

SickKids Palliative Care & Bereavement Services



Palliative and Bereavement Care at SickKids is part of the continuum of care for children and youth facing a progressive life threatening illness and their families with the goal of enhancing choices, relieving suffering, and ensuring the best quality of care during living, dying and grieving.

The team provides counseling, pain and symptom management, comfort, and spiritual and bereavement care where needed – in the hospital, or at home.

They work within a network of community palliative care resources Linked in to the network in the Toronto region are information, counselling, financial, funeral, and government services.

Sometimes the hardest truth to accept for those who have care of a child with a life-threatening illness is that, in some cases, our best efforts will not prevail. There comes a time when a cure is no longer likely and the best service we can provide is palliative – easing the child’s pain and helping both child and family through this hardest of all passages.

For twenty years the Palliative and Bereavement Care team at SickKids has been helping the curative care-givers and the patient and family deal with the impact of uncertainty, and, if death becomes inevitable, bringing empathy, understanding and experience to help in a very difficult time. Over that period the program has grown to encompass pain and symptom management, home-based visits, grief and bereavement support, advocacy, and research.

Thanks to the generosity of *the Sasha Bella Fund* the service has been able to bring the therapeutic power of art and music to the child and family, and to provide important materials, books, cameras and more, for families to use to learn, record and remember.

New initiatives in 2006-07

New Therapies

An exciting area of growth is the expansion of our expressive therapies. These services are of enormous value in both bringing comfort and cheer and also in creating something beautiful – a gift the dying child can give – that will be a treasured keepsake after the child is gone. In 2006 a Therapeutic Clown joined us; followed by an art therapist and a massage therapist. The music therapy programme expanded to the Kitchener-Waterloo region – a wonderful benefit to families in that region and from one day a week to 2.5 days a week here at SickKids with the addition of a new Music Therapist.

New Awards

Thanks to a number of generous and committed families, we now have a way to honour the untiring work of our own people. Our first Leadership award was made in November 2006, as part of our celebration of our 20th anniversary, and honoured our nurse practitioner Maria Rugg. It was fitting that this award should be both named after Maria, and awarded to her, as a leader who has been with the program for the past 13 years, and a driving force behind its growth.

Our second award is a very exciting new award in education and we are very grateful to *the Sasha Bella Fund* for underwriting this opportunity for our professional staff. We cannot say enough how inspiring and enriching recognition of professional accomplishment can be. Once the specifics are decided the award will target excellence in the key area of Interprofessional Practice.

Research

The research arm of the Palliative Care program is working to develop **TRAC-PG** (Team for Research with Adolescents and Children in Palliation and Grief).

The goals of TRAC-PG are to generate and disseminate knowledge about children with life limiting illness and their families in order to optimize quality of palliative, end of life, and bereavement care.

Highlights from 2006-07 are—

- 11 studies published with over \$2 million in research grants (2004 – 2007)
- 4 presentations
- increased membership from 3 in 2003 to 3 co-directors and 11 interdisciplinary clinical researchers in 2007
- development of dynamic website with the generous support of Jonathan Blumberg
- introduction of new Co-director (Dr. Christine Newman)

Educational Initiatives

In 2006-07 the Palliative Care team continued its educational initiatives both within the hospital, in the community, and this year overseas as well!

- Our nurse practitioner, Maria Rugg, was part of a group of international faculty who presented at the XIVth International Annual Conference of the Indian Association of Palliative Care, held at the Tata Memorial Centre February 10-12, 2007. She participated in a full one day nursing workshop on paediatric palliative care, as well as a workshop on pain and symptom management and an expert panel on communication with children. Maria was also involved in presenting at two other hospitals in a one-day workshop on paediatric palliative care in children with cancer.
- *Paediatric Hospice Palliative Care – Offering Excellence Together*, our four day course aimed at professionals, was presented twice last

year. Once as usual in a regional centre (2006 – Scarborough), and an additional session was given at SickKids.

- The “What Do I Say?” and “Legacy Creation” courses were both run twice in 2006-07 year.
- Every other month the team presents *Telehealth Rounds* – videoconferenced rounds on a different topic each month, that are broadcast nationally across the country to different paediatric centres – in Halifax, Montreal, Quebec, Ottawa, BC, Calgary, and Edmonton.

We continue to work closely with Community Care Access Centres (CCAC) and other centres, especially the Max and Beatrice Wolfe Centre for Children’s Grief and Palliative Care housed at the Temmy Latner Centre for Palliative Care. Our special thanks to *Care for Kids* for your continued support to families as they make the choice of where their child receives palliative care; providing essential medical and respite support so that they can if they wish, choose to take their child home.

A Special Space in the Hospital

For the first time in the team’s 20 year history it has been possible to establish a palliative care library. Early in 2007 a small but adequate space was set aside, bookshelves were built, and the task of filling those shelves with books and pamphlets for professionals and parents, as well as the team’s collection of story books and activity books for children, has been completed. With easy chairs, a table and a coffee maker, plus a computer with an Internet connection, the room is becoming a welcome retreat for reading, for relaxing, or for consulting.

This space brings the Palliative Care Team together so we can talk to each other! But it is also available for families and professionals. Appropriately, a beautiful picture of the visual themes that families treasure is being created and will be displayed there for the pleasure and comfort of all who visit.

Thank You!

The accomplishments of the palliative care team would not have been possible without the generous support of *the Sasha Bella Fund*. For your commitment to the comfort and care of the dying and their grieving families we are deeply grateful.