

Brief Submission for Human Resources Committee – Motion 110

Perinatal Hospice Program - Roger Neilson House
399 Smyth Road Ottawa Ontario K1H 8L2
613-523-6300

Authors:

Carol Chevalier, MSW, RSW - Palliative Care Social Worker Roger Neilson House
Lesley Sabourin RN – Perinatal Hospice Coordinator Roger Neilson House
Jodi Ouellette RN, BScN – Perinatal Hospice Coordinator Roger Neilson House
Megan Wright RN, BScN, MN - Executive Director Roger Neilson House, Director Palliative Care, CHEO

Summary:

The loss of a child of any age is “a profound, difficult and painful experience.” Both research and the experiences of bereavement counsellors, nursing staff and management at Roger Neilson House clearly indicate that the emotional and financial needs of parents grieving the loss of a child of any age are not being met. Roger Neilson House supports Motion 110, but recommends that the Committee ensure its recommendations to the Government be inclusive of all families suffering the loss of a child.

Background:

Roger Neilson House is a free-standing pediatric palliative care hospice located in Ottawa, Ontario which, since 2006, has welcomed infants, children and youth with progressive life-limiting palliative diagnoses and their families. Roger Neilson House supports these families through end of life care, pain and symptom management, respite care, hospital to home transition care and, perhaps most relevant to Motion 110, a perinatal hospice and extensive grief and bereavement counselling.

As a result, the staff and management of Roger Neilson House are uniquely qualified to speak to the need for improved support for parents suffering emotional and financial hardship from the loss of an infant or child.

Discussion:

- **Needs of Families Following the Loss of a Child or Infant**

The Bereavement Program at Roger Neilson House is available to any parent who has lost an infant perinatally, or to any family who has suffered the loss of a child under the age of 19. The Bereavement Program is not limited to the loss of children by illness. Referrals are received from all area hospitals, and from community partners such as the Ottawa Police Victim Crisis Unit for families who have lost children to violence, trauma or accident. As such, we are well versed in the differing needs of families and the time families need to grieve for their child.

It is well documented that many parents who have lost a child are at high risk for Post-Traumatic Stress Disorder. Vitelli writes:

“...a child’s death is especially traumatic because it is often unexpected as well as being in violation of the usual order of things in which the child is expected to bury the parent. The emotional blow associated with child loss can lead to a wide range of psychological and physiological problems including depression, anxiety, cognitive and physical symptoms linked to stress, marital problems, increased risk for suicide, pain and guilt. All of these issues can persist long after the child’s death and may lead to diagnosed psychiatric conditions such as complicated grief disorder (currently under review for inclusion in the DSM-5) which can include many symptoms similar to posttraumatic stress disorder.” (Vitelli 2013)

Parents who have lived through the death of a child experience numerous emotional and physical reactions. Many of our families tell us that caring for a medically fragile child can be an incredibly stressful time and that they experience their own physical and mental health symptoms due to this stress. These symptoms include sleep deprivation, depression, feelings of isolation and weight loss. Given the circumstances these symptoms are appropriate and expected. Parents experiencing intense emotions and ongoing stress report being unable to sleep and eat, poor concentration and an inability to attend to regular home and work responsibilities. Most parents will experience significant sleep issues during the first year of bereavement, including bouts of insomnia and night terrors.

All parents require time to grieve the loss of their child so that they are able to return to work in a healthy and productive manner.

“The death of a child of any age is a profound, difficult, and painful experience. While bereavement is stressful whenever it occurs, studies continue to provide evidence that the greatest stress, and often the most enduring one, occurs for parents who experience the death of a child.” [1-7]

Regarding the loss of an infant, Roger Neilson House recognizes that the presenting therapeutic needs of these parents are unique and that they require a tailored therapeutic intervention. Informed by research, Roger Neilson House developed a Perinatal Loss Support group as a means to better support this population of parents.

From research and from our professional experience working with parents who have lost an infant previous to or soon after birth, parents who have lost a child perinatally may experience significant grief and, like any parent who has lost an older child, their emotions are not resolved quickly.

Further, many parents report that they do not believe others around them validate the significance of their loss as the parents had “not known their child for very long.” Many of these parents report that their colleagues, friends, family members and neighbours have pressured them to resolve their emotions quickly.

During sessions and groups, parents have disclosed that within a short time frame after losing their infants, persons in their lives have wondered why they were “still” having a difficult time with their grief. These parents then expressed confusion as to why their loss experience was so challenging to “resolve” as others clearly believed they should be “getting better.” They were left asking questions about whether they were “crazy” for still grieving and mourning their child. It is

not uncommon for parents to subsequently isolate themselves from people who do not understand what they are experiencing, even those closest to them.

Roger Neilson House support groups and counselling programs offer a safe space to assure parents that their emotions, reactions and difficulties are normal. While they will mourn their child for a lifetime, with support and time, it will become less acutely painful.

Bereavement therapeutic work takes time, effort and a tremendous amount of energy by the parent. Many bereaved parents refer to the first three months of loss as the “fog”, and as the fog lifts over time, the intensity of the emotion increases. Moment by moment can be difficult and the stress of returning to the daily activities of life such as employment can be overwhelming.

- **Current Issues with Employment Insurance Benefits Available to Bereaved Parents**

Briefly, the current available benefits for families facing bereavement are:

- 15 weeks of maternity leave for the mother, in the case of an infant lost perinatally. The mother loses her parental leave as her child is no longer living.
- Sickness Benefits payable “only to those people who are unable to work because of sickness, injury or quarantine, but who would otherwise be available for work if not for their incapacity due to medical reasons. To receive sickness benefits, you need to obtain a medical certificate signed by your doctor or approved medical practitioner.”

Currently, bereavement is not considered an illness and, in our experience, most parents do not pursue this avenue. As well, there are no standardized criteria to determine an individual’s readiness to return to work. For example, if a family physician believes the best way to resolve difficult emotions is by getting back to work as soon as possible, they are unlikely to communicate to an insurance company that the parent requires a period of paid leave to address their emotional health.

As a result many parents are faced with

- unpaid leaves of absence from work
- if insured, making a case to the insurance company that they are too unwell emotionally to return to the workplace, or
- losing their employment.

Recommendation:

From the research and the daily experience of Roger Neilson House counsellors, it is apparent that the emotional and financial needs of parents grieving the loss of a child of any age are not being met. While the experiences and emotions felt by parents suffering the loss of an unborn child may differ from those of a family mourning the loss of a teenager with a life-limiting illness, they all suffer the emotional and financial impacts of grief. Therefore it is recommended:

- That the Committee make recommendations to the government to improve the level of support for grieving parents and to seek to ensure parents no longer suffer any undue financial or emotional hardship as a result of the design of government programming, and

- **That these recommendations be inclusive of all families suffering the loss of a child by whatever means.**

Roger Neilson House:

Perinatal Hospice has been offered since 2007 by Roger Neilson House and has been supported by a designated coordinator since 2018. Pregnancy and infant loss is devastating and impacts those involved forever. Perinatal Hospice & Bereavement offered by the Roger Neilson House team is provided to parents and families in cases where there is a prenatal, perinatal or neonatal diagnosis of a life-limiting illness or a life-ending diagnosis. It is specialized care that prepares parents for the birth, death and sorrow of the impending loss of their much loved child. Care is dependent on parental/family needs and wishes.

Parent Testimony:

“When my daughter Teigan passed away I felt like I was drowning all alone. I could see the outreached hands of my family there to help but as kind as their words of support were, I never felt like there was someone in the water with me. When I received a call from Rogers Neilson House to join them for their bereavement group I decided to go. It was the life raft I was looking for. I found other parents who were swimming in the grief alongside me- moms and dads who I could relate to, a place where I could feel safe and free to talk about my experience. A place where my daughter Teigan was just another kid, like everyone else’s not a sad story that made people upset and feel sorry for me. Roger Neilson House and the people I met there became my friends, a much needed support system that helped lead me out of the water.”

Bereavement Support Services:

Bereavement support is available for families who have experienced the death of a child (under the age of 19).

We offer a safe and healing environment. At RNH our philosophy is to accompany families through their grief journey. The following principles guide our services:

- Grief is unique for each family member.
- Sharing your experience with others who understand can bring comfort.
- Being part of a group helps reduce the sense of isolation common to bereaved families.
- Bereavement groups are closed and require advance registration.

A complete description of Roger Neilson House programs and services can be found at

<https://rogerneilsonhouse.ca/our-services/>

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