour was to be induced." Natalie continues:

> After labour began, only then were we informed that the 20-week old baby may be stillborn or take her last gasps after being born. We weren't prepared for that…. We did not know that we would be facing a fully formed small baby….She was brought to us in a basket with a blanket over her. We weren't encouraged to hold her, one quick glimpse and she was whisked away.

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When Natalie and her husband left the hospital, they hoped that they would soon put this experience behind them. However, as Natalie reports:

> This was not to be. Grief, coupled with guilt, began to take over. We were totally ill-prepared for the profound effect this experience was going to have upon our hearts, minds and souls…. We both suffered as individuals and the foundations of our relationship were also affected.

Thankfully, they stayed together. However, it took both of them "many years" to work through their distress, and indeed they only felt ready to try for another child six or seven years later. Even after all this time, Natalie insists, "[T]here is not a day that goes by that we are able to forget what this termination has done and we are full of regret about making a decision based on misinformation and lack of understanding."[1]

How do tragic cases like this come about? This is the next topic which we must consider:

The core issue is this: when an unborn child is diagnosed before birth with a life-limiting or life-threatening condition, many obstetric health professionals now believe that the best course of action is to terminate the pregnancy.[2] Indeed, this is often their automatic and unquestioned belief. Many within the general public hold this belief too, though it does seem that this belief is more widely and more passionately held among obstetric health professionals than within the general public. When you think about it, it is a strange belief. If we were told that our elderly mother only had about six months to live, most of us would not suggest that she should instead be killed immediately. And yet, this is what the early termination of an unborn child really involves.

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Health professionals claim that they give their patients non-directive counsel. In these situations, however, advice is often extremely directive. Sometimes, as in the case reported above, termination is presented as the only possible option.[3] In these circumstances, a health professional may also press the parent(s)[4] to agree almost immediately to the termination, even though the parents really cannot think clearly because they have just been told devastating news about their unborn child. Other times, the option of continuing the pregnancy is mentioned, but it is presented as an inferior option which would only appeal to people who are themselves deficient in some way. For example, terminating the pregnancy might be presented as decisive action to end a nightmare, whereas continuing the pregnancy could be presented as the only option for those who are incapable of decisive action. Or again, I was once told of a health professional who said in a clearly sneering tone that continuing the pregnancy would probably only appeal to "religious people."

… in almost all cases, the physical risks to the mother of continuing these pregnancies are no greater than the normal risks of pregnancy. ...

Health professionals may also speak rather coyly of "inducing the pregnancy" without giving clear details of what this would involve and without explaining that this is really an abortion.[5] They also fail to advise that "abortion for foetal disability is particularly traumatic and can be psychologically damaging for women."[6] We will shortly examine peer-reviewed evidence about this, but the experience of Natalie Withers and her husband is already sad testimony to this fact.

Some health professionals also overstate either the risks to the mother or the possibility that the unborn child might suffer if the pregnancy continues. Parents should certainly seek unbiased professional advice about their particular situation. However, in almost all cases, the physical risks to the mother of continuing these pregnancies are no greater than the normal risks of pregnancy. Indeed, after about 21 weeks, the physical risks of abortion are actually greater than the risks of continuing the pregnancy.[7] With most conditions, it is also unlikely that the unborn child will suffer before birth. The mother's body is very often able to compensate for any functions that the baby's body cannot perform. (Women who know this often feel very proud that they are therefore able to keep their baby inside them protected and safe.[8]) After birth – or in some situations, even before birth – wise treatment decisions and careful palliative care can also effectively protect the child against pain and suffering.[9]

There are a number of reasons that the option of terminating the pregnancy might appeal to obstetric health professionals. Firstly, parents whose unborn child has a life-limiting or life-threatening condition are very distressed. To care for these parents and these pregnancies requires a lot of time and emotional energy. Especially if health professionals are already very busy and particularly if they are unready or unwilling to take on the emotional demands of these parents and this pregnancy, they may well prefer to avoid this emotional challenge by terminating the pregnancy. Secondly, these sorts of pregnancies may

also challenge the knowledge and skills of obstetric health professionals. Especially if they have never managed a pregnancy like this before and particularly if they have limited experience in perinatal palliative care, health professionals may well prefer to avoid this professional challenge by terminating the pregnancy. Finally, health professionals are both trained and expected to 'do something' so as to almost instantly make everything right. Far more than the slow and faithful commitment of palliative care, surgical termination of pregnancy might appeal to those health professionals who feel compelled to provide instant solutions.[10]

Health professionals tell themselves that terminating these pregnancies is the best choice for the parents. This may be something which they were taught in their training and which they have not yet critically evaluated. From a limited perspective, too, it may seem successful, for something which was causing a couple distress is removed. (From a wider perspective, this so-called solution does not honour the life of the unborn child. It also does not honour the situation of the parents, who still love their child and who wish to do the best by that child. Also, it may cause serious psychological problems especially for the mothers who terminate.) Our societal debate about abortion also impacts this perspective, for those who support abortion and the woman's right to choose find it difficult to acknowledge that abortion harms many women. At the very least, health professionals need to think much more critically about their professional practice in these situations.

There are a number of reasons why the termination of these pregnancies might not be the best choice for these parents. The first is the harm that this sort of abortion does particularly to women. In 2005, Selena Ewing from Women's Forum Australia reviewed all 168 articles about abortion in peer-reviewed journals over the previous fifteen years. Her report contains a large section on 'Harm resulting from abortion for disability or disease in the foetus.' It cites ten studies to conclude that "for women who abort because of disability or disease in the foetus, the procedure and the years afterward can be extremely traumatic, characterised by grief and guilt." One study found that among women who had terminated because of foetal anomaly, "67% screened positive for post-traumatic stress at 6 weeks, 50% at 6 months and 41% at 12 months. Emotional distress was experienced by 53% at 6 weeks, 46% at 6 months, and 43% at 12 months, and grief by 47% at 6 weeks, 31% at 6 month and 27% at 12 months. Depression was diagnosed in 30% at 6 weeks, 39% at 6 months and 32% at 12 months." Another study found that "termination of pregnancy due to foetal malformation is an emotionally traumatic major life event which leads to severe post-traumatic stress response and intense grief reactions which are still evident 2-7 years after the procedure." Yet another study found that "among 196 women aborting for foetal abnormality, grief and post-traumatic symptoms did not decrease between 2 and 7 years after the event… pathological post-traumatic scores were found in 17.3% of participants."[11] Note that all of these studies are entirely consistent with the experience of Natalie Withers and her husband.

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A second serious concern is that in many cases parents are not being allowed to make their own, truly informed decisions. They can be pressured to decide when they have just been told devastating news and are not yet able to think clearly. They are sometimes not told all the alternatives. They are usually not fully informed about the risks and benefits of these alternatives. Nor are they given the ongoing support that they need to make a truly informed decision. If all these helps are provided, some couples will probably still decide on termination. (As we will see, the percentage of couples who will do so may be considerably less than we might at first think.) Even these couples are harmed if they are not helped to make this important decision in a truly informed way. Other couples might be coerced into termination even though they would not have made this choice if they had been fully informed and properly supported. They are greatly harmed by this. As Byron Calhoun and his colleagues have observed, this "problem of inadequate consent" is serious and "alone warrants serious consideration of other alternatives."[12] We simply must improve on what is so often the current practice.

A Better Way

What do people need so they can make informed choices in these circumstances? It seems to me that they need at least four things:

The first of these is **time**. Thus, an experienced counsellor named Monica Rafie says that her first suggestion to parents in this situation is that they "slow down and take a deep breath."[13] Parents need time to at least begin to get over the initial shock of learning that their unborn child has a life-limiting or life-threatening condition. They need time to begin to understand their child's condition. (Often, couples spend many hours in research, accessing the internet and other resources.) They need time to consider thoroughly the alternatives of termination and continuing the pregnancy, and the risks and benefits of each alternative. They need time to seek counsel from family and friends, and from trusted mentors and advisors. If they have even a

slight affiliation with a religion or belief, they may also seek counsel from a minister of that religion. They need time to consider their own values. Until now, what have they thought or felt about abortion? Given that our values are at a deep place within us, what are they thinking and feeling now in the depths of their being? Two years or five years from now – when the crisis is over – what will they think and feel about the choices which they are now considering? Couples also need time to ensure that they are making a joint decision which sits well with both of them. This is particularly important because even in some marriages it takes time for women to speak and sometimes even more time before women's voices are heard. Given all these things and all these steps, it would not be surprising if parents needed at least a week if not longer before they were truly ready to decide.

The second thing that parents need is **ongoing support**. Parents who know that their unborn child will probably die before, during or shortly after birth experience deep pain and tremendous grief. As Byron Calhoun and his colleagues have noted, these painful emotions are accompanied by a profound fear of abandonment.[14] Thus, parents fear that no one will be with them in their grief, and that they will be left alone in devastating pain. Calhoun and his colleagues have also found that parents are not able to make a truly informed decision unless this fear of abandonment is addressed. They must experience ongoing support as they decide what to do. They must be assured that, if they choose to continue the pregnancy, there is a team of health professionals who will be readily available to them and who have both the professional knowledge and the human compassion to guide them and journey with them through this experience. They must be assured that they will be looked after, and that their unborn child should not experience pain and suffering as he or she lives through to his or her natural death. Ongoing support must cast out fear, and parents need this support even from the beginning as they ponder the alternatives of termination or continuing the pregnancy.

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Thirdly, there must be a **full description of the proposed termination**. This information might be confronting or even disturbing. Even so, how can the parents choose in a truly informed way unless they have complete information about this alternative? As they decide, the couple – and particularly the woman – must know what procedure she will undergo in termination.

In the first trimester, the most common method is suction (or vacuum) aspiration surgical abortion. In this, the placenta and the unborn child's head, limbs, body and organs are sucked out of the womb through a narrow tube. Another first trimester procedure is dilation and curettage (D&C) abortion, in which a loop -shaped surgical knife called a curette is used to scrape out the placenta and the baby. In the second trimester, the most common surgical technique is dilation and evacuation (D&E) abortion, in which various surgical instruments are used to remove the baby in pieces. In all these techniques, because of the damage to the child, parents will not be permitted to see the remains afterwards.[15]

In the third trimester or late in the second trimester, the most common surgical technique is intact dilation and extraction (D&X) or partial birth abortion. After the baby is partially delivered feet first, the doctor makes a cut at the base of the skull and inserts a tube to suction out the baby's brain. Another possibility in the second and third trimesters is premature induction of labour, in which drugs and other techniques are used to bring about an early delivery. Because the mother's body is not physiologically ready for labour, this process often takes more than a day. After 21 or 22 weeks, in some cases drugs might used to kill the child before birth.[16]

Finally, parents must also be informed of the peer-reviewed evidence that "abortion for foetal abnormality is particularly traumatic and can be psychologically damaging for women."[17] Once again, this information is needed before an informed decision can be made.

Finally, the alternative to termination must be **perinatal palliative care**. Instead of termination, some health professionals and centres only offer *routine care* – that is, care that is appropriate for a normal pregnancy. Others offer *routine care minus*. For example, they do not bother to provide regular scans and other tests in these pregnancies. However, *routine care* is not appropriate for these pregnancies, and *routine care minus* is even less appropriate. Instead, these pregnancies require *different care* – care which is specifically designed for these sorts of pregnancies. This is perinatal palliative care (or perinatal hospice, as it is sometimes called). This *different care* is shaped by two profound realities. First, these pregnancies involve a great deal of grief, and that grief must be managed appropriately. Above all, this involves a team of carers who are readily available to the parents and who possess both the professional knowledge and the human compassion to guide and accompany them through this grief. The second profound reality is that the opportunity to experience and care for this child

will exist only for a short time during the pregnancy and perhaps shortly after birth. Perinatal palliative care is therefore designed to affirm the existence of this child and to maximise the opportunities to experience and parent him or her. For example, there should be not less but more scans, so that the parents and all their family and friends can see and experience this child. There is the hope that the child might be born alive and perhaps for a very short time that the parents might be able to see their child breathe, to hold and to love their baby, to take photographs and collect other keepsakes such as a lock of their child's hair or the child's footprints and handprints in plaster of Paris moulds, and even to bathe or breastfeed him or her.

Termination is a bitter experience with few positive features. On the other hand, continuing the pregnancy is a bittersweet experience: bitter because of the grief, sweet because of the many opportunities to experience and parent this child. If perinatal palliative care is offered, experience has taught that a significant number of parents will choose this, and ultimately that very few will regret their choice. This is why perinatal palliative care must be offered as the alternative to terminating the pregnancy.

Traditional Morality

Some people reject traditional morality nowadays – especially when it suits them to do so. This, for example, is why the laws of many jurisdictions now permit abortion – either with some restrictions or in some jurisdictions with hardly any restrictions at all. However, many people still accept that there are real standards of right and wrong, and that we are called by our very humanity to strive to do what is right and to avoid what is wrong. Parents who accept that there are real standards of right and wrong will therefore surely want to engage with traditional morality as they seek to discern what they should do after their unborn child is diagnosed with a life-limiting or life-threatening condition.

… These children are not a legitimate exception to the general prohibition against taking human life. It is morally wrong to kill them. ...

Traditional morality – along with the universal human moral sense which we all possess – tells us that it is wrong to kill other human beings. This ethical prohibition admits of few exceptions. In these few exceptions, two conditions must simultaneously be present. First, someone must pose a serious and imminent threat either to innocent human life or to values such as liberty which are virtually as important as life. Second, the only way in which we can eliminate this threat is by killing this person. In practice, there are only four sorts of situation in which these two conditions simultaneously apply. If we are attacked and our life is at risk, we may legitimately use lethal force if this is the only way to save either our own life or the life of another. Killing enemy combatants is also permitted in war. Bringing about a death is accepted in some obstetric cases such as an ectopic pregnancy in which our only choices are either to allow two to die or to save the life of the mother. Capital punishment might also be acceptable if a criminal threatens human lives and cannot be constrained in other ways such as imprisonment. (Nowadays, however, such circumstances are "very rare, if not practically non-existent."[18]) By contrast, however, an unborn child with one of these conditions poses nothing more than the normal risks of pregnancy. This does not constitute a serious and imminent threat to human life. These children are therefore not a legitimate exception to the general prohibition against taking human life. It is morally wrong to kill them.

Does this violation of the ethical prohibition against killing contribute to the more profound psychological sequealae which many women experience after these sorts of terminations? Several authors have speculated that it may. For example, Byron Calhoun and his colleagues quote another clinician named Irving Leon who reported "the usually profound guilt that follows [termination], exceeding, at least in my clinical experience, that resulting from spontaneous perinatal loss." They then shrewdly speculate that these extreme grief reactions and this profound guilt "may well be explained" by an "intuition" arising from the human moral sense, or indeed "the dread that follows active participation in the early termination of the infant's future, however brief and bittersweet that future might have been."[19] In my opinion, these observations merit thoughtful consideration.

I conclude this section with quotes from two women who continued their pregnancy after the diagnosis of a lethal foetal condition. Both recognise that doing so was the morally right thing to do. Jane G put it this way: "I have a tremendous amount of peace that I did the right thing and that Lucy was able to live the days ordained for her." Similarly, Katherine said, "I am very certain that we did the right thing by letting Lily live her life in the way we did." Sensing that she was making good progress through her grief, Katherine continued, "I know that I wouldn't be where I am emotionally if I had terminated her life early."[20]

Byron Calhoun and Colleagues

Byron Calhoun and his colleagues are important pioneers of perinatal palliative care. Calhoun is an American obstetrician-gynaecologist with a sub-speciality in maternal-foetal medicine. He and his colleagues developed the concept of perinatal

palliative care (which they call perinatal hospice) between 1995 and 2002 at Madigan Army Medical Center in Tacoma, Washington.[21] He is currently Professor and Vice-Chair of the Department of Obstetrics and Gynecology at West Virginia University, Charleston.[22]

Let us consider Calhoun's comprehensive description of perinatal palliative care. This care requires a multi-disciplinary team. Along with the mother, her unborn child and her family, the central team contains "the physician or team of physicians providing primary care, a social worker, and a nurse with training in bereavement issues." Other members, including "neonatologists, anaesthesiologists, psychiatrists, psychologists, chaplains, local priests/pastors, bereavement counsellors, labour nurses, sonographers, and neonatal nurses," are added as required. The central team must meet regularly, and "care is provided at the timing and intensity of family desires."[23]

Antepartum and intrapartum care focuses above all on allaying fears and reducing feelings of isolation and abandonment. Contact with other families who are undergoing unproblematic pregnancies can cause distress and grief, so some families prefer to be seen at times when other patients are not present. There is communication back and forth about the "anticipatory grief" that the family experience throughout the pregnancy, and advice about ways of relating with other children in the family, extended family and friends, and strangers whose uninformed questions may cause distress. Because memories of the child are important in the grieving process, there are frequent ultrasounds, and other family members and friends – especially siblings and grandparents – are invited to attend and see the baby. Parents are invited to learn the gender of their child and to give him or her a name. There is much emphasis on the development of a birth plan which gives the parents some sense of control over this difficult time, which establishes clear plans, which prevents unnecessary medical interventions, and which helps the parents to develop realistic hopes of what they might experience if their baby is born alive.[24] "Caesarean delivery may be offered in the event the parents want to see and hold their living child. If parents are adequately counselled regarding the increased maternal risk for caesarean delivery, we will provide this service." At delivery, the diagnosis is confirmed, and the baby is kept with the parents to maximise their time together. The appearance of these children is usually not as abnormal as some parents fear, but staff may facilitate bonding by pointing out non-anomalous features such as cute hands or feet or soft skin. Being able to care for their baby even in the smallest ways is of tremendous significance for the parents. Some babies whose conditions are not immediately fatal may be able to go home with their families.[25]

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… Because memories of the child are important in the grieving process, there are frequent ultrasounds, and other family members and friends—especially siblings and grandparents - are invited to attend and see the baby. ...

Care continues after the death of the baby. The team may help with arrangements for a funeral or memorial service, and usually attend this service. The family's postpartum visits to the team allow continued communication about the grieving process, discussion about future pregnancies, and where appropriate the provision of genetic counselling. The family are usually contacted "seventy-two hours after delivery, monthly thereafter for one year and on the first anniversary of the death of their child."[26]

Calhoun and his colleagues have produced two case-series reports on the effectiveness of perinatal palliative care. The first considered all those cases which occurred at Madigan Army Medical Center between 1995 and 2002, as well as a smaller number of cases at Travis Air Force Center in Sacramento, California between 1996 and 1999. In all, there were 33 cases in which a lethal foetal condition was diagnosed before birth. Twenty-eight families (85%) chose perinatal palliative care rather than termination. Eventually, there were 11 intrauterine deaths (39%), and 17 live births (61%). Of the 17 live births, there were 12 normal or vaginal deliveries, and 5 caesarean deliveries either for obstetric reasons or on maternal request. Four of the caesareans and 4 of the normal deliveries were preterm. The 17 live-born infants lived for somewhere between 20 minutes and 2 months. There were no maternal infections, operative complications, blood product transfusions or post-partum admissions.[27]

The second of these reports considered all those cases which occurred in a pilot perinatal palliative care programme at Rockford Memorial Hospital in Illinois from 1 January 2000 to 1 July 2004. In all, there were 28 cases in which a lethal foetal condition was diagnosed before birth. Twenty-one families (75%) chose perinatal palliative care rather than termination. Eventually, there were 5 intrauterine deaths (21%), and 16 live births (76%). Of the 16 live births, there were

14 normal or vaginal deliveries, 1 caesarean delivery for obstetric reasons, and 1 caesarean delivery on maternal request. Four or five of the normal deliveries were preterm, but neither of the caesareans. The 16 live -born infants lived for somewhere between 20 minutes and 256 days (more than 8 months). There were no maternal infections, operative complications, blood transfusions or post-partum admissions.[28]

Because so many of these pregnancies are terminated in our society, the high take-up of perinatal palliative care (85% in the first report and 75% in the second) might at first appear counter-intuitive. When we think about it, however, it is really not surprising. The deepest instinct of parents is not to kill but rather to protect and nurture their baby. When they are offered this alternative, it is really not a surprise that so many choose it.

A Gift of Time

Calhoun and his colleagues present perinatal palliative care in broad outline. This broad outline is exquisitely filled in by *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief*, by Amy Kuebelbeck and Deborah L. Davis. Davis is a developmental psychologist with particular expertise in perinatal bereavement. Kuebelbeck is a journalist who did continue the pregnancy after her unborn son Gabriel was diagnosed with a life-threatening condition and who is now part of a grassroots movement to promote perinatal palliative care. Their book is a wise and compassionate guide for parents whose unborn child has been diagnosed with a life-limiting or life-threatening condition. It is also an indispensable resource for health professionals and chaplains who work in this field.

… I cried many times as I read this book - sometimes in sorrow, sometimes in joy. … It is a moving testimony to the love that parents have for their children even in very difficult circumstances. …

In this book Davis and Kuebelbeck draw on their own vast experience in companioning parents through these sorts of pregnancies. They have also spoken in various ways to more than 120 mothers and fathers in the United States, Canada, Europe and Australia who have continued a pregnancy after their unborn child was diagnosed with a life-limiting or life-threatening condition, and their comments are liberally reproduced throughout this book. The wisdom, compassion and experience of Kuebelbeck and Davis have much to teach us. However, it is the comments of these parents which most powerfully convey the human experiences in these pregnancies. These comments – their honest sharing, their pain, their courage, and their joy – are deeply moving. I cried many times as I read this book – sometimes in sorrow, sometimes in joy. If the experience of continuing these pregnancies is a bittersweet experience, the experience of reading this book is also in its own way bittersweet. It is also a moving testimony to the love that parents have for their children even in very difficult circumstances.

With a total of just over 400 pages, this is a big book. After a short Introduction, it has 10 chapters which vary in length from 17 to 53 pages. As well as a sample birth plan and 8 pages of end-notes, there is a useful Index at the back of the book. The brief summary which follows is in no way a substitute for reading this book. However, it will give you some idea of the book's contents:

… If parents feel pressured to terminate, they should "start by talking with [their] caregivers, who may be open to helping [them] continue. If they remain resolutely closed to [this] idea," parents should "ask to be referred to someone else who will support [them]." …

Chapter 1 of this book is about the initial experiences of parents when they are first told that their unborn child has a life-limiting or life-threatening condition. The stories of the parents remind us just how devastating this diagnosis is. Kuebelbeck and Davis offer advice about weathering this sudden emotional storm. There is also information about prenatal diagnostic tests. While some parents decline these tests, the authors note that such tests "can offer critical information for making decisions on behalf of [the] baby."[29]

Chapter 2 is about making decisions about what to do. There is honest information about the option of termination, and about perinatal palliative care. If parents feel pressured to terminate, they should "start by talking with [their] caregivers, who may be open to helping [them] continue. If they remain resolutely closed to [this] idea," parents should "ask to be referred to someone else who will support [them]."[30] There is also advice about researching the child's condition, researching possible risks to the mother, consulting with people one trusts, sorting out one's own values, and making decisions with one's partner.

Chapter 3 is about the emotional journey which at once involves understanding and managing grief, confronting fears, and reclaiming hope. There are sections on anticipatory grief, the various emotions that grief evokes, the fears that parents may experience, and useful coping techniques. There are helpful sections on communicating with one's partner (especially if he or she has a different coping style from one's own), and

on explaining what is happening to other, older children in the family. Parents begin to hope not for an improbable miracle, but that their child might be born alive, or that they might have a short time to hold their child and to say 'I love you,' or that their child will not feel pain as he or she dies.

Chapter 4 is about relationships with other people during this pregnancy. There are sections about telling other people about this pregnancy, and what to do if their opinions about continuing this pregnancy are not helpful. There are sections about finding support, and about finding appropriate prenatal care. Kuebelbeck and Davis counsel, "If you are dissatisfied with the attitude or care you're receiving, do not hesitate to search for practitioners who are willing to assist you."[31] There is also a helpful section on finding ways to feel close to one's baby. Many parents decide to name their baby before birth.

Chapter 5 is about making medical decisions for the baby. The most difficult decisions involve treatments after birth which may possibly sustain the baby's life but which may also be either futile or excessively burdensome. Kuebelbeck and Davis note that "many religions that passionately defend the sanctity of life also teach that one is not obligated to undertake disproportionate medical means in order to sustain life." When parents refuse these disproportionate treatments, "[they] are not saying 'yes' to death; [they] are saying 'yes' to [their] baby's natural life."[32]

Chapter 6 is about preparing a birth plan. There are many decisions about vaginal or caesarean birth, pain relief for the mother, foetal heart monitoring during labour, who cuts the umbilical cord, spiritual rituals such as baptism, planning for keepsakes such as photographs, a lock of their child's hair or the child's footprints and handprints in plaster of Paris moulds, and - sadly - planning for a funeral or memorial service, burial or cremation.

Chapter 7 is about giving birth. Parents are sometimes ambivalent about birth, because the baby is safe in his or her mother's womb, and the day of his or her birth may also be the day of his or her death. Sometimes, delivery is of a child who has died in utero. However, many children are born alive, and this chapter reports the many, deeply significant experiences that parents have had with their newly born child.

Sadly, **Chapter 8** is about saying goodbye. So that parents won't be surprised or overwhelmed, there is an explanation of the dying process. Many experiences are reported, including spiritual experiences which gave some parents a sense that their child's spirit endured beyond death. There are also helpful sections about spending time with one's baby after death, and about funerals or memorial services, burial or cremation.

… Annette H. said, "I really have peace that we carried her to term. I know in my heart that I have given my daughter all that I could and loved her every day of her life." …

Chapter 9 is about continuing the journey after one's baby dies. There is a section on the mother's postpartum recovery. There is a large section about grief, and other sections about relating at this time with one's partner, one's other children, and the outside world. There is a helpful section about the ambivalence that parents might feel about subsequent pregnancies.[33]

Chapter 10 is about the sorts of things that parents might consider in a few years as they look back at this experience. These parents are universally positive about their experience. Let me select three of their comments. Jennifer put it this way: "A perinatologist said things to us like 'the outcome will be the same'… I know that the outcome would *not* be the same. We would not have had all of the special time to share with Gianna during her life in my womb. We would not have been able to share some amazing, precious moments with our baby and our sons." Annette H. said, "I really have peace that we carried her to term. I know in my heart that I have given my daughter all that I could and loved her every day of her life." Finally, Tracey put it very simply: "It was worth it. He was worth it."[34]

Amy Kuebelbeck

Amy and Mark Kuebelbeck's son Gabriel was diagnosed with hypoplastic left heart syndrome about five and a half months into the pregnancy. After much research and heartache, they decided before his birth not to attempt therapy after birth which they judged to be far too burdensome. Amy's memoir *Waiting with Gabriel* tells the story of this pregnancy, Gabriel's birth, the two and a half hours they shared with him before his death, and Gabriel's ongoing significant presence in so many lives.

The Kuebelbecks were not assisted by a perinatal palliative care team, because at that time this service was not offered in the region where they lived. Instead, they found their own way, assisted by caring health professionals. Kuebelbeck therefore insists that where perinatal palliative care does not exist, a family – ideally assisted by at least one health professional – can be the trailblazers in developing this service. Many health professionals have done a great deal to promote and develop perinatal palliative care. However, Kuebelbeck also regards the development of perinatal palliative care as a grassroots movement in which parents are demanding the provision of services which are respectful both of their unborn child and of their own situation as the loving parents of that child.[35]

… a website – perinatalhospice.org – provides a great deal of useful information about perinatal palliative care. …

Kuebelbeck is associated with a website – perinatalhospice.org – which provides a great deal of useful information about perinatal palliative care. Its page Frequently Asked Questions is particularly helpful.[36] The website also lists over a hundred and twenty centres world-wide which offer perinatal palliative care.[37]

Other Resources and Guidelines

There is now a considerable amount of peer-reviewed literature about perinatal palliative care. This reflects the burgeoning development of perinatal palliative care around the world. In this section, I survey some of this literature:

In 1996, Lyn Chitty and her colleagues in the United Kingdom interviewed five couples who chose to continue pregnancy after their unborn child was diagnosed with a life-limiting condition. The article notes the "inappropriateness of routine obstetric care for these women" and offers a number of useful recommendations for the provision of perinatal palliative care.[38]

Lizabeth H. Summer and her colleagues in the United States provide two articles which overview perinatal palliative care. They challenge institutions "to review their current practices and to consider planning for the integration of this type of palliative care."[39]

Both Lisa Welborn in USA and Roger Collier in Canada also provide overviews of the practice of perinatal palliative care. Mark Kirby and his colleagues provide yet another useful overview which appeared as an Editorial in the *British Medical Journal*.[40]

Steven Leuthner and his colleagues in the United States have published four detailed accounts of perinatal palliative care.[41] In a previous section, we noted two case-series reports about the effectiveness of perinatal palliative care. In their report about the Wisconsin Fetal Concerns Program (FCP), Leuthner and Emilie Lamberg Jones provide another case series. From September 2000 (when the FCP began) until 2007, there were 185 cases in which the unborn child was diagnosed before birth with a lethal condition. While 117 families (63%) chose termination, 68 families (37%) chose to continue the pregnancy. No maternal morbidity was reported.[42]

Breeze and colleagues from Addenbrooke's Hospital at Cambridge in the United Kingdom provide another case series. From 2001 to 2005, they had 20 cases of lethal foetal abnormality diagnosed before birth. While 12 families (60%) opted for termination, 8 families (40%) chose to continue the pregnancy. There were 2 intrauterine deaths (25%), and 6 live births (75%). The live-born infants lived for somewhere between 1½ hours and 3 weeks. No maternal morbidity is reported. The parents who chose perinatal care "gave positive feedback about their decision and the care provided."[43]

In total, then, we have four case-series reports on perinatal palliative care. The percentage of parents who chose to continue the pregnancy after a lethal foetal diagnosis ranged from 37% to 85%. Combined, the four articles report on 124 cases (out of a total of 266) in which the pregnancy was continued after a lethal foetal diagnosis. There was no maternal morbidity in any of these cases. Without exception, too, the parents who chose this option were highly positive about their experience. These results make an impressive case for perinatal palliative care.

… we have four case-series reports on perinatal palliative care. The percentage of parents who chose to continue the pregnancy after a lethal foetal diagnosis ranged from 37% to 85%. …

Albert Balaguer and his colleagues recently reviewed the literature on perinatal palliative care. While they found less material than they had anticipated, they drew upon this material to detail the gradual evolution of this model of care. They conclude that "it seems desirable for obstetric and neonatal units to have available an active and efficient Perinatal Palliative Care programme."[44]

In August 2010, a working group from the British Association of Perinatal Medicine has produced a 7-page Report and an 11-page Supplement titled *Palliative Care (Supportive and End of Life Care): A Framework for Clinical Practice in Perinatal Medicine*.[45] Balaguer and his colleagues rightly call these guidelines "an excellent synthesis" of perinatal palliative care. They are an indispensible guide for any health professional who works in this area.

… Albert Balaguer and his colleagues … conclude that "it seems desirable for obstetric and neonatal units to have available an active and efficient Perinatal Palliative Care programme." …

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) states that even before prenatal screening is undertaken, parents should be informed that "continuation of the pregnancy is a valid option should an abnormality be

diagnosed, and that couples would receive appropriate counselling and care in preparation for birth."[46] However, the College does not yet have a statement about proper management after the prenatal diagnosis of a lethal foetal abnormality. In my opinion, such a statement should now be prepared. It should warn women of the greater risk of psychological harm following termination in these circumstances.[47] It should also offer as an alternative to termination, not routine care appropriate for a normal pregnancy, but perinatal palliative care specifically designed for these sorts of pregnancies.

By contrast, guidelines from the (UK) Royal College of Obstetricians and Gynaecologists do include both recommendations about proper management following the prenatal diagnosis of a foetal abnormality, and information about perinatal palliative care.[48]

Parents who are told that their unborn child has a life-limiting or life-threatening condition are in a tragic situation. It would be even more tragic if they were either not offered the support and information that they need in order to make a truly informed decision about what to do, or if they were not offered perinatal palliative care. It is therefore extremely important that individual health professionals, their professional associations, hospitals and other health care institutions do all they can to promote the development of perinatal palliative care throughout Australia. It is vitally important that parents are informed about this option, and that this option is readily available to them.

ENDNOTES

[1] Natalie Withers, "A mother's grief" (9 September 2008), Australian Broadcasting Corporation, http://www.abc.net.au/unleashed/32304.html

[2] Lyn S. Chitty, Chris A. Barnes, and Caroline Berry, "Continuing with pregnancy after a diagnosis of lethal abnormality: experiences of five couples and recommendations for management," *British Medical Journal* 313, no. 8 (24 August 1996): 478-480 at 480.

[3] In their report on a series of five cases in which the parents decided to continue the pregnancy after the diagnosis of a lethal foetal abnormality, Chitty and her colleagues offer yet another example of this. One of their couples was "not aware that continuation of the pregnancy was a real option until they reported to the labour ward for 'induction' at 21 weeks…. 'It was like we were in a tunnel and there was only one way out. I just didn't think that I had any choice but to go with what was suggested. I don't understand why they didn't discuss all the options.'" See ibid., 478-479.

[4] A pregnant woman sometimes faces this situation without support from the unborn child's father. I will use the term 'parents' throughout this article to mean either a mother and a father together, or a mother by herself.

[5] The case from Chitty and her colleagues also provides an example of this. Until the couple reported for a 21-week "induction," "up to that point the word 'termination' had not been used…. Once the couple realised what induction meant they decided not to proceed and returned home." See ibid, 478-479. Further examples are found in Amy Kuebelbeck and Deborah L. Davis, *A Gift of Time: Continuing Your Pregnancy When Your Baby's Life is Expected to Be Brief* (Baltimore: John Hopkins University Press, 2011), 22. There, a mother named Missy reported that, while the health professionals "encouraged me to terminate my pregnancy," they "never used the word 'abortion.'" Another mother named Sue reported that it suddenly hit her what they were trying to say: "that 'termination of the pregnancy' meant aborting my baby." Yet another mother named Kathleen, a trained nurse, had to explain to her husband that their health professional was advocating a late-term abortion: "My husband was appalled because the doctor was making it sound like it was nothing. He was so misrepresenting the truth. I was very grateful that I had some medical background to know what he was talking about, because I think we may have been talked into that option, and that wasn't at all what we wanted."

[6] Selena Ewing, *Women & Abortion: An Evidence Based Review* (Women's Forum Australia, 2005), 2.

[7] Kuebelbeck and Davis, 35.

[8] Ibid., 70, 91, 93, 130-31, 345, 368.

[9] Ibid., 70.

[10] Byron D. Calhoun, "Perinatal Hospice: Compassionate and Comprehensive Care for Families with Lethal Prenatal Diagnosis," *Linacre Quarterly* 77, no. 2 (May 2010): 147-156 at 148; Kuebelbeck and Davis, 25.

[11] Ewing, 23-25, cf 10-11. For other reports on the psychological harm of termination after the diagnosis of a life-limiting condition, see Byron C. Calhoun, Nathan J. Hoeldtke, and James S. Reitman "Perinatal Hospice: A Response to Early Termination for Severe Congenital Anomalies," *Issues in Law and Medicine* 13, no. 2 (Fall 1997): 125-143 at 127; Calhoun, *Linacre Quarterly*, 148; Kuebelbeck and Davis, 37.

[12] James S. Reitman, Byron C. Calhoun, and Nathan J. Hoeldtke, "Perinatal Hospice: A response to early termination for severe congenital anomalies," in *Genetic Engineering: A Christian Response*, ed. Timothy J. Demy and Gary P. Stewart (Grand Rapids, MI: Kregel Books, 1999), 197-211 at 201.

[13] Peter Baklinski, "Be Not Afraid: Hope for Parents Whose Babies Will Likely Die," 1 February 2012, FebLifeSiteNews, http://www.lifesitenews.com/news/be-not-afraid-providing-hope-to-parents-whose-babies-will-likely-die-soon-a

[14] Nathan J. Hoeldtke and Byron C. Calhoun, "Perinatal Hospice," *American Journal of Obstetrics and Gynecology* 185, no. 3 (September 2001): 525-529 at 527.

[15] For more information about the various methods of termination, see Kuebelbeck and Davis, 33-35.

[16] For example, the (UK) Royal College of Obstetricians and Gynaecologists (RCOG) recommends, "In accordance with

prior RCOG guidance, feticide should be routinely offered from 21 weeks of gestation." For this, see RCOG, *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales* (May 2010), 31, RCOG, http://www.rcog.org.uk/files/rcog-corp/TerminationPregnancyReport18May2010.pdf

[17] Ewing, 2.

[18] *Catechism of the Catholic Church*, #2267.

[19] Calhoun et al, *Issues in Law and Medicine*, 129; Reitman et al, *Genetic Engineering*, 201.

[20] Kuebelbeck and Davis, 342.

[21] Their writing on this topic includes: Calhoun et al, *Issues in Law and Medicine*, 125-143; Byron C. Calhoun, Nathan J. Hoeldtke, R.M. Hinson, and K. M. Judge, "Perinatal hospice: should all centers have this service?" *Neonatal Network* 16, no. 6 (September 1997): 101-102; Reitman et al, *Genetic Engineering*, 197-211; Byron C. Calhoun and Nathan J. Hoeldtke, "The Perinatal Hospice: Ploughing the Field of Natal Sorrow," *Frontiers in Fetal Health* 2, no. 5 (May 2000): 16-22, Perinatal Hospice, http://perinatalhospice.org/uploads/Frontiers_in_Fetal_Health.pdf; Hoeldtke and Calhoun, *American Journal of Obstetrics and Genecology*, 525-529; Byron C. Calhoun and Nathan J. Hoeldtke, "The Perinatal Hospice: Hope for the Helpless," *Association for Interdisciplinary Research in Values and Social Change* 17, no. 2 (May/June 2002), LifeIssues.net, http://www.lifeissues.net/writers/air/air_vol17no2_2002.html; Byron C. Calhoun, Peter Napolitano, Melisa Terry, Carie Bussey, and Nathan J. Hoeldtke, "Perinatal hospice: Comprehensive care for the family of the fetus with a lethal condition," *Journal of Reproductive Medicine* 48, no. 5 (May 2003): 343-348; Michelle D'Almeida, Roderick F. Hume, Anthony Lathrop, Adaku Njoku, and Bryon C. Calhoun, "Perinatal hospice: Family-Centered Care of the Fetus with a Lethal Condition," *Journal of American Physicians and Surgeons* 11, no. 2 (Summer 2006): 52-55; and Calhoun, *Linacre Quarterly*, 147-156.

[22] For Calhoun's Curriculum Vitae, see http://wecareexperts.org/sites/default/files/affiliate_cv/calhoun.cv_.2-2012%20(1)_0.pdf

[23] Calhoun, *Linacre Quarterly*, 151; cf Hoeldtke and Calhoun, *American Journal of Obstetrics and Gynecology*, 527.

[24] For examples of birth plans, see D'Almeida et al, *Journal of American Physicians and Surgeons,* 54; Center for Maternal and Infant Health (CMIH), University of New Carolina Hospitals, *Special Birth Plan*, CMIH, http://mombaby.org/PDF/UNCPerinatalHospiceBirthPlan.pdf; Steven R. Leuthner, "Fetal Palliative Care," *Clinics in Perinatology* 31, no. 3 (September 2004): 649-65 at 661-63; Kuebelbeck and Davis, 375-376; Amy Kuebelbeck*, Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life* (Chicago: Loyola Press, 2003), 70-71.

[25] Ibid., 151-152; Reitman et al, *Genetic Engineering*, 205-206; cf Hoeldtke and Calhoun, 527-528.

[26] Ibid., 152-153; cf Hoeldtke and Calhoun, 528.

[27] Calhoun et al, *Journal of Reproductive Medicine*, 343-348. Calhoun and his colleagues note that US federal funds cannot be used for pregnancy termination except when the mother's life is at risk. Those patients who chose termination therefore had to pay for this procedure themselves. While this may partly explain the high percentage who chose perinatal palliative care, Calhoun and his associates suggest that the influence of a medical environment which supports the decision to continue such pregnancies is at least as important.

[28] D'Almeida et al, *Journal of American Physicians and Surgeons*, 52-55. The Results section of this paper wrongly says that there were 15 vaginal deliveries; Table 1 confirms that there were really only 14. Whereas financial considerations may have influenced the choice of perinatal palliative care at the US Defense Medical Centers, that is not a factor in this community-based medical centre. D'Almeida and her colleagues comment that the influence of a medical environment which supports the decision to continue such pregnancies only partly explains the high percentage who chose perinatal palliative care.

[29] Kuebelbeck and Davis, 5.

[30] Ibid., 25.

[31] Ibid., 123.

[32] Ibid., 151, 164.

[33] Parents at this stage will also benefit from reading Deborah L. Davis, *Empty Cradle, Broken Heart: Surviving the Death of Your Baby*, Revised and Expanded Edition (Golden, CO: Fulcrum, 1996).

[34] Keubelbeck and Davis, 344, 343, 340.

[35] *Waiting with Gabriel*, 55-57; Kuebelbeck and Davis, 26-29; Amy Kuebelbeck, "Perinatal Hospice: A Holistic Approach for When Death Comes at the Beginning of Life," Perinatal Hospice, http://perinatalhospice.org/uploads/Kuebelbeck-ADEC.pdf

[36] "Frequently asked questions about perinatal hospice and palliative care," Perinatal Hospice, http: www.perinatalhospice. org/FAQs.html

[37] "Perinatal hospice/palliative care programs and support," Perinatal Hospice, http://perinatalhospice.org/Perinatal_hospices.html

[38] Chitty et al, 478, 480.

[39] Lizabeth H. Summer, "Taking Palliative Care into Pregnancy and Perinatal Loss: A Model for Community Collaboration," *National Association of Perinatal Social Workers Forum* 23, no. 4 (Autumn 2003): 9-11; Lizabeth H. Summer, Karen Kavanaugh, and Teresa Moro, "Extending Palliative Care into Pregnancy and the Intermediate Newborn Period: State of the Practice of Perinatal Palliative Care," *Journal of Perinatal and Neonatal Nursing* 20, no. 1 (January - March 2006): 113-116. The quote is from page 115 of the 2006 article.

[40] Lisa Welborn, "Perinatal Palliative Care: A Pathway to Integrated Care," *National Association of Perinatal Social Workers Forum* 28, no. 2 (Spring 2008): 1, 4-7; Roger Collier, "Providing Hospice in the Womb," *Canadian Medical Association Journal* 183, no. 5 (22 March 2011): E267-E268; Mark D. Kilby, Samantha J. Pretlove, and Alison R. Bedford Russell, "Multidisciplinary palliative care in unborn and newborn babies," *British Medical Journal* 342, no. 7802 (16 April 2011): 1808-1809.

[41] Steven R. Leuthner, "Palliative Care of the Infant with Lethal Anomalies," *Pediatric Clinics of North America* 51, no. 3 (June 2004): 747-759; Steven R. Leuthner, *Clinics in Perinatology*, 649-65; Steven Leuthner and Emilie Lamberg Jones, "Fetal Concerns Program: A Model for Perinatal Palliative Care," *MCN: The American Journal of Maternal/Child Nursing* 32, no. 5 (September/October 2007): 272-278; David Munson and Steven R. Leuthner, "Palliative Care for the Family Carrying a Fetus with a Life-Limiting Diagnosis, *Pediatric Clinics of North America* 54, no. 3 (October 2007): 787-798.

[42] Leuthner and Jones, 277-278; cf Albert Balaguer et al, "The Model of Palliative Care in the Perinatal Setting: A Review of the Literature," *BMC Pediatrics,* http://www.biomedcentral.com/1471-2431/12/25 For those who continue the pregnancy, this programme offers the options of either continuing until natural birth or elective induction after

24 weeks. It claims that many women see a "moral distinction between a termination before viability, and an induction with plans to provide palliative care after that threshold [of viability] has been reached." It also claims that this option allows some women "to avoid the psychological burden of continuing a doomed pregnancy." In this case series, of the 68 who continued the pregnancy, 36 (20% of the total of 185 cases) continued to normal birth, while 32 (17%) chose early induction. I find this option of early induction on non-medical grounds disturbing. It seems to me that this option follows the logic which underpins the option of termination, rather than the logic which underpins the option of perinatal palliative care. I therefore do not support this option of early induction on non-medical grounds.

[43] A.C.G. Breeze et al, "Palliative care for prenatally diagnosed lethal fetal abnormality," *Archives of Diseases in Childhood – Fetal & NeoNatal Edition* 92, no. 1 (January 2007): F56-F58 at F58.

[44] Balaguer et al.

[45] *Palliative Care (Supportive and End of Life Care): A Framework for Clinical Practice in Perinatal Medicine*, British Association of Perinatal Medicine (BAPM), Report http://www.bapm.org/publications/documents/guidelines/Palliative_Care_Report_final_%20Aug10.pdf; Supplement http://www.bapm.org/publications/documents/guidelines/Palliative_care_final_version_%20Aug10.pdf

[46] RANZCOG, *Prenatal Screening for Fetal Abnormalities*, 2; and *Prenatal Screening Tests for Trisomy 21 (Down Syndrome), Trisomy 21 (Edwards Syndrome) and Neural Tube Defects*, 2; RANZCOG, http://www.ranzcog.edu.au/womens-health/statements-a-guidelines/college-statements.html?start=1

[47] RANZCOG has already noted that "the decision to terminate a pregnancy due to medical or genetic reasons seems to have more of a negative impact often eliciting grief and depression amongst women." For this, see RANZCOG, *Termination of Pregnancy: A Resource for Health Professionals*, 26, RANZCOG, http://www.ranzcog.edu.au/publications/womens-health-publications/termination-of-pregnancy-booklet.html

[48] *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales*, 20-26.

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