

□ Introduction

It behooves us as medical professionals to acknowledge the continuum of end of life care. It is an interdisciplinary, total person approach with a goal to allow one an opportunity to achieve physical, emotional and spiritual comfort. The following definitions help us to understand Fraser Health's vision and commitment to providing high quality services that are competent, compassionate and respectful of all people who are dying and their families.⁽¹⁾

Palliative Care

“Palliative care means the specialised care of people who are dying – care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term palliative care is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure.”⁽¹⁾

Hospice Palliative Care

Hospice Palliative Care is the nationally accepted term that “aims to relieve suffering and improve the quality of living and dying”. Hospice palliative care strives to help patients and families address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears; prepare for and manage self-determined life closure and the dying process; cope with loss and grief during the illness and bereavement. Hospice palliative care aims to treat all active issues; prevent new issues from occurring; and promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization; it is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or unmet needs, and are prepared to accept care.”⁽²⁾

End-of-Life Care

“End-of-life care is the term used for the range of clinical and support services appropriate for dying people and their families. The goal of end-of-life care is the same regardless of the setting – to ensure the best possible quality of life for dying people and their families.”⁽¹⁾

Hospice Palliative and End-of-Life Care in Fraser Health: Textbook Resources

In our Fraser Health program we have standardized eight textbooks to support hospice palliative and end-of-life care throughout the continuum of care. These textbooks are available to professional caregivers in their clinical practice. The following eight standardized textbooks are located in our home health care offices, hospice residences and hospitals on the tertiary units, acute medical units and pharmacies.

□ Textbooks

1. Canadian Society of Hospital Pharmacists (CSHP). (2000). Care beyond cure: a pharmacotherapeutic guide to palliative care. Available at http://cshp.ca/productservices/otherpublications/carebeyondcure_e.asp
2. Dickman, A., Schneider, J., & Varga, J. (2005). The syringe driver - continuous subcutaneous infusions in palliative care (2nd ed.).
3. Doyle D, Hanks G, Cherny NI, Calman K, editors. (2004) Oxford textbook of palliative medicine (3rd ed.). Oxford, England:Oxford University Press; 2004, paperback 2005.
4. Ferrell, B. R., & Coyle, N. (Eds). (2006). Textbook of palliative nursing. New York: Oxford University Press.
5. Victoria Hospice Society. (2006). Medical care of the dying. (4th ed.). Victoria, B.C.: Victoria Hospice Society, Learning Centre for Palliative Care.
6. Victoria Hospice Society. (2003). Transitions in dying and bereavement: a psychological handbook for hospice and palliative care. Victoria Hospice Society: Health Professions Press.
7. Waller, A., & Caroline, N.L. (2002). Handbook of palliative care in cancer. Boston: Butterworth Heinemann.
8. Twycross R., Wilcock A., Dean M, Kennedy B., editors. Palliative care formulary. Canadian edition. Nottingham (UK): palliativedrugs.com Ltd; 2010.

□ References

1. British Columbia Ministry of Health. A Provincial Framework for End-of-Life Care : 2006
2. Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, et al. A model to guide hospice palliative care 2002. [cited 2006 November]; Available from: <http://www.chpca.net/publications/norms/A-Model-to-Guide-Hospice-Palliative-Care-2002.pdf>

□ What is Evidence-Based Palliative Care?⁽¹⁾

Four important points are:

- “Evidence-based practice is the conscious, explicit and judicious use of current evidence in making decisions about the care of individual patients.
- It is more difficult to measure quality of life and altered outcomes in patients and families whose illness or frailty make it difficult to collect data.
- Outcome and quality of life measures need to be sensitive to the wider aspects of palliative care, not merely mortality, function, or absence of symptoms.
- Those working in palliative care must use existing research through appropriate systematic reviews to maximize the value of data yielded in caring for patients and families”.

What is a Clinical Practice Guideline (CPG)?

Clinical Practice Guidelines are “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.”⁽²⁾ “Their purpose is to make explicit recommendations with a definite intent to influence what clinicians do.”^(3,4)

Why do we need to use Evidence-Based Clinical Practice Guidelines in Hospice Palliative Care?

We need to use Clinical Practice Guidelines in Hospice Palliative Care to help us provide the best care possible. Hospice Palliative Care Clinical Practice Guidelines will help us to:

- Inform health care providers, patients and families.
- Educate health care providers and the public.
- Include all members of the health care team.
- Improve clinical decision-making.
- Reduce variation in professional practice.
- Ensure equitable allocation of resources.
- Measure the quality of our care.
- Identify opportunities for improvement.
- Improve management of the health care system.
- Provide a foundation for the future.

What are the Hospice Palliative Care Symptom Guidelines?

These guidelines are one of many resources available to health care professionals in Fraser Health to improve health care outcomes in hospice palliative/end-of-life care. These guidelines provide recommendations based on scientific evidence and expert clinical opinion. They provide practical and easy to follow advice to health care providers for effective patient care.

The guidelines are not an all inclusive list of symptom guidelines. Rather, they are intended to be a convenient resource for some of the more common symptoms experienced by adult patients (≥ 19 years of age) and their families who are living with advanced life threatening illness. As they are symptom guidelines only, they do not replace individual patient and family assessment and/or clinical judgment within the scope of professional practice. As these Hospice Palliative Care Symptom Guidelines are a work in progress and as evidence changes, we encourage providers to be aware of this. We welcome and appreciate feedback.

What is the background of the Hospice Palliative Care Symptom Guidelines in Fraser Health?

The Abbotsford Palliative Care Program, under the leadership of Dr. Lynn Kobierski published the first edition of the Symptom Guidelines in 1996. The Fraser Valley Health Region, under the leadership of Dr. Lynn Kobierski updated these Symptom Guidelines in 1999. In December 2001, Fraser Health came into being as the largest health authority in British Columbia. Dr. Lynn Kobierski led the third edition revision of the Hospice Palliative Care Symptom Guidelines in 2005 with a team of Fraser Health authors who are clinical leaders in their field and who have lived and worked with hospice palliative care patients and their families (*see The Authors*).

Prior to publishing the third edition, the Fraser Health Hospice Palliative Care Program, under the leadership of Carolyn Tayler, made seven decisions to guide the review and publication of the fourth edition. The seven decisions were:

1. To partner with the Fraser Valley Cancer Center and engage in a comprehensive review process using the AGREE Instrument to assess the levels of evidence.
2. To adopt and slightly modify the British Columbia Medical Association's (BCMA) Clinical Practice Guidelines and Protocols template.⁽⁵⁾ (Michael Roch, personal communication, November 20, 2006).
3. To form a joint Fraser Health and Fraser Valley Cancer Center fourth edition review team.
4. To remove four sections and realign them to other reference locations within Fraser Health. The four sections removed are: subcutaneous administration of medication, management of malignant cutaneous wounds, compassionate care benefits, and the BC Palliative Care Benefits Program.
5. To have the layout of the Hospice Palliative Care Symptom Guidelines done by Shervin Communications, Inc., Burnaby, BC.
6. To use the Symptom Assessment Acronym "OPQRSTUV".
7. To use Vancouver Style for referencing.

The fourth edition review team re-templated and refined the Hospice Palliative Care Symptom Guidelines using a rigorous process to produce standardized, evidence-based guidelines.⁽⁶⁾ During the fourth edition reformatting and review process, members of the review team may have invited others to provide a fresh perspective. For example, Bruce Kennedy collaborated with Pharmacist Sue North and Della Roberts consulted with Dr. Charles King in the ALS Guideline.

What is the purpose of using the AGREE Instrument?

The purpose of using the Appraisal of Guidelines & Evaluation (AGREE) Instrument is to provide a framework for assessing the quality of clinical practice guidelines. Fraser Health used the AGREE Instrument to ensure a structured and rigorous development process and as a self-assessment tool to ensure that the guidelines were sound before adopting the recommendations. It is suggested that the AGREE Instrument is perceived as reflecting the current state of knowledge in the field.⁽⁴⁾

The number of appraisers for each of the Fraser Health Symptom Guidelines ranged between five and eight. All guidelines received two external reviews by a physician and pharmacist at the Fraser Valley Cancer Center. Each guideline received an overall assessment based on four options: ❶ 'strongly recommend', ❷ 'recommend (with provisos and alterations)', ❸ 'would not recommend' and ❹ 'unsure'. A summary of the quality of the Symptom Guidelines is included (*see Appendix A*).

□ References

1. Higginson IJ. Evidence-based palliative care? *European Journal of Palliative Care*. 1999;6(6):188-93.
2. Field MJ, Lohr KN, editors. *Guidelines for clinical practice. From development to use*. Washington, D. C.: Institute of Medicine, National Academy Press; 1992.
3. Hayward RSA, Wilson MC, Tunis SR, Bass EB, Guyatt G, for the Evidence-Based Medicine Working Group. Users' guides to the medical literature VIII. How to use clinical practice guidelines. Are the recommendations valid? *Journal of the American Medical Association*. 1995;274:570-4.
4. The Agree Collaboration. Appraisal of guidelines for research and evaluation (AGREE) instrument. September 2001 [cited 2006 November]; Available from: <http://www.agreecollaboration.org/>
5. The BC Ministry of Health Guidelines and Protocols Advisory Committee. August 9, 2006 [cited January 18, 2005]; Available from: <http://www.health.gov.bc.ca/msp/protoguides/index.html>
6. Weschules DJ. Development of guidelines for palliative care. *Pharmacotherapy, Journal of Pain and Palliative Care Pharmacotherapy*. 2005;19(4):25-38.

Summary of the Hospice Palliative Care Symptom Guidelines using the AGREE Instrument

Under Development

