braintumour
foundation
OF CANADA

Ask the Expert Information Sheet

What is advance care planning and why make it an important part of your care?

By: Catriona Leckie, NP

The diagnosis of a brain tumour brings a period of rapid change for you and your family. You are faced with new symptoms, surgery, a new diagnosis and treatment decisions, all in a very short period of time. Given these realities, it is extremely important for you and your family to understand your illness and the treatment options available. It is equally important that health care providers understand your beliefs, values and wishes, and how these guide you in your decision-making.

Advance care planning is a process used to enhance communication about your health care preferences between you, your family and your health care providers. The most important part of advance care planning is initiating and continuing the conversation. In order to do this, you are encouraged to learn more about your diagnosis and to think about what is important to you when faced with treatment decisions. These conversations lead to a shared understanding of the benefits and burdens of treatment in light of your goals and wishes. Advance care planning is not just about medical decisions but may include conversations around your spiritual needs and/or other wishes for end-of-life care. These conversations provide your substitute decision-maker with guidance and confidence if they need to make decisions on your behalf.

Research shows that these conversations don’t always take place: An Ipsos-Reid poll performed in March 2012 found that only 14 per cent of Canadians had ever heard about advance care planning and only 9 per cent of patients had ever spoken to a health care provider about their wishes for care. This is unfortunate as studies indicate that advance care planning improves satisfaction and quality of life for patients and their families. Loved ones experience fewer symptoms of depression, anxiety and post-traumatic stress if these conversations occur.

Advance care planning is like a form of insurance; something put in place and only used when necessary.

... continued on Page 2

For additional Information Sheets or to learn more about other brain tumour topics, visit **www.BrainTumour.ca**

Brain Tumour Foundation of Canada is generously supported by individuals, corporations and employee groups. It is through the tireless dedication of donors that help is available for anyone affected by a brain tumour, including patients, survivors and their loved ones.

While we are capable, we all should reflect on our values and beliefs, talk about them with the people close to us, choose someone who will represent us well, and ultimately write our wishes down to keep others informed. If the topic is not brought up by your health care providers, bring it up yourself. Ask the questions and engage in discussion with your health care team. It will make a difference, ensuring your voice is always present in health care decisions.

For further resources about Advance Care Planning, please visit the online Northey Family Library, found at www.BrainTumour.ca.

ABOUT THE AUTHOR:

Catriona Leckie is a Nurse Practitioner in Neuro-Oncology at the Tom Baker Cancer Center in Calgary, AB. Catriona has worked in Neurosciences since 1991 as a staff nurse, nurse clinician and nurse educator as well. Catriona was the recipient of Brain Tumour Foundation of Canada's 2010 Canadian Association of Nurses in Oncology (CANO) award to acknowledge the exemplary work of nurses in the area of neuro-oncology nursing. The purpose of the award is to promote the dissemination of information related to the nursing care of children and adults with brain tumours and their families. Catriona has also spoken at the Annual Calgary Health Care Professionals' Workshop facilitated by Brain Tumour Foundation of Canada.

Additional support, information and education offered by Brain Tumour Foundation of Canada:

Adult, Pediatric and Non-Malignant Brain Tumour Handbook available in English and French.

"A Friend in Hope" children's storybook available in English and French.

20+ Adult Support Groups across Canada (in-person and virtual)

Toll-free information and support line

BrainWAVE Pediatric Support Program

Print BrainStorm Newsletter
Email Newsletters:
- E-BrainStorm
- Peace of Mind

"Grey Matters" Blog

All patient resources are available free-of-charge in Canada. Call 1-800-265-5106 or visit www.BrainTumour.ca for additional details and information.