



# Net News

## CNPCC Meeting at the 2005 CHPCA National Conference

The Canadian Hospice Palliative Care Association (CHPCA) National Conference was held September 25th-28th in Edmonton, Alberta. The CNPCC met for 3 hours on the first day of the conference during the time allotted for special interest groups. This was a fabulous opportunity to connect with others who work or have an interest in pediatric palliative care.

Some of the key items

identified as priorities for the future include:

- Consensus on Norms of Practice for Pediatric Hospice and Palliative Care
- Core pediatric palliative competency for the adult palliative care fellowship program
- A national fellowship program for pediatric palliative care
- Fundraising for the CNPCC

- Public education—this resulted in the addition of a “media watch” area on the CNPCC website in order to help the CNPCC be aware of media coverage that may impact on the provision of palliative and end-of-life care for children

Minutes of this meeting and others are available on the CNPCC website at <http://cnpcc.ca>

## CNPCC Survey on Pediatric Palliative Care

The preliminary results of the CNPCC Survey on Pediatric Palliative Care are now available on the CNPCC website at:

<http://cnpcc.ca>.

Some highlights to share about the results include:

- 229 surveys were returned
- 86 % of the respondents provide care

&/or services to children with life-threatening illnesses or life-limiting conditions

- Only 40 % of the respondents have a specific program for children with life-threatening illnesses or life-limiting conditions
- 70% of respondents

thought that not enough services were available or children with life-threatening illness

Thanks to all of you who completed the survey! A special thanks to the CNPCC executive and provincial survey champions! Further results will be shared in future issues of the newsletter.

### CNPCC Net News

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### Special points of interest:

- ☺ Preliminary results of the CNPCC survey
- ☺ Information about the palliative and bereavement care service at Sick Kids

### INSIDE THIS ISSUE

CNPCC Meeting at CHPCA National Conference	1
CNPCC Survey—Preliminary Results	1
Program Highlight—Toronto	2
Griefworks BC	4
Still not there - Quality End-of-life care—A progress report	4

# Program Highlight— The Palliative and Bereavement Care Service at Sick Kids

## Celebrating 20 Years of Care

### *A Brief Intro to Sick Kids*

The Hospital for Sick Children or SickKids, as we are now affectionately known, is situated in Toronto, Ontario and is the largest hospital providing specialized care for children in Canada. As a provincial children's centre located in a large multi-cultural urban city, we provide care for children who come from all over the city, province and country, many of whom speak a variety of languages. Sick Kids provides care to about 265 inpatients each day, sees over 154,000 children in outpatient visits each year and treats over 43,000 children annually in its Emerg. Over 200 children who are cared for at Sick Kids die each year, with the majority dying in hospital.

### *History and Overview of the Palliative and Bereavement Care Service*

The Palliative and Bereavement Care Service (PCBS) at The Hospital for Sick Children has been steadily growing since its creation in 1986 as one of the first hospital based paediatric palliative care services in North America. What started as a one person nursing consult service servicing the neurosurgical population and under the umbrella of Clinical Pharmacology is now a thriving team within the dynamic Haematology/Oncology, Immunology, BMT, Allergy and Immunology Child Health Services Cluster. Referrals to the PCBS have significantly increased over time, from 15 pa-

tient referrals in 2000 to 68 referrals in 2003 to 94 referrals in 2004. As well as providing care at the hospital bedside, our team supports families who have chosen a home death in their communities and their health care providers (this accounts for about 50% of our patient group). Our patient volume ranks us as one of the busiest palliative care services alongside Montreal Children's Hospital and Canuck Place/BC Children's Hospital.

Sick Kids, like most children's hospitals, does not have a designated palliative care unit. However, family rooms are designated for dying children and their families, in our 2 intensive care units (neonatology and critical care). A recent donation from the Children's Wish Foundation has enabled us to establish a comfort care cart for our paediatric medicine floor. The cart is a mobile unit consisting of items that help make the dying child's hospital room more comfortable (we've included things like comforters, a laptop, sensory stimulation toys, aromatherapy products, etc).

### *An Introduction to Our Team*

We are a small interdisciplinary team made up of a .5 palliative care physician (Dr. Christine Newman), a full time clinical nurse specialist/nurse practitioner (Maria Rugg), a .8 coordinator/social worker (Laura Beaune) and an externally funded music

therapist (Ruth Roberts). We are closely affiliated with palliative and bereavement coordinators in the hospital's CCU (Vera Nenandovic) and NICU (Lori Ives-Baine) and draw on clinical expertise such as chaplains, social workers, physicians, a therapeutic clown and discharge planners from across the hospital and the community.

We would like to formally thank Maria Rugg for her tenacity, her hard work and her never ending generosity to the children and families that she has care for over the years. Maria has been the heart and soul of our team since her arrival to palliative care in 1993. Congratulations Maria and to the whole team for providing excellent care on our upcoming 20th anniversary of providing palliative care at Sick Kids.

### *What We Do*

We work in collaboration with primary health care teams at HSC or within the community to provide the following:

- Consultation/shared care regarding pain or other symptom management issues
- Consultation/shared care around discharge planning of the palliative care patient
- Consultation to primary care teams regarding difficult conversations, decision making, care for the caregiver support

- Consultation/shared care regarding palliative, end of life and bereavement care
- Provide home visits with the Greater Toronto Area or within a 90 minute drive of HSC to support a child's discharge home, medical crisis, death at home and/or after care/bereavement care.
- Participation in program development, policy/advocacy and research initiatives

### ***Community Highlights***

We are excited to be sharing Dr. Christine Newman in her new role as Co-Director of the newly developed Max and Beatrice Wolfe Children's Centre, affiliated with the Temmy Latner Centre for Palliative Care, Toronto. This new program will focus on providing interdisciplinary care for the dying child at home and for children of dying parents.

In the Spring of 2005 the Palliative Care and Bereavement Team hosted a pre-conference workshop at 15th Annual Provincial Conference on Palliative

and End-of-Life Care, Toronto, Canada called "*Adding Life to a Child's Time: Paediatric Palliative Care Issues and Skills*". A portion of this presentation will be published in *Rehabilitation & Community Care Medicine* this Fall.

Maria Rugg has been and continues to be an active member of the Board of Directors of the Rose Cherry's Home for Kids since the dream of building a stand alone home for respite and palliative care for children in Ontario began in 1995. Maria proudly reports that Rose Cherry's Home for Kids, located in Milton, Ontario, is now open,

providing 4 to 6 respite beds and in the near future, 2 palliative care beds and services.

### ***Educational Highlights***

In the Fall of 2004, in partnership with a number of community organizations, we launched a 4 day 6 module course called "Pediatric Hospice Palliative Care: Offering Excellence" which has been offered to over 60 professionals and volunteers to date.

Thanks to Maria's hard work we lead an initiative to provide monthly transcontinental telehealth educational rounds that are specific to the field of paediatric palliative care.

Nursing, physician, volunteer, research and social work internships and fellowships are offered through the team and we are especially excited about having Dr. Mike Harlos join us for a month this coming Fall.

### ***Policy Highlights***

Members of our team lead or are members on a number of hospital and community based committees specific to advocate for palliative care issues. For example we are members of the tissue and organ donation committee; the pediatric pain research interest group; haematology/oncology bereavement committee and the invasive long term ventilation committee. Our advocacy initiatives extend into the community as members of regional, national and international palliative care networks.

### ***Research Highlights***

In 2004 we initiated the Pediatric End of Life Research Group which received start up grant dollars from the Research Institute at Sick Kids. Currently, members of the group include: Laura Beaune, Maria Rugg, Dr. Beverley Antle (social work) and Dr. Maru Barrera (psychology) and we are looking to formalize our partnership with Dr. Rose Steele (nursing professor, York University) in the near future. The research group is involved in a number of research activities as principal investigators, co-investigators and collaborators. Some of our current research activities include: a CIHR grant to study the psychosocial and health service consequences of SARS on children and their families; a Sick Kids Foundation grant to evaluate an integrated service delivery model for pediatric palliative care; a second CIHR grant to explore the parent's experiences of hope when a child has cancer and a Sick Kids Foundation/B.R.A.I.N grant to develop a secure website to support the hope research project.

*Article by Laura Beaune—  
Palliative and Bereavement  
Care Coordinator*

**We would like to feature different programs from across Canada, please share information about your program, the people who work with your program and the things you are doing and have done! Just email your information to:**

**newsletter@cnpsc.ca**

# Griefworks BC

## Resources

### for Grieving Children, Teens and Adults

Griefworks BC began in January 2001 as a partnership between BC's Children's & Women's Health Centre and Canuck Place Children's Hospice in Vancouver, British Columbia as a result the identified lack of service coordination within the organizations and lack of coordinated access to bereavement services around BC.

[www.griefworksbc.com](http://www.griefworksbc.com) @2005 is for both service providers and grievers to access loss and grief information, seek out support resources in BC communities and beyond, and connect to support groups on-line. There are also selected articles in Chinese, an Honour Page, an on-line bereavement support training program and a bookstore.

75 printable articles for children, teens and adults discuss responses to loss, helping siblings when a child dies, infant/pregnancy loss, teen loss, grandparents' perspectives, activities for children, and more.

Click on Centres in Your Area to access a 700 entry database, type in the city to reveal & print off a list of resources. 200 entries identify other language service providers with the majority providing Chinese, Punjabi, Korean, Vietnamese, Spanish and French. One can also search on services for the deaf, gay/lesbian, and First Nations communities.

The Honour Page provides a permanent posting of a tribute in honour

of a loved one who has died. (Also available in Chinese) This activity is popular with teens since their developmental stage embraces the need to memorialize the death in a concrete way.

An eight lesson bereavement support training program takes participants through the theory of loss, a self-reflection journey and communication skills. The Bookstore offers:

*A Guide for a Family Caring for a Dying Child, Supporting A Family Caring for a Dying Child, When a Child Dies: A Resource Guide for the Family, When Someone Dies: Supporting a Child in Grief, After the Death: Burial, Cremation, Funeral, Memorial, Traditional Celebrations & Grief, After the First Year, Now What? Children, Teens & Grief: A Guide for the Family (English/Chinese version), and an End-of-Life Information Series for Toddlers, Pre-schoolers, School-age kids and teens @2005.*

For more information about Griefworks BC, call 604-875-2741 or call toll free in BC 1-877-234-3322.

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## Still Not There - Quality End-of-Life Care: A Progress Report

Senator Sharon Carstairs releases Report on the 5-year anni-

versary of: Quality End-of-Life Care: The Right of Every Canadian.

Senator Sharon Carstairs released a Report on June 2, 2005 entitled: Still Not There - Quality End-of-Life Care: A Progress Report.

This report highlights progress made since the release of the 2000 Senate report Quality End-of-Life Care: The Right of Every Canadian.

The updated report highlights key areas that still need to be addressed to ensure that every Canadian can die with dignity, free of pain, surrounded by their loved ones in the setting of their choice.

Highlights of the Report include recommendations in the following key areas:

- National Strategy
- Patient and Caregiver Support
- Training and Education for Formal and Informal Health Care Providers
- Government and Citizens Working Together
- Planning for the Future

A copy of the Report is available at: [http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare\\_e.asp](http://sen.parl.gc.ca/scarstairs/PalliativeCare/PalliativeCare_e.asp)

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