

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

Brain Tumour Foundation of Canada Information Sheets are provided as an informational and educational tool and are not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute for medical care. We urge you to seek specific medical advice on individual matters of concern.

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.

Ask the Expert Information Sheet

Are "Palliative Care" and "Supportive Care" one and the same?

By: Dr. Brenda Sabo, RN, PhD

"Palliative care" and "supportive care" are often used interchangeably leading to confusion among health care professionals, patients and families. The World Health Organization (WHO) defines palliative care as, "an approach that improves the quality of life of patients and their families...through the prevention and relief of suffering..." (http://www.who.int/cancer/palliative/ definition/en/). In contrast, supportive care may be considered an intervention to address disease or treatment related symptoms. This care includes supporting the patients with his / her physical, psychological, emotional, spiritual, and social needs.

In a palliative care approach, emphasis is placed on ensuring a 'good life' not just a 'good death.' It is about how people choose to live out whatever time remains. Further, a palliative approach to care has much to offer and can coexist alongside other treatment modalities. A failure to acknowledge and attend to palliative and end-of-life issues early on may lead to poor patient-familyhealth care professional relationships, decreased quality of life, and increased frequency of invasive treatments with minimal-to-no benefit and a decreased ability to make fully informed decisions.

Why the need for early introduction to palliative care?

Palliative care is an important component to ensuring quality of life, yet timely access to palliative for all Canadians has yet to become a reality. Many factors may play a role in the delay including reluctance on the part of health care professionals, patients and families to engage in conversations about palliative and end-of-life care. The reasons are varied and include the perception that a referral to palliative care means hope will be destroyed, patients will feel abandoned (conversely, the health care professional may feel as if they are abandoning the patient), emotional distress may result and/or health care professionals feeling ill-prepared to address the resulting emotions from such conversations (Anselm et al., 2005; Stajduhar, 2011; Thorne, Hislop, Armstrong, & Oglov, 2005).

... continued on Page 2

you are not alone

you are **not** alone

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. Research also highlights that patients and families want to have conversations about palliative and end-of-life care, want them earlier and wonder why they don't take place (Stajduhar, Thorne, McGuinness, & Kim-Sing, 2010; Thorne, Kuo, et al., 2005).

Given the concerns highlighted in the research about the lack of timely patient referral to palliative care for malignant brain tumors it would seem reasonable to introduce palliative care when patients and families are able to take in information, make informed decisions about end-of-life care and benefit from supportive care. A delay in introducing palliative and end-of-life conversations may result in the patient's inability to convey their wishes as a result of compromised physical, cognitive and psychological / emotional status. Family members also need to have these conversations with health care professionals.

Next Steps

Improving the understanding of palliative care is a necessary first step to supporting quality of life for patients diagnosed with a non-curable, life-limiting illness. Earlier referral to palliative care has been shown to improve quality of life, lengthen life and decrease emotional distress, its role in primary and acute care settings, as well as how to have open, supportive conversations with patients and family members is key to improving care delivery.

References

- Anselm, A., Palda, V., Guest, C., McLean, R., Vachon, M., Kelner, M., & Lam-McCulloch, J. (2005).
 Barriers to Communication Regarding End-of-Life care: Perspectives of care providers. Journal of
- Critical Care, 20, 214-223.
 - Stajduhar, K. (2011). Chronic Illness, Palliative Care, and the Problematic Nature of Dying. Canadian Journal of Nursing Research, 43(3), 7-15.
 - Stajduhar, K., Thorne, S., McGuinness, L., & Kim-Sing, C. (2010). Patient perceptions of helpful communication in the context of advanced cancer. Journal of Clinical Nursing, 19, 2039-2047.
 Thorne, S., Hislop, G., Armstrong, E., & Oglov, V. (2005). Cancer Care Communication: the power to
 - harm and the power to heal? Patient Education & Counselling, 71, 34-40.
 - Thorne, S., Kuo, M., Armstrong, E., McPherson, G., Harris, S., & Hislop, G. (2005). 'Being Known': Patients' perspectives of the dynamics of human connection in cancer care. Psycho-Oncology, 14, 887-898.

Dr. Brenda Sabo is the Associate Director, Undergraduate Program and Associate Professor at Dalhousie University School of Nursing. Until recently she maintained a clinical practice as a psychotherapist with the Cancer Care Program, QEII Health Science Centre in Halifax, NS. Dr. Sabo teaches oncology and palliative care. Her research focuses on quality of life, psychosocial health and wellbeing within the context of cancer and caregiver stress (professional and family).



205 Horton St E Suite 203 London, Ontario N6B 1K7 519.642.7755
1 [800] 265.5106
519.642.7192
www.braintumour.ca

