



Honouring the voices of our children: how bereaved parents contribute to pediatric health care

Contributors: Valerie McDonald, Joanie Turner, Jonathan Blumberg, Shari Morash, Malcolm Berry, Michelle Murray, Winnie Seto, Denise Bebenek, Elizabeth Peeters.

Honouring children's voices

Although bereaved parents are no longer involved as partners in the care of their own children, many seek to make meaning out of their loss by helping others. Research shows that bereaved parents who help others are better able to find meaning in their child's death; this experience contributes to effective coping (Videka-Sherman: 1982; Schwab: 1990). Parents also report that talking with other parents and maintaining contact with staff at the treating hospital helped healing (D'Agostino: 2008.) This presentation is a preliminary inventory of the ways in which bereaved parents continue to contribute to paediatric health care services.

Methodology

This preliminary inventory presents the activities of a small sample of parents (20) whose children were treated at Sick Kids and who continue to contribute to paediatric health care in some way. Activities fall within the following areas:

Advocacy
Direct Service to other families
Research
Policy and program development
Fundraising
Education

Advocacy

Some parents advocated for improved services or increased funding at Sick Kids and beyond.

- ❖ Toronto Central Palliative Care Network
- ❖ Media interviews (CITY TV, Toronto Star)
- ❖ Guest speaker 20th anniversary of Palliative and Bereavement Services
- ❖ Perspectives of a mother on "Now I lay me down to sleep" legacy photography.
- ❖ Interview for NFB film *Griefwalker*

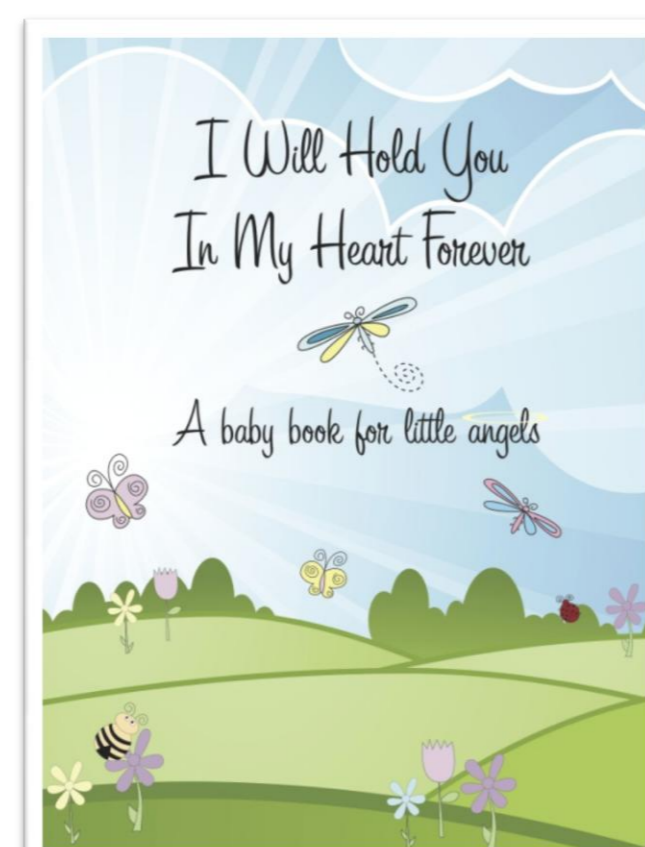
Specific issues included:

- ❖ Wayfinding sign for Palliative Care Service offices
- ❖ Establishing hospital memorial service
- ❖ Celebration of deceased in Sick Kids Atrium
- ❖ Advocating for more Foundation support of Palliative Bereavement Care service events.

Direct service to other families

The majority of parents reported that they offer informal support to other families experiencing the end-of-life treatment or death of a child in-person, by telephone or email. Other activities included:

- ❖ Participation at Memorial Events
- ❖ Participation in annual b.r.a.i.n.child conference
- ❖ Gift & Estate Planning Team at Sick Kids Foundation
- ❖ Bereaved Parents Network
- ❖ Max & Beatrice Wolfe Centre
- ❖ Blogs e.g. <http://sashabella.blogspot.com/>
- ❖ Facebook pages and websites e.g. <http://www.foreverheart.ca/angel-guestbook>



Legacy creation

- ❖ "I Will Hold You In My Heart Forever" a baby book for little angels by Michelle Murray.
- ❖ "Forget me not" flower arrangements for bereaved parents.

Policy and program development

Many bereaved parents volunteer for hospital committees or other health organizations to offer a family perspective.

- ❖ Family Centered Care Advisory Council
- ❖ Advisory board of TRAC-PG
- ❖ Sick Kids Bereavement Task Force
- ❖ NICU parent council
- ❖ Families as Partners in Patient Safety
- ❖ Care for Kids fund
- ❖ Max and Beatrice Wolfe Centre (Mount Sinai)

Research

Parents in our sample have assumed many different roles in the area of research including:

- ❖ Parent Liaison, TRAC-PG
- ❖ Study participants
- ❖ Grant review committee members
- ❖ Co-investigators/co-authors
- ❖ Reviewers

Fundraising

Since 2000, families donated over \$1 million to the Palliative and Bereavement Care Service. Many families reported that they were not aware of the different types of donations available.



Memorial donations

❖ direct donations to NICU, Palliative Care Bereavement Service, Expressive Therapies, Reading Room, brain tumour research and undesignated donations, applied to high priority needs as determined by the hospital executive.

In-Kind Donations

- ❖ Trac-pg.ca
- ❖ "I Will Hold You In My Heart Forever, a baby book for little angels
- ❖ Song written to benefit NICU bereavement program

Special Events

- ❖ Wyatt's Warriors (Labatt Family Heart Centre)
- ❖ Meagan's Walk (brain tumour research)
- ❖ Josiah's Walk (neo-natal intensive care, St. Joseph's Hospital, London)

Tribute Named Funds

Since 2000, four family funds have contributed \$100,000 to palliative care initiatives. Family funds honour children with income from direct donations, special occasion gifts, or events. Funds can be directed to a specific program, or priority areas. Once donations exceed \$25,000, a plaque is added to the donor wall. Two examples are:

- ❖ The Sasha Bella
- ❖ Paige Berry Memorial Fund

Endowment Funds

Families make a minimum donation of \$10,000, which is invested as part of a permanent fund (currently \$600 million). When the family fund reaches \$50,000, 4.5% is paid out annually for a designated purpose or priority area. **Bequests** are donations made through Wills that may include money, a percentage of the estate, stocks, life insurance or property. One family has made a bequest.

Education of staff and students

Bereaved parents contributed to different types of education programs and initiatives:

- ❖ medical, nursing and OT students
- ❖ PERLS- Paediatric Residents Learning Seminars.



- ❖ staff training in ICU, Cardiac Critical Care Unit, Heart Centre interprofessional practice days, RTS (Resolve Through Sharing Perinatal Grief Training)
- ❖ Palliative Care Symposium
- ❖ Support to Sick Kids Foundation staff working with bereaved families
- ❖ Development of training documents and resources
- ❖ Advise staff about helpful palliative/end of life family resources

Community education

- ❖ Sick Kids palliative care training course
- ❖ Inter-professional Practice Education Week
- ❖ Canadian Association of Paediatric Health Centres
- ❖ Perinatal Bereavement Conference
- ❖ National Palliative Care Week
- ❖ Canadian Palliative Care Conference
- ❖ Canadian Family Advisory Network
- ❖ St. Joseph's Hospital London "Creating Legacies for Children with Now I Lay Me Down To Sleep remembrance photography."
- ❖ London Children's Hospital Palliative Care Symposium
- ❖ Institute for Family Centred Care Palliative Care

Discussion and future directions

Bereaved parents give voice to their children's lives through volunteer work and significant financial contributions to Sick Kids and other organizations. Many parents were not aware of the range of volunteer and donor options available. These kinds of opportunities could be more actively shared with grieving parents to help them find concrete ways to create positive experiences from their own bereavement and thus facilitate their healing.

It would be useful to further investigate the impact of participating in specific types of fundraising and volunteer work on coping with grief.

References

- D'Agostino, N., Berlin-Romalis, D, Jovcevska, V., Barrera, M. (2008). "Bereaved parents' perspectives on their needs." *Palliative and Supportive Care*, 6, pp 33-41.
- Schwab, R. (1990) "Paternal and maternal coping with the death of a child." *Death Studies*, 1091-7683, vol. 14 no. 5, 407-422.
- Videka-Sherman, L. (1982), "Coping with the death of a child: A Study Over Time." *American Journal of Orthopsychiatry*, 52: 688-698.

