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# Hospice Palliative Care Program Symptom Guidelines



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\*Excluding the B.C. Inter-professional Palliative Symptom Management Guidelines (<https://www.bc-cpc.ca/cpc/symptom-management-guidelines/>), each of which has been used with the express permission of the BC Centre for Palliative Care as noted in the FHA Guidelines’ Table of Contents.

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## Acknowledgements

As we strive to advance our knowledge and improve the quality of care in serving patients and their families living with advanced life threatening illness, many hospice palliative care clinicians have contributed to the publication of these Hospice Palliative Care Symptom Guidelines during the past thirteen years. We are greatly indebted to each and every one of these dedicated professionals (*see The Authors*).

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We would like to acknowledge the BC Centre for Palliative Care, who led a provincial, collaborative process to update selected guidelines. Every health authority in B.C. participated and the BC Inter-professional Palliative Symptom Management Guidelines were released in Nov 2017” <https://www.bc-cpc.ca/cpc/symptom-management-guidelines/>.

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***“Synergy is the highest activity of life; it creates new untapped alternatives; it values and exploits the mental, emotional, and psychological differences between people”***

~ Stephen Covey.

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## □ 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.<sup>(1)</sup>

### **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.”<sup>(1)</sup>*

### **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.”<sup>(2)</sup>

### **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.”<sup>(1)</sup>*

### **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](http://cshp.ca/productservices/otherpublications/carebeyondcure_e.asp)
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1. British Columbia Ministry of Health. A Provincial Framework for End-of-Life Care : 2006
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## □ What is Evidence-Based Palliative Care?<sup>(1)</sup>

### 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.”<sup>(2)</sup> “Their purpose is to make explicit recommendations with a definite intent to influence what clinicians do.”<sup>(3,4)</sup>

### 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 ( $\geq 19$  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.<sup>(5)</sup> (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.<sup>(6)</sup> 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.

Barbara McLeod, Fraser Health Palliative Care Clinical Nurse Specialist and Bruce Kennedy, Clinical Pharmacy Specialist Palliative Care collaborated with Dr. Doris Barwich, Executive Director and Kathleen Yue Education Coordinator at the BC Centre for Palliative Care (BC-CPC) on December 10, 2015 following the Fraser Health Palliative Care Practice Council September 25, 2015 recommendation to partner with the BC Centre for Palliative Care to sponsor the revision and updating of the existing 2016© Fraser Health Hospice Palliative Care Symptom Guidelines. The Fraser Health Palliative Care Practice Council wanted to ensure evidence-based Palliative Care Symptom Guidelines but did not have the resources to complete this review process. Therefore, Fraser Health entered into an agreement with the BC-CPC to lead this work.

On October 19, 2016 Fraser Health learned that the BC-CPC agreed to sponsor the revision and upgrading of the existing Fraser Health Palliative Care Symptom Guidelines.

On October 16, 2017 the BC-CPC formally endorsed the B.C. Palliative Symptom Management Guidelines for Inter-Professional Teams. The goal of these guidelines is to support care provision to people with life-limiting illness by health care professionals who are not specialized in palliative care.

Fraser Health launched the ***Fifth Edition of the Fraser Health Hospice Palliative Care Symptom Guidelines***, January 2019. On behalf of the Fraser Health Palliative Care Practice Council (Co-Chairs Patsy Lam and Barbara McLeod) we are grateful to Dr. Doris Barwich and the BC-CPC team who led a provincial, collaborative process to upgrade selected guidelines in British Columbia. We continuously strive for quality and excellence in providing evidence-based care for our palliative patients and families in Fraser Health.

### 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.<sup>(4)</sup>

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: ① ‘strongly recommend’, ② ‘recommend (with provisos and alterations)’, ③ ‘would not recommend’ and ④ ‘unsure.’ A summary of the quality of the Symptom Guidelines is included (see Appendix A).



December 4, 2017 – Fraser Health Palliative Care Practice Council Launch



November 30, 2017 – BC-CPC Launch

## □ References

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## □ Symptom Assessment Acronym

The Symptom Assessment Acronym is a tool to aid in a systematic assessment approach to whatever hospice palliative care symptom you are reviewing. Other aids are available however; in Fraser Health we found this Symptom Assessment Acronym helpful. We recommend this tool for our Fraser Health care providers to guide a consistent and comprehensive symptom assessment in hospice palliative care.

*Assessment using Acronym O, P, Q, R, S, T, U and V* <sup>(1,2,3,4,5,6,7,8,9)</sup>

<b>O</b> <b>Onset</b>	When did it begin? How long does it last? How often does it occur?
<b>P</b> <b>Provoking / Palliating</b>	What brings it on? What makes it better? What makes it worse?
<b>Q</b> <b>Quality</b>	What does it feel like? Can you describe it?
<b>R</b> <b>Region / Radiation</b>	Where is it? Does it spread anywhere?
<b>S</b> <b>Severity</b>	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
<b>T</b> <b>Treatment</b>	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
<b>U</b> <b>Understanding / Impact on You</b>	What do you believe is causing this symptom? How is this symptom affecting you and / or your family?
<b>V</b> <b>Values</b>	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

\* Physical Assessment (as appropriate for symptom)

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