SUPPORTING FAMILIES AFTER THE LOSS OF A CHILD

HUMA

Abstract

Written submission for standing committee on Human Resources, Skills and Social Development and the Status of Persons with Disabilities.

Our Story

My husband and I are healthy, active, contributing members of society and we have never been so thrilled and full of joy as we were when we were expecting our first child. My pregnancy was a "textbook" pregnancy and our son was perfectly healthy and thriving, until he suddenly died with no explanation - 4 days before I was scheduled to be induced into labour at 37 weeks.

Our world was destroyed that day, and we have spent each hour since then attempting to find our footing in a devastating "new normal" that we never chose.

After we learned our son had died, I was induced. I laboured to bring our son into the world, with the support of an incredible midwife and members of our family. He was perfect in every way, and he never took a breath. I suffered significant medical complications immediately after delivery, which required immediate surgery and a slow and frightening physical recovery. My body also went through all the postpartum changes that all mothers experience, however my baby was not with me to nurse and mother.

Here are some of the things that have made this nightmare experience more humane and helped us to be supported, so far:

- The nurses and medical staff had recently been trained in compassionate bereavement care
- A cuddle cot (cooling device) had been donated to the hospital, which allowed us to extend our limited time with our son
- We stayed in a designated bereavement delivery room that is set aside for families suffering the loss of a baby
- With the help of family, we were able to make memories with our son and have photos and keepsakes of our time with him
- My husband and I are both fortunate to have supportive employers that allowed for extended leave, and health benefits that include counseling services

There is no way to adequately convey the shock, pain and horror of losing a child to those who have not experienced it firsthand. The grief is immense, and its effects extend to every aspect of our lives. After meeting countless other bereaved parents online and in person, we have learned that we will be carrying this pain with us for the rest of our lives.

Recommendations

The challenges commonly faced by bereaved parents include feelings of sadness, depression, anxiety, anger, guilt, and disbelief. Losing a child is a truly horrific experience that transforms a person both instantaneously and over the course of time. After losing a child, a parent is no longer the same person that they used to be, and time away from the pressures of work (without the burden of financial strain), is essential for the parents to take in order to tend to their wounds and rebuild a new sense of identity.

At present, what the government provides, in terms of financial assistance to bereaved parents, is insufficient. While mothers are entitled to maternity leave (this is a good start), fathers are entitled to no particular benefit related to the death of their child. This is unacceptable, and frankly, rather shocking for a progressive western democracy.

In the UK, the Parental Bereavement (Leave and Pay) Act 2018¹, entitles parents up to two weeks' leave after the experience of the loss of a child under the age of 18 or a stillbirth after 24 weeks of pregnancy. In Canada, similar legislation should be put forward or the Employment Insurance Act should be amended to provide for such an entitlement, however we recommend increasing the leave time for both parents to at least 12 weeks, and reducing the length of pregnancy to 20 weeks (to fit with the Canadian medical definition of stillbirth). This leave should be paid, similar to how maternity benefits are currently paid out.

From a compassionate social perspective, it is time Canada takes a stand and gives grieving parents a much needed helping hand. The Liberal government has already committed to making parental benefits more flexible, developing a modern child care framework, and making the compassionate care benefit easier to access. Is it not time to acknowledge that bereaved parents need help too?

From an economic perspective, providing the space and financial means for a family to grieve, without being forced back to work, may help lower rates of psychiatric disorders resulting from inadequate self-care time. If potential psychiatric disorders can be reduced (or avoided) in this way, then this will help ensure that in the long term, more parents can return to healthy and productive full-time employment.

Canada needs to implement changes to the parental leave benefit program for parents who have experienced a loss. The current framework is unacceptable and provides undue hardship on a vulnerable and fragile population.

In addition to the above, funding for research into stillbirth is essential. When our son died of no known cause, the Maternal Fetal Medicine specialists advised that roughly two thirds of all late term stillbirths are unexplained. Other countries, such as Australia and the UK, have shown leadership in researching the causes of death and promoting prevention through education. Canada is currently lacking any substantive research body to investigate the causes of stillbirth and how future losses can be prevented.

Finally, the government should consider providing the provinces with additional funding to improve health care supports and resources for grieving parents surrounding the birth of their stillborn baby. For example, we were fortunate to have a cuddle cot available for our son which enabled us to spend more time with him, however these devices are privately donated to hospitals and therefore are not available in all hospitals across the country. Grieving parents should have equal access to compassionate healthcare services whether they live in rural Alberta or in Halifax, but access to these services should not be premised upon whether enough money has been pooled together by the citizenry to purchase these services. Funding for healthcare services, which include supports for grieving parents surrounding the birth of their stillborn baby, should come from the federal government.

¹ Parental Bereavement (Leave and Pay) Act 2018:

http://www.legislation.gov.uk/ukpga/2018/24/enacted

Summary of Recommendations

- 1. Put forward new legislation or amend the Employment Insurance Act to provide both parents with a minimum of 12 weeks of paid leave after the experience of a stillbirth after 20 weeks of pregnancy.
- 2. The government should implement or increase funding for stillbirth research and prevention.
- 3. The government should provide the provinces with additional funding to improve healthcare supports and resources for grieving parents surrounding the birth of their stillborn baby.