



Net News

Improving communication during the palliative care of children with brain tumours – learning from experience

From 1994-1998, cancers of the brain and spinal cord were the second most common group of cancers among Canadian children and youth, which translates to about 60 deaths per year in Canada, due to childhood brain tumours. The palliative care of these children focuses on maximizing quality of life, with the goals of alleviating physical pain, fear and anxiety while providing adequate medical, spiritual, social and psychological support to the child and family.

Management of a child's symptoms requires a good understanding of his or her personal feelings. A consistent, reliable and efficient means of communication, verbal or non-verbal, is critical for establishing and maintaining supportive relationships among the child, family and health care team. Open and honest communication bears substantial rewards encompassing spiritual and psychosocial domains.

The majority of children with brain tumours resis-

tant to treatment rapidly lose their ability to speak and write due to increasing neurological impairment or fatigue. It becomes increasingly difficult to determine whether the child is in pain, uncomfortable or to simply decipher their preferences and wants. Compromised communication can be emotionally devastating, significantly increasing the child and family's distress and diminishing their ability to cope. Unable to communicate

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CNPCC Net News

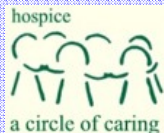
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Special points of interest:

- Mentorship initiative in Quebec
- Getting together at the CHPCA conference in Winnipeg

Mentorship Initiative



It seems like yesterday but a year and a half has passed since we experienced an extraordinary mentorship initiative involving 3 great Canadian palliative care organizations. The staff and volunteers of Roger's House (Ottawa)

benefited greatly from the support and mentoring received from Canuck Place Children's Hospice (Vancouver), the Hospice at May Court (Ottawa), and the IWK Palliative Care Program (Halifax) in the spring of 2007. Since then we have been anxious to

share our emergent expertise, knowledge and skill.

Roger's House Hospice (Ottawa, ON) in collaboration with the Children's Hospital of Eastern Ontario (CHEO) Palliative Care Outreach Team has

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Improving Communication

hopes, fears and feelings, the child may experience a loss of independence and autonomy and become withdrawn and isolated. While communication skills are impaired, the child's intellect is often intact, further contributing to frustration and despair. With progressive disability and generalized weakness, there is a pining need to set up alternative communication strategies, such as lip reading, pointing, or augmentative communication devices.

In order to meet this need, our research team developed and administered an interview with 13 bereaved families who had a child who was voiceless while in the palliative care of the Brain Tumour Program at Sick-Kids Hospital, to collect and learn from their experiences. Interviews focused on 3 main themes: communicative needs and abilities of dying children; important messages and issues for families to discuss; and suggestions for the design of a computer-based communication device.

Participants described a range of strategies used to communicate with their children including: framing questions in order for children to

respond with 'yes' or 'no'; developing signals using facial expressions, hand gestures and sounds; creating picture and message boards; and computer-based augmentative communication devices. While picture or message charts and computer-based devices created access to a greater number of messages, some families felt that strategies requiring an interface between the parent and child detracted from personal and emotional aspects of communication.

Knowledge of these experiences and preferred, modifiable strategies would be invaluable to families and children who do not have access or the ability to use a computer-based device, or in conjunction with such technology. To enhance communication opportunities for children in palliative care so that preferences, needs, concerns and emotions can be appropriately respected and addressed, this team is working to compile this information in a clear, comprehensive handbook for families, to assist them in developing effective and meaningful strategies for communication.

Submitted by: Ceilidh Eaton Russell

Originally published in: HotSpot: The Newsletter of the Rapid Response Radiotherapy Program of Toronto Sunnybrook Regional Cancer Centre, Volume 9 Issue 2. (2007)



Canadian Hospice Palliative Care Conference

Congrès canadien de soins palliatifs

October 18-21, 2009 in Winnipeg, Manitoba

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

It would be nice to get together for a dinner with pediatric palliative care providers. Since the conference is in Winnipeg this year, I thought I'd take on the role of social coordinator and plan for us to meet at a location close to the conference center on one of the evenings when other events are not planned. If this is something you are interested in, please email me at sstenekes@wrha.mb.ca and I will send out further info via email.

Mentorship Initiative

embarked on a mentoring initiative with la maison Mathieu-Froment-Savoie, a hospice in the Outaouais (western Quebec). In the past, la maison Mathieu-Froment-Savoie has offered mostly adult palliative care services but it is poised to offer pediatric palliative care in its new and expanded location. At their new location, one pediatric bed will be available for respite and end of life care. This is part of a larger initiative supported by the "Agence de la santé et des services sociaux de l'Outaouais" to enhance palliative care services and supports in this region of Quebec.

We have learned so much in the past 3 years at Roger's House! We have had great mentors and have collaborated with many organizations! It is felt that it is time to share our expertise regarding the care of children with life limiting illness in the hospice setting. We are pleased and proud to be able to assist the staff and volunteers of la maison Mathieu-Froment-Savoie develop and expand their pediatric service in the Outaouais. We wish them well in their new home!

Submitted by:

Lynn Grandmaison Dumond
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PEDIATRIC PALLIATIVE CARE RESOURCES

This section of the newsletter is continuing to highlight pediatric palliative care resources. If you would like to

recommend any resources to include, or if you would like to submit informa-

tion on a resource, just email:

newsletter@cnpsc.ca



Excerpt from Introduction to *Living Dying*: "This book is intended to help you to understand the experience of a child or teenager, to know what support and information they need; and how to meet those needs in healthy, meaningful ways. Questions, quotes and strategies are based on clinical work with families who have helped children and teenagers learn to live with the death of a loved one. Strategies described in this book are meant to help you support a child or teenager no matter what their relationship to the dying person—or if it is the child themselves who is dying—and regardless of whether the death was expected or sudden and or even if it has already happened.

The aim of this book is to help grief be manifest rather than pushed aside, so that it can be shared by loved ones, offering a chance to support one another and to find a new way live with a deeper understanding of life and relationships, together"

An excellent Canadian resource for families with children affected by the illness and death of someone important in their life.

Copies can be purchased for \$7.50 per copy or \$5 if greater than 5 copies are purchased. For further information, contact:

info@tlcpc.org

LIVING DYING

A Guide for Adults Supporting Grieving Children and Teenagers

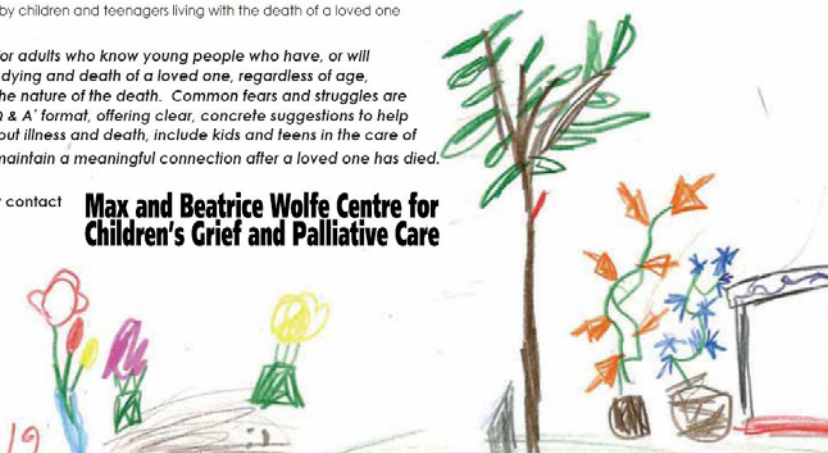
Written by Ceilidh Eaton Russell, CCLS

Art work created by children and teenagers living with the death of a loved one

'Living Dying' is for adults who know young people who have, or will experience the dying and death of a loved one, regardless of age, relationship or the nature of the death. Common fears and struggles are explored in a 'Q & A' format, offering clear, concrete suggestions to help readers talk about illness and death, include kids and teens in the care of the dying and maintain a meaningful connection after a loved one has died.

To order a copy contact
info@tlcpc.org

Max and Beatrice Wolfe Centre for Children's Grief and Palliative Care



Email your suggestions for pediatric palliative care resources to include in the next newsletter!

newsletter@cnpsc.ca

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