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SCOTTANDERSON SOUTHWEST BOOSTER The following article is the fourth in a series of stories produced by the Southwest Booster to raise awareness of Palliative Care in the Southwest.

# Canadian Virtual Hospice answers hard to ask End of Life questions

Getting a direct answer for a hard-to-ask question, or having access to a comprehensive resource of palliative care issues, is only a key stroke away for people accessing the Canadian Virtual Hospice website ([www.virtualhospice.ca](http://www.virtualhospice.ca)). The multitopic website has been a vital palliative care resource for both the public and healthcare professionals since being launched on-line in 2004. Over the ensuing nine years the site has blossomed into an award-winning, key source for family members who often need guidance and detailed information regarding life-limiting illness, end of life, loss and grief.

"There are so many things that people do not know about serious illness, dying and death because it's not part of their experience. Canadian Virtual Hospice provides an accessible place to find trusted information and ask questions. We help people to have informed conversations with health care providers about quality care. Visitors tell us that the information on the website gives them piece of mind," explained Shelly Cory, Executive Director of the Canadian Virtual Hospice.

As a hub for a diverse range of evidence-based information, the website tackles palliative care topics such as emotional health, spiritual health, symptoms, providing care, communication, decisions, financial assistance, final days. The site generates 1,200 to 1,500 unique visits every day, with a full 75 to 80 per cent of these visits come from across Canada. However, they are generating international traffic, having been accessed by individuals in over 200 countries, with the majority of the out-of-country traffic coming from the United States, Australia, France and UK. In fact, in June 2010 the website was selected for a silver award at the U.S.-based Health and Sciences Communication Association's Media Festival.

"One of the benefits of Virtual Hospice is you know that the site has been developed by a team of health experts who are among the best in their field in Palliative Care," she said. "There's such an incredible amount of trusted information you can find on the site."

Cory feels that the website makes a profound difference in connecting with people, despite the lack of direct face-to-face contact.

"So many people come to the site and say 'we felt all alone in this'. That doesn't mean that they're physically isolated, it means that they felt emotionally isolated," she points out. "They come on the site and they say 'we don't feel alone anymore.' They see that the issues and questions they are have are common to many people; that there are answers. That they can get information that they can trust." The Ask A Professional section of the website was launched nine years ago and at the time was unique in the world by giving the public direct access to healthcare providers on-line.

This section of the website allows people to open up more and ask some tough questions confidentially and without fear of judgment.

"What we're finding

is that the anonymity of the Internet is really enabling people to ask some very difficult questions. When you read some of the questions you wonder whether they would have felt comfortable asking these questions face-to-face, even to a trusted healthcare professional or close friend."

Questions asked range from queries about physical symptoms, emotional issues, spiritual issue, and specific concerns over what to expect as illness progresses.

An interdisciplinary team is in place to handle these wide ranging inquiries, with team members including palliative care physicians, clinical nurse specialists, a psychosocial consultant, spiritual care advisors, plus ethicists. Through a collaborative team approach they provide detailed, personal answers that are based on the best and most recent evidence. The clinical team is led by Dr. Mike Harlos, winner of the 2007 Eduardo Bruera Award recognizing national excellence in the field of palliative medicine. The team has generated answers to over 1,800 questions since going on-line. A full 60 per cent of questions are from patients, family, friends, and others involved, with the remaining 40 per cent of questions submitted by healthcare providers who are seeking advice regarding difficult or complex cases.

The only thing necessary to ask a question via the website is a valid email address and a postal code.

"We protect

people's anonymity to make it as easy as possible to ask the questions they need answers to," Cory noted. "Ask A Professional is really a powerful, dynamic opportunity for people to be very honest about the questions that they have and what they are feeling and receive an answer from an incredibly caring team of people."

There is also a section of the website which features answers to over 100 of the most common questions asked (all personal or identifying information has been removed to protect confidentiality). This section called

Asked and Answered contains answers to previously asked questions and the team's responses on a range of topics including what to expect with various illnesses, nutrition, medications, grief and loss, dying at home, symptoms of illnesses, decision making and communications.

"It serves a number of functions. Firstly, it tells people they are not alone in what they're going through. A lot of people think certain concerns are unique to their situation, but Asked and Answered shows patients and families that others have travelled the same road, faced the same challenges," Shelly explained.

"Patients and families find it a very useful, rich source of information. Healthcare providers are telling us they use the responses to help frame their discussions with patients and families about difficult issues."

The Topics section includes over 60 articles written by the Virtual Hospice health care team on symptoms such as confusion, shortness of breath, anxiety, sleeplessness; provides information on emotional and spiritual health and helps families negotiate a variety of concerns and issues.

Cory points out the most downloaded article on the site is entitled When Death Is Near, with over 6,000 downloads a month.

"When Death Is Near helps people prepare logistically and emotionally for what's ahead. It's very difficult for healthcare providers to pinpoint how long someone has to live. It's a common question but it's very difficult because every situation is different."

"Many healthcare teams across the country are providing this article to families so they have the information and can read it when they are ready. It helps them feel more informed."

Caregivers can find practical information, including a very popular caregiving series video that provides easy-to-follow demonstrations of 16 common tasks such as making a bed with someone in it, how to help someone move safely from a bed to a wheelchair and administering medication.

Another feature on the

site that is blossoming is a Discussion Forum that allows people to share their feelings and reach out to others for support and advice. The recently reorganized portion of the site is a moderated forum which tackles numerous discussion topics.

Cory indicates that recently a Forum member described this important networking and sharing environment as akin to a "big, warm blanket".

"When you think about people living in rural and remote regions, who might not have access to support groups that are available in larger communities. Or for people who can't leave the house, who can't access others easily because of geography, illness or weather. This is an opportunity to link with people who share your experiences, fears and hopes, from the comfort of your home, and to do so anonymously. People can connect as much or as little as they want, in a safe, supportive environment. There's no pressure, there are no expectations."

Since being relaunched a year ago, the Discussion Forum has hosted over 2,200 posts, and each individual comment is seen by at least 200 other users.

"Patients, caregivers, other family members, are getting support on living with

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illness and dealing with grief from others who have traveled the same road."

In addition to demystify life-limiting illness, dying and grief for patients and families, the site supports healthcare providers to provide quality palliative care.

It includes a For Professionals portal hosting a series of features for healthcare professionals, including peer written articles and research, tools to support practice, private networks to allow people working in palliative care to network and collaborate.

The variety of features on the site makes it an invaluable tool which can be accessed 24 hours a day.

Is it any wonder Virtual Hospice has been ranked as one of the best health websites in the country by the Canadian Health Libraries Association.

"We're a one-stop-shop. People can come onto Virtual Hospice and find practically any information on end of life they're looking for, whether you are a patient or family, or a healthcare professional."

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tual Hospice.

The theme of Hospice and Palliative Care Week was "Canadians are aging. We've done the math. Have you?" Seniors are currently the fastest growing age group in Canada, and it is estimated that by 2036 seniors aged 65 and over could account for up to 35 per cent of Canada's population.

"This statistic will require a need for more coordination of palliative care services and a higher awareness of the benefits of integrated palliative care efforts.

Cory shared a quote from one site user who benefited from information provided through the site during an

elderly parents last year of life.

"My mother passed away on January 21. She had excellent care and was at home until the end. Thank you so much to everyone who helped us in understanding the illness and answering many questions we had. The oncologists, the palliative care doctor and the nurses were very helpful but as everyone knows, there are many other patients and just so many hours in a day. It was very helpful to be able to go to CVH and access Ask a Professional and tools offered on the website. It gave us a lot of reassurance," the site feedback response stated.