



Net News

The *Hear My Voice* Activity: A Resource to Support Advance Care Planning for Children and Youth

Alberta **Children's** Hospital

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It is widely acknowledged within the field of palliative care that advance care planning is an integral component of care. However, initiating these conversations and supporting families through a process of reflecting on their own values, beliefs, and wishes can be a challenging process. The following article will provide the background of the *Hear My Voice* activity that has been developed for families to support advance care planning for children and youth. In addition, a web-based link is provided to the resource thereby making this resource accessible to professionals and families.

Background:

The purpose of this project was to develop resources for families of children with potentially life-threatening illnesses to encourage an exploration of decision making through the

time of illness and around the end of life. Within the pediatric population, decisions are most often made along the trajectory of a child's progressive life-limiting illness, or in the context of a sudden traumatic event. Accordingly, within this population, the voices of multiple family members need to be attended to: the child or youth, the parent/guardian, the siblings and extended family. Therefore, an interactive family activity was developed to encourage inclusion of all ages and all relationships to the child or youth coping with an illness.

This project commenced at Alberta Children's Hospital in Calgary, Alberta, during the summer of 2008. The activity was developed through a collaborative effort involving a wide range of groups including physicians, nurses, social workers, child life specialists,

play therapists, chaplains, parents and youth. The activity was launched in the spring of 2009 following multiple revisions to the original design.

The Resource:

The *Hear My Voice* activity is an innovative resource specifically developed to support the process of advance care planning for children and youth, though it could be useful for advance care planning for adults as well. The activity includes 52 cards that explore thoughts, values, and beliefs related to specific domains of care: physical, social, emotional, spiritual/cultural, and future planning. The activity has been designed to be flexible and adaptable to family needs. It is suitable to be facilitated by a professional or to be used independently by families. The resource does not replicate existing *continued on page 2*

Special points of interest:

- *Hear My Voice*—a great resource for your practice!
- CHPCA Conference in October!

INSIDE THIS ISSUE

Hear My Voice Activity	p.1+2
CNPH, CHPCA Conference, ELNEC & NHPCCO Conference	p.2
TRAC-PG Research Symposium	p.3
Paediatric Hospice Palliative Care Course—SickKids	p.4

The *Hear My Voice* Activity *continued...*

resources but rather offers something "new" to the limited resource pool for advance care planning for children and youth.

The activity has been intentionally developed to facilitate conversations that include multiple family members of varying ages. The *Hear Our Voice* workbook is currently being developed to complement this resource as an additional or an alternative method of exploration to support decision making in the face of a child's progressive life-threatening illness.

You can print your own *Hear My Voice* activity at:

<http://www.calgaryhealthregion.ca/programs/advancecareplanning/>

and by clicking on the Pediatric Policy in the menu.

Submitted by: Meaghen Johnston, MSW & Sharron Spicer, MD, FRCPC; Alberta Children's Hospital

END-OF-LIFE NURSING EDUCATION CONSORTIUM

ELNEC-Pediatric Palliative Care Training Program

Presented in collaboration with St. Jude Children's Research Hospital

Held at:
St. Jude Children's Research Hospital
Memphis, TN
October 16-17, 2009

Registration form and course information
available on the ELNEC website:
www.aacn.nche.edu/elneec

The END-OF-LIFE NURSING EDUCATION CONSORTIUM (ELNEC) provides nurses with essential training in palliative care, along with the knowledge and resources to share this content with other nursing colleagues in clinical and educational environments, in order to improve end-of-life care for children and their families.



Please consider joining us and/or promoting the 2nd Annual Pediatric Intensive held as part of the NHPCO Clinical Team Conference **September 24-26, 2009** in Denver Colorado. Information available at: www.nhpco.org

The Pediatric Intensive features a range of clinically-oriented content designed and taught by leading experts in pediatric hospice and palliative care. It also features a Preconference Seminar, Hope for the Best, Plan for the Worst: Decision-Making and Advance Care Planning for the Child with a Life-Limiting Condition presented by Mary Kay Tyler, MSN, CNP, Sarah Friebert, MD, & Suzanne S. Toce, MD.

To submit information, email
Simone Stenekes, the
newsletter editor at:

newsletter@cnpcc.ca

Canadian Network of Pediatric Hospices (CNPH)

The mandate of the CNPH is to foster collaboration among pediatric hospices in Canada. The Network will use existing standards of care and guidelines and adapt them to free-standing pediatric hospices. CNPH will develop a model and guidelines for the development and operation of a pediatric hospice, which will serve as a framework for the endorsement of pediatric hospices in Canada.

Current participating hospices are: Canuck Hospice (in Vancouver), Le Phare/The Lighthouse (in Montreal) and Roger's House (in Ottawa).

For more information on this network: <http://cnph.ca>



Canadian Hospice Palliative Care Conference

Congrès canadien de soins palliatifs

October 18-21, 2009 in Winnipeg, Manitoba

For more information: <http://www.chpca.net>

We are planning to get together for dinner in the evening with pediatric palliative care providers on **Monday, October 19th.**

If you are interested in participating, please email [sstenekes@wrha.mb.ca](mailto:ssenekes@wrha.mb.ca) so that we know how many people will be attending. Further details will be sent by email in early October.



PEDIATRIC PALLIATIVE CARE

INAUGURAL FULL DAY RESEARCH SYMPOSIUM

DISPELLING MYTHS: BENEFITS AND CHALLENGES IN RESEARCH WITH CHILDREN & FAMILIES

Grand Rounds • Panel Discussion • Café Scientifica
Parent & Researcher Workshops • Evening Social

WEDNESDAY OCTOBER 14, 2009 at SickKids

Open to family members, researchers,
clinicians, and volunteers

FREE REGISTRATION:

Laura Beaune

laura.beaune@sickkids.ca

More information at www.tracpg.ca

Sponsored by: SickKids Foundation
Sasha Bella Fund

TRAC  PG

Team for Research with Adolescents and
Children in Palliation and Grief



SickKids®

PAEDIATRIC HOSPICE PALLIATIVE CARE: OFFERING EXCELLENCE TOGETHER

*October 13th, October 27th,
November 10th, November 24th*

This 4-day course is designed for all professionals (nurses, physicians, social workers, etc) and volunteers in hospitals and the community who care for dying children and their families.

Topics will Include:

- Bio-ethical Considerations
- Communication
- Decision Making
- Team Dynamics
- Working with Children & Families
- End of Life Care
- Anticipatory Grief
- Mourning & Bereavement
- Care for the Caregiver
- Spirituality
- Assessment and Management of Symptoms

Registration Fee: \$450.00 per learner (includes lunch and breaks)

SickKids staff members are encouraged to make use of the Education Fund through HR

For more details and to register contact Sabrina Menezes at 416.813.6905

Offered by the Palliative & Bereavement Care Service at the Hospital for Sick Children