



PERSPECTIVES

The deVeber Institute for Bioethics and Social Research

2023

Research and Scholarship for an Informed Social Response to Human Life Questions

I am with you

FALL LECTURE SERIES

A lecture series on supporting women and families through pregnancy and after.

TUESDAY | OCT 24 & NOV 7 | 8 PM (ET)

Register online at www.deveber.org



A New Service for a New Era: Perinatal Palliative Care

Each year, approximately 4% of children born in Canada are diagnosed with one or more serious congenital anomalies. These anomalies may present from conception, such as with a chromosomal defect (ie. Down syndrome) or later in gestation as is the case with structural defects such as spina bifida. Many children who are born with an anomaly live fulfilled adult lives. However, some children with severe anomalies, only live a short life and may never leave the hospital or celebrate their first birthday. Congenital anomalies are second only to immaturity as the leading cause of infant death.¹

A new service, perinatal palliative care, is emerging as an essential lifeline for those children with life-threatening anomalies and their families. Perinatal palliative care provides comfort and relief from pain and symptoms for newborn babies who are dying, and emotional support and healing for their families.



Perinatal palliative care provides a hopeful option that values and supports the life of both the parent and the child.

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Prenatal Testing and Abortion

Prenatal testing has drastically increased the number of diagnoses of congenital anomalies in children before birth. Parents of babies in utero with anomalies are asked to make decisions for aborting or carrying to term. These decisions are often made with very little information about their child's illness or disability, about the effects of abortion, or about the services available to support the baby once born.

As a result of increased prenatal testing, the vast majority of children with genetic anomalies, whether moderate or severe, are aborted before birth. While for many, the termination of pregnancy is an attempt to eliminate the suffering, research finds that **40% of women who abort for fetal anomaly suffer long-term emotional distress.**² A leading authority writes that the level of psychological consequences often doesn't decrease in the first few years after the abortion, with studies showing that "17% of women experienced symptoms of post-traumatic stress for 2 to 7 years after pregnancy termination due to fetal anomalies."³

Women who chose abortion continued to grieve years later.

Supporting Parents During Decision-Making

The choice between abortion and giving birth to a disabled child after genetic diagnosis often depends on the type of counseling offered to parents. In one study, 80% of parents who received 'non-directive' counseling chose to abort, while 80% of parents who were provided with the option of perinatal palliative care chose to carry their child to term.⁵ **Parents who are offered support in continuing pregnancy and caring for their disabled child overwhelmingly choose to carry to term.**

Amy Kuebelbeck, author of *Waiting with Gabriel*, a memoir about her own experience with her son who had a fatal fetal anomaly, writes,

"I know that some people assume that continuing a pregnancy with a baby who will die is all for nothing. But it isn't all for nothing. Parents can wait with their baby, protect their baby, and love their baby for as long as that baby is able to live. They can give that baby a peaceful life – and a peaceful goodbye. That's not nothing. That is a gift."

A Hopeful Alternative

For many parents whose child has received a prenatal diagnosis of a life-threatening congenital abnormality, the outlook may seem bleak. Parents are usually urged to make the decision to terminate quickly.²

An alternative to abortion for children with severe genetic anomalies is perinatal palliative care.

Perinatal palliative care programs offer counseling and support to the terminally ill child and the family. These programs typically include a support team of obstetricians, neonatologists, nurses, chaplains and social workers. The primary focus in perinatal hospice care is on the family who is placed in the centre of the care so that there is a **continuum of support** from the diagnosis through to the potential passing and grief.⁴

Together they provide a hopeful option that values and supports the life of both the parent and the child by providing counseling and information during the pregnancy, birth, and after the child is born, however brief that time may be.

1. Irvine, Luo, and León. "Congenital Anomalies in Canada 2013: A Perinatal Health Surveillance Report." Health Promotion and Chronic Disease Prevention in Canada: Research, Policy and Practice 35, no. 1 (March 2015): 21–22.

2. Lanfranchi, Gentles, and Ring-Cassidy. (2018) "Complications: Abortions Impact on Women." 2nd Ed. The deVeber Institute for Bioethics and Social Research.

3. Kamranpour, Bahareh, Mahnaz Noroozi, and Masoud Bahrami. "Psychological Experiences of Women with Pregnancy Termination Due to Fetal Anomalies." Reproductive Health 17, no. 1 (July 9, 2020): 109. <https://doi.org/10.1186/s12978-020-00959-y>.

4. Institute, Charlotte Lozier. "The Perinatal Hospice: Allowing Parents to Be Parents." Lozier Institute (blog), May 1, 2012. <https://lozierinstitute.org/the-perinatal-hospice/>.

5. Calhoun, BC, Napolito, P et al. (2003) "Perinatal hospice: comprehensive care for the family of the fetus with a lethal condition." JReprodMed. V48: 343–348.

6. Amy Kuebelbeck. Quote from meeting, "Perinatal Palliative Care with Compassion, Care & Confidence", 29–30 April 2009, Lancaster General Hospital, Lancaster, PA.

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Dr. Jane Pritchard is a family medicine physician in Toronto. Her practice is comprised of marginally housed or homeless people in Toronto and Latin American refugees from El Salvador, Guatemala, Nicaragua, and Columbia. “My family practice is in an urban setting, but with a very special group of people; who have experienced much trauma, and overcome many obstacles, but the memories are always with them.”

Dr. Deborah Zeni is a family physician in Georgetown, Ontario. She shares a family practice with her husband, Dr. Paul Zeni, and together they provide medical care for all ages—including prenatal care and palliative care. “Currently my practice has an above average number of women who have experienced trauma or considerable hardship.”

In this lecture, two doctors will share their experiences and wisdom caring for pregnant women from varied backgrounds, circumstances and experiences. We will glimpse the work of two individuals guided by their life-affirming values, faith and overwhelming commitment to their patients.

Dr. Zeni explains, “Our patients not only respect, but expect us to uphold our life respecting, equity and diversity centered practice where everyone is a somebody.”

*I am with you:
Dr. Pritchard and
Dr. Zeni on journeying
with women through
pregnancy*

TUESDAY

OCT 24 | 8 PM (ET)



*I am with you:
Dr. Thomas Bouchard
on supporting families
through perinatal
palliative care*

TUESDAY

NOV 7 | 8 PM (ET)



Dr. Thomas Bouchard, a family medicine practitioner in Calgary, will discuss his own experiences accompanying families through perinatal palliative care and Perinatal Hospice. The term “Perinatal Hospice” was coined by Dr. Byron Calhoun and is a “model of care that incorporates the strengths of prenatal diagnosis, perinatal grief management, and hospice care to address the needs of families.”¹

“I started the family physician navigator program in Calgary,” explains Dr. Bouchard, “to help guide couples through a difficult pregnancy journey when the interpretation of consults from obstetricians, neonatologists and other specialists can be overwhelming.”

In this lecture, Dr. Bouchard will share stories and images from the families he has supported in Perinatal Hospice care — highlighting the guiding role of a family doctor and reminding us all of the beauty of a life, no matter how short.

“A new child is miraculous, even if they may have a short life. When love and life are concentrated in a short timeline of life, there are often more intense emotions and opportunities for deep transformation and hope, even in what seems like very dark moments.”

1. Calhoun. 2015. “The Myth That Abortion is Safer Than Childbirth: Through the Looking Glass.” *Issues Law Med* 30(2), 209–215.

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Thank you!

Once again, I am asking for your donation to help us continue our work.

We are a very small organization, but we are taking big steps towards our goal of achieving ongoing research on key life-issues, bi-annual lecture series, and a vast collection of academic, reliable reference materials. **To meet these goals we rely on the support of donors – like you.**

After 40 successful years, we are facing increased financial strain. **We desperately need your help to ensure the continuity of the deVeber Institute.** We need to raise \$20,000 by the end of the year to continue to provide free lectures, new research, and materials in 2024.

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Thank you for all you do to further research and discourse on today's human life issues.

Thank you!

Zoe

Zoe Stewart-Bedard
Executive Director



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