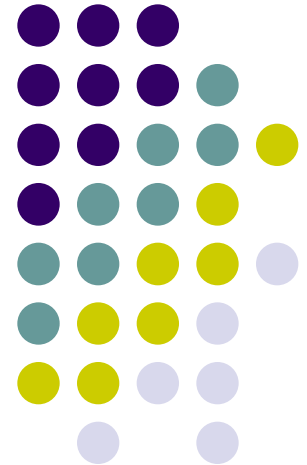


Perinatal Palliative Care: **Continuing the pregnancy when the** **unborn child has a life-limiting condition**

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St John of God Raphael Centres - Western Region,
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Overview

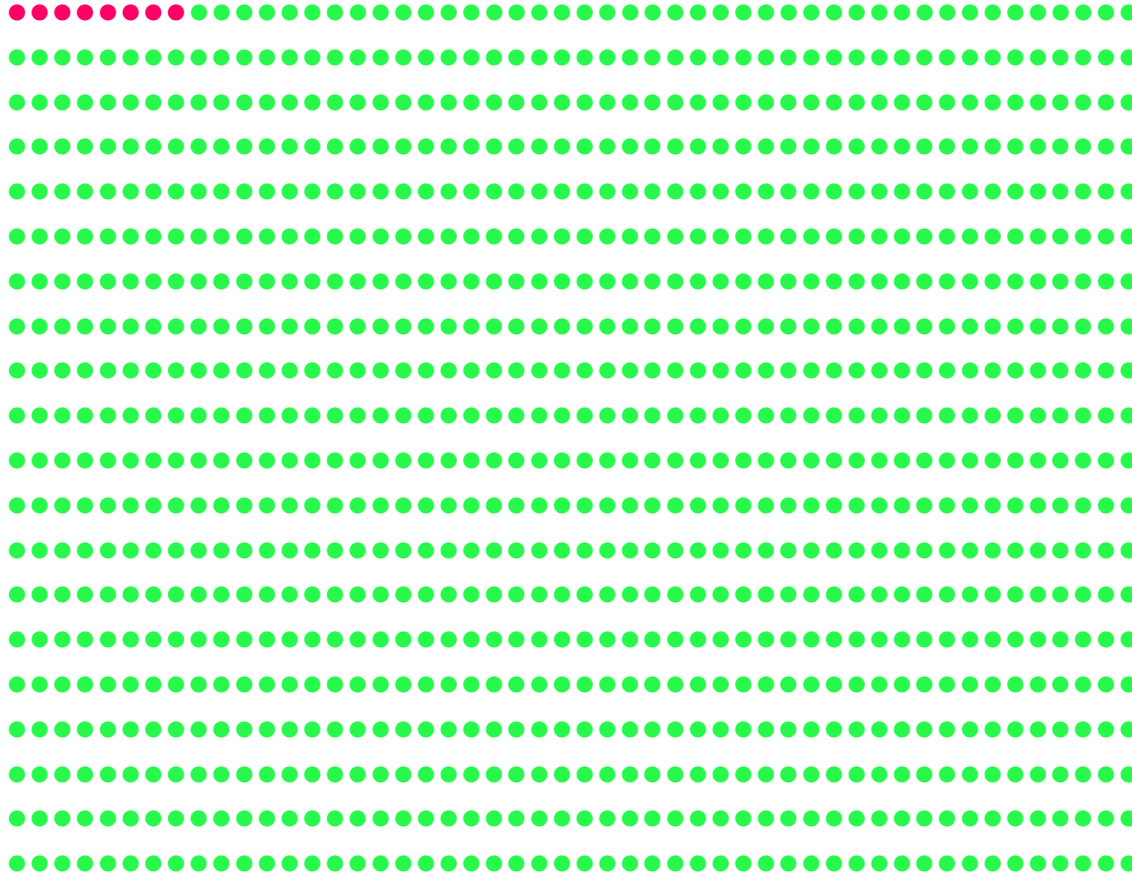
1. Prenatal diagnosis of life-limiting conditions
2. Views about termination or continuing the pregnancy
3. Problems with current practice
4. Informed decision-making
5. Perinatal Palliative Care (PPC)
6. What is happening
7. Continuing the pregnancy
8. *Video Health Providers Overview*

1. Prenatal diagnosis of life-limiting conditions



- Prenatal screening & prenatal diagnosis
 - ultrasound scans, nuchal translucency test, maternal serum screening, chorionic villus sampling (CVS), amniocentesis, non-invasive prenatal testing (NIPT) →
- congenital anomalies = 5% of pregnancies
- potentially lethal = 15% of these = 0.75% of pregnancies
- often, diagnosed near the end of the first trimester →
- terminate OR continue the pregnancy?

Pregnancies involving a life-limiting condition: Incidence



2. Views about termination or continuing the pregnancy



1) General Population

- Sexton Marketing (2004) in *Common Ground?* (2007)
- Support for Legal Abortion:
 - Choosing the child's sex 9%
 - A form of contraception 16%
 - Effect on career 27%
 - Healthy fetus, no abnormal risks to mother 33%
 - Mild disabilities 60%
 - Severe disabilities 85%

2. Views about termination or continuing the pregnancy



2) Termination is the only rational option

- Bob Williamson (2011): “There will always be some people who, often for fundamental religious reasons, oppose embryonic stem cell research. But they also oppose IVF, contraception and termination of pregnancies affected by serious disorders.”

3) Anxious and lost on the road less travelled

2. Views about termination or continuing the pregnancy



4) Traditional morality & Catholic teaching

- It is usually wrong to kill another human being.
- For the few exceptions to this general rule, two conditions must simultaneously be present:
 - i. Someone poses a serious and imminent threat to human life or to values virtually as important as life (eg liberty).
 - ii. The only way to eliminate the threat is to kill this person.
 - resisting lethal attack, enemy combatants in war, some obstetric cases (eg ectopic pregnancy), capital punishment in rare circumstances
- An unborn child with a life-limiting condition usually poses nothing more than the usual risks of pregnancy. They are not a serious and imminent threat to life. It is morally wrong to kill them.

2. Views about termination or continuing the pregnancy



5) Pro-Informed Choice

- **Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG):** even before screening, parents must 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.”
- **Genetic counsellors at Royal Children’s Hospital & Royal Women’s Hospital in Melbourne:** if parents decide to terminate very quickly, they ask them to take a week before making a final decision.

3. Problems with current practice



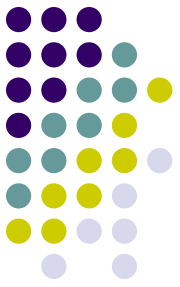
- Thiele (2010) & Wilkinson (2010):
 - Pauline Thiele and her husband decided to continue the pregnancy after their unborn son Liam was diagnosed with Trisomy 18 (almost always a life-limiting condition).
 - A/Prof Dominic Wilkinson: “They then encountered apathy, misunderstanding, miscommunication and apparent hostility from medical professionals.”
 - Perhaps the most egregious example occurred at 36 weeks. Because Liam was not moving, Pauline went to her hospital: “It was here that a registrar performed a basic scan and swinging the monitor for me to see said curtly, ‘See? No heart beat!’ Stunned by her callousness I had been unable to say anything...”
 - They also experienced great care from health professionals whom they describe as “wonderful.”
 - Perhaps the most profound example occurred after Liam’s delivery: The paediatrician “took Liam and wrapped him securely in a blanket,” “tenderly held Liam in his arms,” and said, “If a baby can know stress in utero then surely it can know love. Liam knew that he was loved!”

3. Problems with current practice



- Natalie Withers (2001):
 - After a 19-week scan, Natalie and her husband were told that their unborn daughter had a rare congenital heart condition which also affected her stomach, liver and spleen.
 - The health professionals “immediately suggested terminating [the] pregnancy.” “No one explored any alternatives” with them and they “felt pressured into that course of action.”
 - “We didn’t know that we would be facing a fully formed small baby.... We weren’t encouraged to hold her, one quick glimpse and she was whisked away.”
 - “Grief, coupled with guilt, began to take over.... We both suffered as individuals and the foundations of our relationship were also affected.”
 - It took them “many years” to work through their distress, and they were only ready to try for another child six or seven years later.
 - “There has not been 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.”

3. Problems with current practice



- Faith and Hope (2014):
 - A scan before 19 weeks revealed that the unborn child of Renee Young and Simon Howie had craniofacial duplication (diprosopus).
 - “Ms Young was originally told to terminate the pregnancy.”
 - Renee and Simon declined to terminate. It was against their values.
 - At 19 weeks, Renee said, “If I only get 2 days with the baby.... at least I have some time with her.”
 - Hope and Faith were born (at 32 weeks and 4 days) on 8 May 2014.
 - When asked what he thought when he looked at the girls, Simon said, “Beautiful...”
 - Faith and Hope lived for 19 days. They “touched so many people’s hearts.”
 - See *A Current Affair*, <http://aca.ninemsn.com.au/article/8843524/meet-miracle-twins-faith-and-hope>

3. Problems with current practice



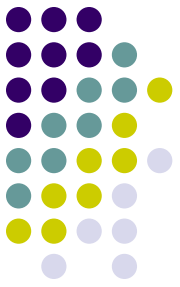
- Selena Ewing's *Women & Abortion (2005)*:
 - A section titled 'Harm resulting from abortion for disability or disease in the foetus' cites 10 peer-reviewed studies to conclude that "for women who abort because of disability or disease in the foetus, the procedure and the years afterward can be extremely traumatic, characterised by grief and guilt."
 - One study concluded 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."
 - 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."

4. Informed decision-making



- What is required?
 - 1) Time: “slow down and take a deep breath.”
 - 2) Ongoing support: Part of the pain is a profound fear of abandonment. Families must be assured that there will be ongoing support if they decide to continue the pregnancy.
 - 3) Information: In almost all cases, the physical risk to the mother is no greater than the normal risks of pregnancy. And with most conditions, it is unlikely that the child will suffer.
 - 4) A full description of the proposed termination, along with information that “abortion for foetal abnormality is particularly traumatic and can be psychologically damaging for women.” (Ewing)
 - 5) Perinatal palliative care is offered as an alternative to termination.

4. Informed decision-making



- With the offer of perinatal palliative care, what will parents decide?
 - Four case series reports:
 - Breeze et al (2007): 8 out of 20 families (**40%**) chose to continue the pregnancy.
 - Leuthner & Jones (2007): 68 out of 185 cases (**37%**) chose to continue the pregnancy.
 - D’Almeida et al (2006): 21 out of 28 families (**75%**) chose to continue the pregnancy.
 - Calhoun et al (2003): 28 out of 33 families (**85%**) chose to continue the pregnancy.
 - In total, 124 out of 266 families (**47%**) chose to continue the pregnancy.
 - There was no maternal morbidity in any of these cases.
 - None of the parents regretted their decision. To the contrary, all were highly positive about their experience.

5. Perinatal Palliative Care (PPC)



- not *routine care*
- certainly not *routine care minus*
- *different care* specifically designed for these sorts of pregnancies
- “an active and total approach to care, from the point of diagnosis or recognition, throughout the child’s life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child and support for the family. It includes the management of distressing symptoms and care through death and bereavement.” (British Association of Palliative Medicine *Report*, page 1)

5. Perinatal Palliative Care (PPC)



- Dr Byron Calhoun is a pioneer of PPC
- now, over 40 peer-reviewed articles by many authors on PPC
 - clinical practice guidelines, clinical reports, and comments
 - which mostly detail a consistent practice
 - KMcG in *Chisholm Health Ethics Bulletin* 17:3, online at <http://www.mercyhealth.com.au/au/ccche/Pages/Bulletins.aspx>
 - *An Annotated Bibliography* (KMcG)
 - Albert Balaguer et al (2012):
 - “it seems desirable for obstetric and neonatal units to have available an active and efficient Perinatal Palliative Care programme.”

5. Perinatal Palliative Care (PPC) - for health professionals



- Catlin & Carter (2002)
- British Association of Perinatal Medicine
Report & Supplement (2010)
 - ALL available on PeriNatal Palliative Care website
at <http://www.pnpc.org.au/health-providers-overview>
- seek guidance from experienced practitioners, e.g. at *King Edward Memorial Hospital, Mercy Hospital for Women...*

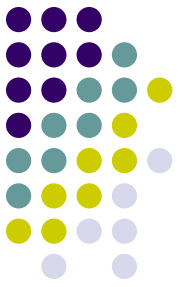
5. Perinatal Palliative Care (PPC) - for parents



- Video *Health Providers Overview*
- Video *The Zimmer Family Story*:
<https://www.youtube.com/watch?v=DRYN01RGLp4>
- PeriNatal Palliative Care website:
<http://www.pnpc.org.au>
- Perinatal Hospice website:
<http://www.perinatalhospice.org/>
- SANDS *Making a difficult decision*:
<http://www.sands.org.au/images/sands-creative/brochures/132911-Making-a-Difficult-Decision-Brochure.pdf>

A Gift of Time

by Amy Kuebelbeck & Deborah Davis



1. Receiving your baby's diagnosis
2. Making decisions about continuing your pregnancy
3. The emotional journey
4. Waiting for your baby
5. Making medical decisions
6. Getting ready for your baby's birth, life and death
7. Welcoming your baby
8. Saying goodbye
9. Continuing your journey
10. Reflections

5. Perinatal Palliative Care (PPC)



- a team approach. Usually, the core team is the family, their primary physician and a specially trained nurse/social worker/genetic counsellor who is their readily available contact. Other health professionals and religious practitioners are involved as required.
- support and education about grief, including anticipatory grief
- advice and help with talking to other children and other people
- as required, private appointment times
- as required, extra ultrasounds, involving family and friends
- choosing a name for baby

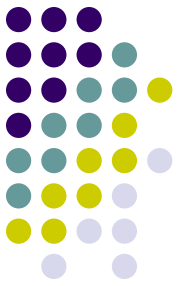
5. Perinatal Palliative Care (PPC)



- Birth Plan
 - often, a personal Introduction, then detailed plans
- at birth, staff may facilitate bonding by pointing out non-anomalous features of the baby (eg cute hands or feet, soft skin, etc)
- keepsakes and mementoes (eg ultrasound pictures, photographs during pregnancy, photos of baby with family, foot or hand prints, baby's blanket, baby's clothes, etc)
- advice about the dying process
- planning for funeral/memorial service and final resting place
- perhaps, taking baby home with community support services
- often, a day or so with baby after death
- for the next year, ongoing contact with the family

6. What is happening:

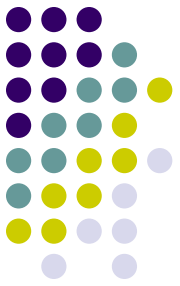
A. Catholic Hospitals



- *Walking with Love Practical Guide*, pp 6-7. At <http://www.walkingwithlove.org.au/>
- *Catholic Health Australia* (CHA) host *PeriNatal Palliative Care* website <http://www.pnpc.org.au>
- ongoing quality improvement at *Mercy Hospital for Women & Mater Hospitals Brisbane*
- networking with other Catholic hospitals & services
 - Mater hospitals (Mackay & North Queensland)
 - Calvary Health Care
 - St John of God *Raphael Centres*

6. What is happening

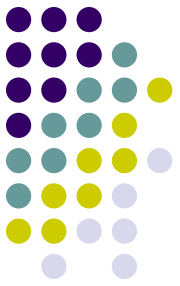
B. Senate Inquiry into Palliative Care



- Submission 68 by Christine Campbell
 - also, speech in Victorian Legislative Assembly on 7 December 2011
- Submission 53 by Dominic Wilkinson, Victoria Brookes, Jan Hodgson, Alice Weeks & Jenny Hynson
 - Dominic Wilkinson was interviewed by the Senate Committee on 13 August 2012
- The Report discusses perinatal & neonatal palliative care on pages 165 to 167

6. What is happening

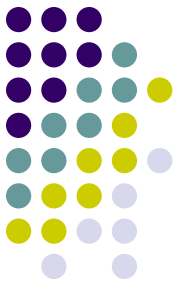
B. Senate Inquiry into Palliative Care



- Recommendation 27: “The committee recommends that the Australian government give increased attention to the need for improved research, education and services to support the perinatal and neonatal palliative care needs of health professionals, pregnant women and their families and newborn infants.”

6. What is happening

C. Health Professionals Organise

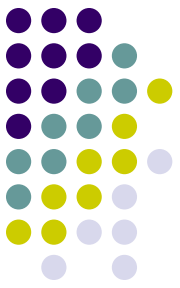


- Dr Jan Hodgson & Dr Melody Menezes at Melbourne University
 - study (funded by the Australian Research Council) of about 100 women after prenatal diagnosis of fetal abnormality
- Perinatal Society of Australia and New Zealand (PSANZ) held one-day workshop on PPC in Melbourne on 15 July 2013
- PSANZ Special Interest Group on Perinatal Palliative Care
- Presentation on PPC by Dr Liz McCarthy (Mercy Hospital for Women) at Chisholm Centre conference on 3 October 2013
- Second PSANZ PPC Symposium in Melbourne on 19 April 2015
- There is now sufficient information and support for a family or health professional to trail-blaze PPC almost anywhere in Australia
- **Can you help us in promoting and developing Perinatal Palliative Care in Australasia?**

7. Continuing the pregnancy



- Chelsea: “I learned... that there was a possibility that our baby would live up to an hour after birth. I decided that even five minutes with my baby alive in my arms would be worth it.”
- Annette H: “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.”
- Jamie: “My whole family wanted me to terminate... In the end everyone was so glad that I decided to continue. We all fell in love with her.”
- Camille: “If we had decided to terminate this pregnancy I would still have dealt with pain, suffering, loss, and regret. By carrying Brayden until natural death I was able to love him longer, give him everything I could, and there is zero regret. You cannot avoid the pain, suffering and loss either way.”



7. Continuing the pregnancy

- Pierre: “Twenty minutes with him, maybe seventeen....
Twenty minutes of happiness and tears....
Twenty minutes for him to educate me, my own son,
because he teaches me the important things in life....
Twenty minutes to be able to continue to talk to him
to be able to tell him how much I love him.”
- Katherine (sensing good progress through grief): “I know that I wouldn’t
be where I am emotionally if I had terminated her life early.”
- Annette G: “My soul has grown and matured. Nathaniel’s life has taken
me in new directions and given me a larger, more patient and
understanding heart. I am more focussed on relationships as the most
important thing in life. I feel I live more purposefully and deliberately
than I did before.”
 - These seven quotes are from *A Gift of Time*, pp 30, 343, 367, 343, 296-7, 342 & 369



8. Video *Health Providers Overview*

- <http://www.youtube.com/watch?v=tY7mq1g9pGk>
- On Perinatal Hospice website at http://www.perinatalhospice.org/Resources_for_care_givers.html
- On PeriNatal Palliative Care website at <http://www.pnpc.org.au/health-providers-overview>

8. *Video Health Providers Overview*

