



Net News

The Alberta Children's Hospital Pediatric Palliative Care and Grief Support Services: An Update

Recent months have been exciting times for all of us here in Calgary. The Alberta Children's Hospital has made a successful move to a new state of the art facility. We are all settling in, infused with the contagious energy of our fresh and startlingly innovative new surroundings.

The work of building a comprehensive palliative and grief support program for children and families continues. The story of our modest beginnings and extraordinary tapestry of growth over the past ten years is inspiring, but perhaps a subject for a future newsletter.

While reviewing the history of our program it became very clear to me that the initial and ongoing support of the Alberta Children's Hospital Foundation has been a critical

force in establishing and sustaining the work we do. The strong support we initially received, both relational and monetary, has been fundamental to the successful transition to a more permanent and sustainable service delivery model.

The Calgary Health Region funding base as well as the ongoing organizational and managerial support from the Child and Women's Health Portfolio allows us to continue to deliver innovative care, provide creative community services and develop opportunities for ongoing projects and research.

In conjunction with this structural support there has been an unwavering commitment from the Department of Pediatrics in ensuring physician involvement. Our Department Head and colleagues have

supported us both philosophically and concretely through Alberta's Alternate Reimbursement Program for physicians. This program has also allowed us to increase our complement of nursing, social work and administrative support. We continue to have strong backing for spiritual care services.

Clinical Service

Balancing resources remains an ongoing challenge. Starting from an initial .5 FTE position we currently have a 1.5 FTE physician complement, shared among three physicians in addition to 1.1 FTE for both social work and nursing positions. Administrative support is .7 FTE. All of our positions are filled on a part time model allowing for sustainability and diversity of talent and contribution.

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CNPCC Net News

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Special points of interest:

- Alberta Children's Hospital Update
- Video Premier—
Precious Lives
Meaningful Choices

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We function as a Pediatric Palliative and Grief Support Consult Service addressing the needs of our pediatric hospital and neonatal units and our broader community. We serve patients from Southern Alberta, South Eastern B.C and a few patients from Saskatchewan.

Our referral model includes the ability to self-refer in addition to referrals from allied health providers and physicians. We are making inroads towards formal service model agreements with the health regions of Southern Alberta.

Our vision is to be able to identify children who may need palliative resources at any time along the spectrum of diagnosis, illness trajectory and the transition through to death and bereavement. Once identified, providing care and appropriate resources to patients and families remains the fabric of our work together as we confront the daily challenges this work brings.

Our 1.5 FTE physician complement allows us to realistically provide 24 hour on call support to patients and consulting physicians.

Electronic Data Base

We currently maintain a comprehensive electronic database and use this as a clinical communication tool within our health records system. Research potential incorporating this data remains a future possibility.

Grief and Bereavement Support

Our Bereavement team follows all deaths that occur, not only patients seen by the palliative service. Contact is initiated and further re-

sources made available depending upon desire and need. Bereavement packages are then sent out to families with individualized resource information included. Follow up is ongoing.

Grief Groups are offered to bereaved parents in addition to the recently established Parent Support Group. Holiday workshops and our springtime Memorial Service are two annual events that are also offered.

Education

Education is an important aspect of our vision.

In this past year our group has established a series of four "Seeds of Understanding Workshops" covering a wide range of topics.

We participate on the EFPPEC Committee (Educating Future Physicians in End of Life Care), working towards integrating pediatric palliative care and grief issues into the UME curriculum. This is yet

An electronic version of *Pediatric Hospice Palliative Care: Guiding Principles and Norms of Practice (2006)* [*Soins palliatifs pédiatriques: Principes directeurs et normes de pratique (2006) en français*] is available for download from the CHPCA web site:

www.chpca.net

another opportunity that allows us to fulfill our goal of promoting interdisciplinary education.

We also contribute to academic half day teaching for pediatric residents as well as teaching in the rural family medicine palliative care course at the medical school.

Our nurses participate as guest lecturers to both the undergraduate and graduate level nursing curriculum.

"How to Care, What to Say"

workshops developed by our grief counselors have been given locally as well as in Lethbridge. Feedback from participants has been outstanding.

Other Activities

Our team was able to meet with our Edmonton colleagues for a full day retreat in Red Deer last spring. We continue to liaise regularly on an informal basis.

Team members have produced a series of films, the most recent will premiere December 4/2006, entitled "Precious lives / Meaningful Choices". This DVD was made specifically as an educational tool for healthcare providers and addresses the complexity of decision making in the care of medically fragile children with life-limiting illness.

Our social workers have been instrumental in helping the hospital foundation to restructure the Alberta Children's Hospital Foundation Memorial Giving Program.

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2007 Canadian
Hospice Palliative
Care Conference—
Hospice Palliative
Care: At a
Crossroads

November 4-7, 2007
Westin Harbour
Castle
Toronto, Ontario

The 2007 Canadian Hospice Palliative Care (CHPCA) Conference will be a dynamic event that aims to engage you in a process of learning, skill building, reflection, networking and renewal. The conference will showcase innovative developments, explore current issues, challenge your concept of hospice palliative care, and provide opportunities to reflect on the meaning and impact of working in the field of hospice palliative care.

The program will include a meeting of the Pediatric Interest Group.

Further information is available on the CHPCA website at:

www.chpca.net

Video Premier
Precious Lives
Meaningful Choices

Presented by the Calgary Pediatric Palliative Care & Grief Support Service

Synopsis of Video

Within the population of children & families requiring palliative care, there are children with multiple special needs. The families of these children embrace their child's life with courage, love and hope in the midst of uncertainty. In this film you will meet four families who share their experiences. The families discuss:

- Their child's condition and the complex care they require
- Conversations with health care professionals
- Living with uncertainty & hope
- Finding meaning in their experiences
- The death of one of the children

Please join the film makers, featured families, and Calgary Health Region staff for this event on

Monday, December 4, 2006

1:00-2:00 pm

Alberta Children's Hospital

Auditorium

Please RSVP to Rhonda

Poetker @ (403)955-7744 by November 23, 2006 for the premier.

For further information, or to order the video, Rhonda can be reached at:

Rhonda.poetker@calgary

healthregion.ca

Alberta Children's
Hospital Update

Research activities include a study on Cultural Competency in Pediatric Palliative Care and our participation in the Parent Caregiver Study funded by the CIHR NET in Pediatric Palliative Care.

Hospice and Respite

The long awaited Pediatric Hospice and Respite facility will soon become a reality in Calgary, with the current initiative underway to build the "Rotary Flames House". This has been made possible through the generous sponsorship of the Calgary Flames Hockey Team and our local Rotarians, as well as through the committed efforts and solid support of The Child and Women's Health Portfolio.

The future possibilities for our program are embodied in the energy of this project. It is on that note that I thank you for the opportunity to share our local activities within our Canadian Hospice community.

Submitted by

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