

B.C. INTER-PROFESSIONAL PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES

















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LETTER OF INTRODUCTION - DR. DORIS BARWICH

The BC Centre for Palliative Care is thrilled to have been able to support the development of these updated B.C. Inter-professional Palliative Symptom Management Guidelines for Inter-Disciplinary providers in BC. It has been an exciting project involving many expert clinicians as well as front-line providers to ensure a product that not only ensures best practices but is also accessible and user-friendly for health care providers throughout BC. Enabling quality of life for patients and families with serious illness is core to what we do. Enabling excellence in pain and symptom management 24/7 throughout BC will ensure quality of care and improve outcomes for patients and families.

A big thank you to all our partners who helped make it possible.

BARUN

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BACKGROUND AND DEVELOPMENT OF THE B.C. PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES

The Fraser Health Hospice Palliative Care Program's Symptom Management Guidelines (Fraser SMGs) were first introduced in Dec 2006. Since then, some have been updated and the 4th edition (2012) is currently available on the Fraser Health website¹. Island Health, Interior Health and Northern Health have adapted and adopted the Fraser Health SMGs as Best Practice Guidelines. Vancouver Coastal uses their Community Palliative Care Clinical Practice Guidelines, while First Nations Health Authority utilized guidelines from their nearest regional health authority.

Educators and clinical leaders from the health authorities using the Fraser SMGs acknowledged a lack of sufficient resources to independently update them and expressed interest in a collaborative process. They offered in kind contribution by palliative educators and clinicians to further the provincial effort.

In addition to the request from regional health authorities, the BC Ministry of Health recognized the need for provincial guidelines for end of life care. The BC Center for Palliative Care (BC-CPC) was mandated by the Ministry to support the creation of new hospice

- spaces by:
 - Promoting excellence in end of life care and innovation / best practices in end of life care;
 - Implementing provincial end of life clinical guidelines, protocols and standards³.

In March of 2016, the project, "Palliative Symptom Management Guidelines; a resource for British Columbia" was approved by the sponsor, Dr. Doris Barwich (Executive Director, BC-CPC) with the goal of creating a provincial set of palliative symptom management best practice guidelines which were:

- Informed by evidence current to May 2016;
- Endorsed by each health authority in B.C.

The objectives of the project were to:

- Utilize an agreed-upon, documented methodology for evidence review;
- Provide a toolkit for future guideline revisions, informed by lessons learned during this project;
- Create an opportunity for provincial collaboration towards shared goals.

¹ Fraser Health. "Hospice Palliative Care Symptom Guidelines". Accessed Feb 8, 2016. https://www. fraserhealth.ca/employees/clinical-resources/hospice-palliative-care

² Vancouver Coastal Health. "Community Palliative Care Clinical Practice Guidelines", 2007.

³ BC Center for Palliative Care Strategic Plan 2015



PART 1 - DEVELOPMENT PROCESS: PHASES 1 - 3

Phase 1 Stakeholder engagement and scoping of the project (March-June, 2016)

The primary goal of Phase 1 was the establishment of a provincial Steering Committee that would provide leadership and guidance throughout the project. The committee was comprised of representatives from six health authorities (Fraser, Providence, First Nations, Island, Northern, and Interior) who worked together to address foundational questions related to the project. As a result, three key decisions were made:

The existing Fraser Health Palliative Symptom Management Guidelines would be the primary source document for revision.

The AGREE II and AGREE II – Global Rating Scale4 would be the principal tools used by the Clinician Review Panel through Phase 2.

Although the committee reinforced the necessity for a holistic approach to care, the scope of this project would be limited to end of life symptoms within the physical domain.

In addition, decisions were made outlining the scope of the project including; the audience, care setting, and patient population. The audience for the guidelines was determined to be nurses and physicians without palliative specialization, working with adults with any life-limiting illness, in any care setting (Ideally, with 24-hour access to palliative specialist consultation). The scope was further defined to exclude refractory symptom management or health authority specific protocols such as pre-printed orders.

At completion of Phase 1, an update and report of key decisions was sent to each health authority and the project sponsor.

Phase 2 Literature review, writing and revisions (July 2016 – Aug 31, 2017)

The literature review included sources from 2012-2016, utilizing a modified GRADE⁵ methodology to determine the strength of practice recommendations. Each guideline

Brouwers M, Kho ME, Browman GP, Burgers JS, Cluzeau F, Feder G, Fervers B, Graham ID, Grimshaw J, Hanna S, Littlejohns P, Makarski J, Zitzelsberger L (2010). AGREE II: Advancing guideline development, reporting and evaluation in healthcare. Can Med Assoc J. Dec 2010; 182:E839-842; doi:10.1503/090449

⁵ Goldet, G. and Howick, J. (2013), Understanding GRADE: an introduction. Journal of Evidence-Based Medicine, 6: 50-54. doi:10.1111/jebm.12018



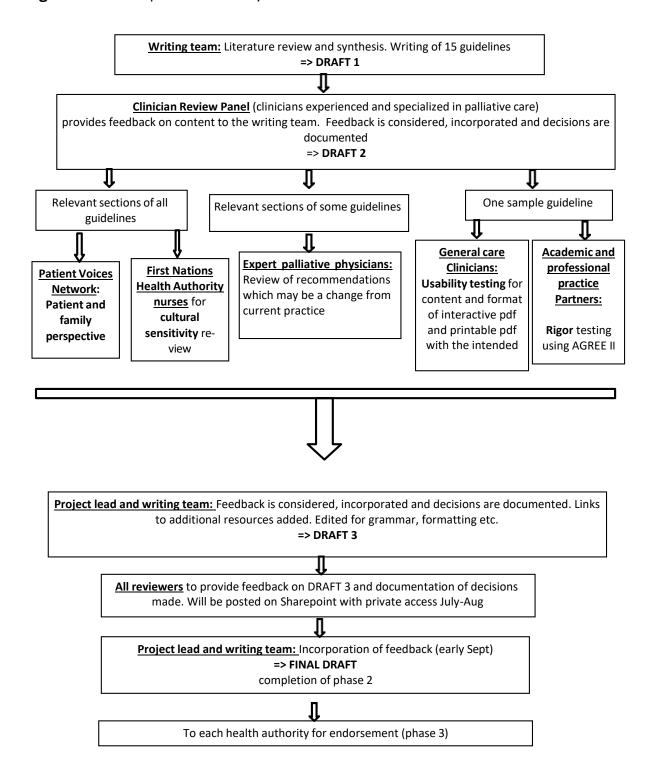
had internal review amongst members of the writing team and the project lead before being released to the clinician review panel. The guidelines were reviewed from many perspectives and then revised based on multiple feedback sources (Figure 1: Phase 2 process summary).

Phase 3 Health authority endorsement and reporting (Sept 1-Dec 23, 2017)

Phase 3 consists of each Steering Committee member putting the guidelines through their health authority's process for adopting new best practice guidelines. Assuming most health authorities endorse the guidelines for clinical use, the project will be complete. The guidelines will then be housed on the BC Centre for Palliative Care website. The anticipated release is at the end of November 2017.



Figure 1: Phase 2 process summary



For more detail, please contact Kathleen Yue, Project Lead kyue@bc-cpc.ca



PART 2, REFRACTORY SYMPTOMS / PALLIATIVE SEDATION AND NURTURING PSYCHOSOCIAL AND SPIRITUAL WELL-BEING - DEVELOPMENT PROCESS

Part 1 of this project resulted in the BC Inter-professional palliative symptom management guidelines (Nov 2017), which have been accessed over 6000 times since their release. At completion of Part 1, a report of lessons learned, a toolkit, an evaluation of user experience and a plan for future revisions was submitted to the project sponsor and relevant stakeholders.

Part 2 is a continuation of the project, with development of 2 more guidelines:

- Nurturing psychosocial and spiritual well-being (and
- Refractory symptoms and palliative sedation therapy.

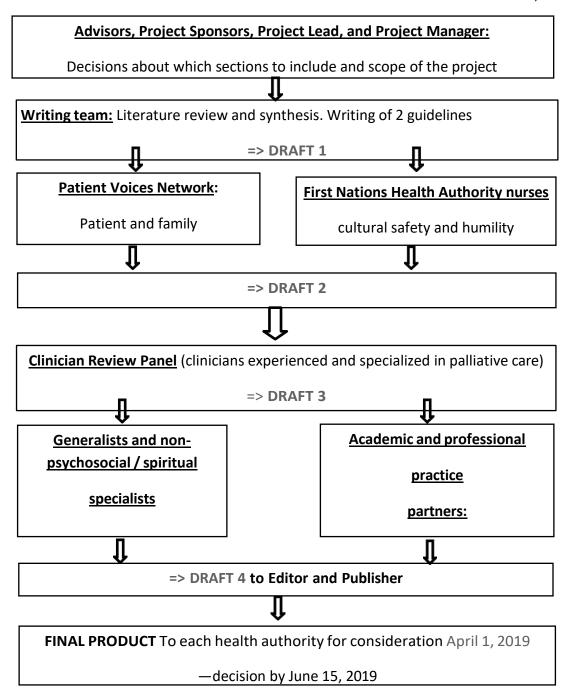
For Part 1 of the guidelines, a modified GRADE process was used. However, the nature of the evidence found in the literature led to a different process for Part 2. For Refractory symptoms and palliative sedation therapy, several Canadian, recently published best practice guidelines already existed. Therefore, the writers compiled the common features of these as well as a few research studies and then had B.C. palliative expert physicians, pharmacists and nurses review and provide significant input.

For Nurturing psychosocial and spiritual well-being, much of the research evidence was qualitative, which is not highly valued using the GRADE tool. Therefore, writers searched for and recommended interventions which were relevant to the patient population and demonstrated consistent positive results as reported in several sources. All recommended interventions are low risk, such as providing active listening. These recommends were validated with palliative expert social workers, counsellors, spiritual health practitioners and nurses.

Process Summary⁶

Feedback on each DRAFT was provided to selected members of the advisors, clinician reviewers, Patient Voices and writing team who incorporated suggestions as appropriate and documented the decisions made







CLINICIAN INTRODUCTION TO THE B.C. PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES

The B.C. Palliative Symptom Management Guidelines were developed to support clinicians to provide effective symptom management for patients with life-limiting illness without a referral to a palliative specialist. Using this reference, we hope you will feel both confident and competent to care for patients and families, enabling them to receive most care from their trusted primary care providers. Each health authority has access to some level of palliative consultation services for advice, coaching and mentorship as well as courses and workshops to strengthen your skills. Please find links to consultation services in the "Additional resources" section of each guideline.

There were several key decisions made about the scope of these guidelines you may find helpful to understand:

- 1. Symptoms chosen for inclusion were:
 - a. Physical in nature (e.g. spiritual distress was excluded);
 - b. Common to more than one life-limiting illness (e.g. cancer-specific symptoms were excluded).
- 2. All care settings were included. To support decision making, each of the nonpharmacological interventions is categorized as "available in the home and residential care facilities" or "requiring additional equipment or admission to acute care".
- 3. Specific protocols, pre-printed orders, or clinical tools were excluded as they may vary between health authorities.
- 4. While we anticipate that allied health professionals will find these guidelines useful, they were written with physicians and nurses in mind.
- 5. Two formats of the guidelines are available; a printable pdf and an interactive pdf (available at the BC Centre for Palliative Care website).

You will notice that the guidelines all have the same structure, this was carefully refined with much feedback. Our intent is to lead you through a process similar to your current practice, with a few modifications to reflect the context of palliative care. We refer to the patient and family as the unit of care (family is whoever the patient finds supportive, regardless of the social relationship).



The standard format

- 1. Definition
- 2. Prevalence
- 3. Impact
- Standard of care

Step 1 | Goals of care conversation

Step 2 | Assessment

Using Mnemonic O, P, Q, R, S, T, U and V⁷

Physical assessment

Diagnostics

Step 3 Determine possible cause (s)

Principles of management (a summary of key items in the guideline)

Step 4 | Interventions

Legend for use of bullets

Bullets are used to identify the type or strength of recommendation that is being made, based on a review of available evidence using a modified GRADE process.

Non-pharmacological interventions

Pharmacological interventions

Patient and family education

5. Appendix A – Additional Resources for management of symptom

Health F. Symptom Guidelines: Hospice Palliative Care, Clinical Practice Committee; 2006 [Available from: https://www.fraserhealth.ca/employees/clinical-resources/hospice-palliative-care]



FIRST NATIONS PERSPECTIVE ON HEALTH & WELLNESS

Resources specific to the symptom

General resources

Resources specific to health authority or region

Resources specific to patient population

- 6. Appendix B Underlying causes of symptom in palliative care
- 7. Appendix C Medications for management of the symptom
- 8. Appendix D Management algorithm
- 9. Appendix E Extra resources or assessment tools



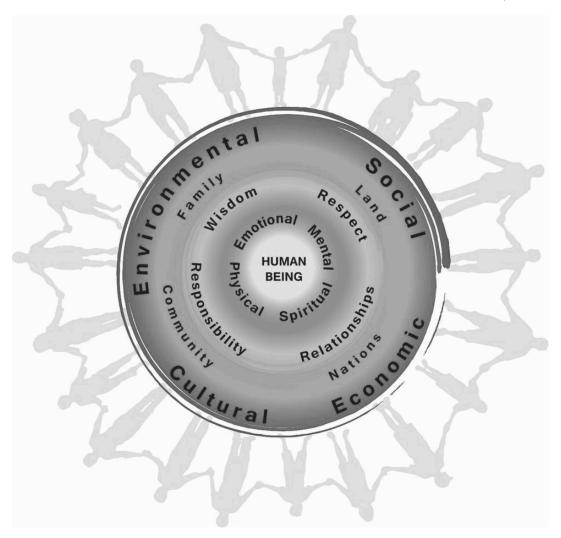
FIRST NATIONS PERSPECTIVE ON HEALTH & WELLNESS

When deciding which symptoms to include in the scope of this project, the Steering Committee chose to include only symptoms directly in the physical facet of life. We included symptoms such as constipation and excluded anxiety, depression and existential distress. The Steering Committee struggled with this decision, as we all agreed it is critical to care for people as holistic human beings, and not to separate them into components. However, two factors influenced this decision: we needed to limit the project's scope to what was achievable with existing resources; and we realized that non-physical distress may not be best classified as a "symptom" per se. To address the other facets of health, we included assessment questions and interventions about non-physical concerns such as anxiety.

We consulted with care providers and members of First Nations communities to try and understand the potential impacts of each physical symptom on the spiritual, emotional and mental facets. Their suggestions have been incorporated into the guidelines, especially in the assessment questions, which include questions about cultural and spiritual values. Many suggestions are applicable for other cultures and beliefs as well, within the overall approach of seeking to understand without judgement.

The "wellness wheel" was the lens through which we viewed health throughout the development of the guidelines. We recognize that a human being can be well within one facet of life while being unwell in another facet. For example, one can be spiritually at peace while physically dying.





First Nations Health Authority. (2014). First Nations Perspective on Health and Wellness. Used with permission.

For a further description: http://www.fnha.ca/wellness/wellness-and-the-first-nations- health-authority/first-nations-perspective-on-wellness

We learned from our First Nations health partners that some symptoms have spiritual significance, for example, dyspnea may be interpreted not just a sensation physical discomfort, rather as a lack of the essential element of air, which is needed for wellness. Another example is how a professional trained in western medicine may interpret visions of passed loved ones as a hallucination, whereas some First Nations' people would see this as a needed part of the passing over process. Without this insight, a medical professional



may attempt to remove these visions with medication, possibly preventing the comforting presence of loved ones.

We are indebted to our health partners for helping us to appreciate the impact of past trauma, for example, how interventions for constipation may re-traumatize those with past sexual abuse. Also, for insights about the significance of remaining within ones' community and being allowed to utilize traditional remedies and participate in spiritual practices.

The guidelines are much richer because of the health partners' thoughtful input. For future revisions and updates, we recommend including patient and family representatives of other cultures as well as First Nations.



B.C. INTER-PROFESSIONAL PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES: A RESOURCE FOR B.C. - ACKNOWLEDGEMENTS

We are so thankful for the many partners who contributed to these guidelines, making it a true collaborative effort we can all be proud of.

A special thank-you to the original authors of the Fraser Health Hospice Palliative Care Program Symptom Management Guidelines http://www.fraserhealth.ca/media/HPC SymptomGuidelines Authors.pdf. The Fraser guidelines have been adapted and adopted in several B.C. health authorities and served as the foundation for this work.

The guideline for management of pain was adapted from the source document written by the following Fraser Health contributers:

- Barbara McLeod , Clinical Nurse Specialist, Palliative Care
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2019 EDITION

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Propofol Expertise

- Vincent Fruci, MD, FRCPC
- In recognition of the significance of adding propofol as a pharmacologic option for PST, in addition to literature review expert consultation was sought from a physician experienced in both palliative care and anesthesia. In addition to palliative expert review, peer review was received from Medical Directors for Palliative Care in every Health Authority in BC.

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