B.C. INTER-PROFESSIONAL PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES
INTRODUCTION
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These Inter-professional Palliative Symptom Management Guidelines are intended to provide general advice to clinicians, physicians, nurses and allied health staff involved in palliative care supports; and have been prepared with regard to general settings using information available at the time. The content is derived from a number of sources on an “as-is” basis without any representation, warranty, or condition whatsoever, whether express or implied, statutorily or otherwise, as to accuracy, completeness, currency, reliability, efficacy, legality or fitness for a particular purpose. Under no condition should the information contained in these Guidelines be relied upon as a substitute for the proper assessment of the circumstances involved in each case and the individual needs of each patient by qualified health care professionals.

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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.

Doris Barwich MD CCFP(PC)
Executive Director, BC Centre for Palliative Care
Clinical Associate Professor, Division of Palliative Care
Department of Medicine, University of British Columbia
300- 601 Sixth Street New Westminster, BC V3L 3C1
T: 604 553-4866 Fax: 604 553-4865
www.bc-cpc.ca
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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 https://www.fraserhealth.ca/employees/clinical-resources/hospice-palliative-care. 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 contributors:

- Barbara McLeod, Clinical Nurse Specialist, Palliative Care
- Dr. Mary-Jane O’Leary, Palliative Physician
- Dr. Charlie Chen, Palliative Physician
- Dr. Nicola Macpherson, Palliative Physician
- Bruce Kennedy, Clinical Pharmacist
- Della Roberts, Clinical Nurse Specialist

Project Sponsor: Dr. Doris Barwich, MD, CCFP (PC), Executive Director, BC Centre for Palliative Care

Project Leads: Kathleen Yue, RN, MN, CHPCN (C) and Carolyn Tayler, RN BN MSA CON (C)

Project Manager: Chris Yue, BSc, MDiv, PMP

Steering Committee: We are especially grateful to the health authorities who generously gave in-kind contributions as members of the Steering Committee

- **Interior Health**: Elisabeth Antifeau, RN, MSN, GNC (C), CHPCN (C) Clinical Nurse Specialist
- **First Nation Health Authority**: Gina Gaspard, RN, MN, GNC (C) Clinical Nurse Specialist, Healthy Living and Chronic Disease
- **Island Health**: Della Roberts, RN MSN CHPCN(C), Clinical Nurse Specialist, Palliative and End of Life Care Program
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• **Patient Voices Network**: Maggie Schulz, who donated her own time to participate in the Steering Committee

**Writing team**

• Bruce Kennedy, B.Sc. (Pharm.), M.B.A. Clinical Pharmacy Specialist, Palliative Care
• Judy Lett RN, BScN, MSc, GNC(C), CHPCN(C), Clinical Nurse Specialist, Hospice Palliative Care
• Deanna Hutchings, RN, MN, CHPCN (C), Nurse Educator, Palliative Care

**References and source management**

• Dr. Amber Husband, MD
• Dr. Anna Cooper, MD, MRCGP
• Canice Ma, BSc, BSN (in progress) – conducted initial literature search

**Editing, design and layout**

• Angela Cragg, Editor, Word Gypsy Editing
• Design and layout: Holy Cow Communication Design

**Patient Voices Network** (Patient and family representatives)

• Maggie Schulz: reviewed each symptom guideline in depth
• Jean Shepherd
• Kent Loftsgard
• Kira Tozer, MPH PMP, Engagement Leader, Southern Vancouver Island, Patient & Public Engagement, BC Patient Safety and Quality Council
• Leah Smith, Engagement Leader, Southern Vancouver Island, Patient & Public Engagement, BC Patient Safety and Quality Council
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Clinician review panel

- Physicians
  - Dr. G. Michael Downing, MD
  - Dr. Jonathan Pearce, MD, CCFP (PC)
  - Dr. Gil Kimel, MD, MSc, FRCPC, Physician Program Director, Palliative Care
  - Dr. Alan Nixon Medical Director Palliative and EOL Care, MD, CCFP, DABHPM, FAAHPM
  - Dr. Marnie Jacobsen, MD CCFP – Palliative Care CAC
  - Dr. Gillian Fyles, MD, CCFP (PC)
  - Dr. Christian Wiens, MD, FRCPC
  - Dr. Amirish Joshi, MBBS; CCFP(PC); MSc. Palliative Medicine.

- First Nations Health Authority
  - Marilyn Dalton, LPN, Wellness Nurse Navigator
  - Carol Machell, RN, BSN Community Health Practice Consultant, Interior Nursing Team
  - Gina Gaspard, RN, MN, GNC (C) Clinical Nurse Specialist, Healthy Living and Chronic Disease
  - Cindy Preston, Pharmacist
  - Lorraine Harry, RN Regional Manager for Vancouver Island

- Fraser Health
  - Bella Wang, RN, MN, CHPCN (C) Clinical Nurse Specialist, Palliative Care Program
  - Nicole Wikjord, RN, MSN, CHPCN (C), Clinical Nurse Specialist, Palliative Care Program
  - Patsy Lam, RN, MSN, CHPCN (C) Clinical Nurse Specialist, Palliative Care Program
  - Sue North, BSc, BSc(Pharm), ACPR Pharmacist
  - Barbara McLeod, RN, MSN, CHPCN (C) Clinical Nurse Specialist, Palliative Care Program
ACKNOWLEDGEMENTS

- Island Health
  - Angela Lorenz Robertson, RN, BScN, CHPCN (C)
  - Holly Anderson RN BScN CHPCN(C), Palliative Care Coordinator
  - Necia Kaechele, RN, MN, CHPCN(C), Palliative Care Coordinator
  - Kelly Weber, RN, BScN, CHPCN (C) Palliative Care Coordinator
  - Amy E. Frey, MSW, HSW, RSW, Nanaimo Kidney Care and Transplant Social Worker
  - Heather Shivas, Pharmacist
  - Shelley Tysick, RN, BSN, BSW, Clinical Nurse Leader, Victoria Hospice

- Interior Health
  - Natalie Manhard, MscN, NP (F)
  - Debbie Montague, RRT, CRE, Respiratory Therapist
  - Susan Kast, BA, BSW, MSW, RSW, Social Worker,
  - Tennille Campbell, BScOT, Community Occupational Therapist,
  - Kathryn Proudfoot, MSc., Registered Dietitian
  - Ayesha Hassan, Clinical Pharmacist, BSc.(Pharm), ACPR, MSc. (Palliative Care)
  - Jacki Morgan, RN, Home Health Regional Knowledge Coordinator
  - Dianne Stockwell, RN BScN, CHPCN (C)
  - Vicki Kennedy, RN, BN, MN, CRE (CNS-C)

- Vancouver Coastal
  - Jane Webley, RN, LL.B., Regional Program Lead, end of life
  - Ingrid See, RN, BSN, Med, CHPCN (C), Clinical Nurse Specialist
  - Annette Cavey, RN BSN CHPCN(C) Clinical Practice Leader Vancouver Home Hospice Palliative Care Services

- Providence
  - Pat Richardson, RN, BScN, CHPCN (C), Palliative Care Nurse Clinician
  - Dr. Caroline Baldwin, CCFP (PC), Palliative Care Physician
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- Northern Health
  - Jennifer Ferguson RN, BScN, CHPCN(c), Palliative Care Nurse Consultant (NI)

First Nations Health Authority Consultants

- Marilyn Dalton, LPN, Wellness Nurse Navigator
- Carol Machell, RN, BSN, Community Health Practice Consultant, Interior Nursing Team
- Gina Gaspard, RN, MN, GNC (C) Clinical Nurse Specialist, Healthy Living and Chronic Disease

Expert palliative physicians (Reviewed key portions of Pain, Delirium, Dysphagia, Nausea and vomiting)

- Dr. G. Michael Downing, MD
- Dr. Neil Hilliard, MCFP (PC), Program Medical Director, Palliative Care Program, Fraser Health, Associate Clinical Professor, Department of Medicine, UBC.
- Dr. Douglas McGregor, MB ChB, Medical Director, Victoria Hospice
- Dr. G Fyles MD, CCFP (Palliative Care)

General care clinicians (Reviewed a sample guidline for usability)

- Residential / long term care
  - Lauren Wiegel
  - Dr. Jocelyn Chase, MD, FRCPC, Geriatrics and Internal Medicine, Clinical Instructor, University of British Columbia
  - Tammy Scott, RN, Clinical Nurse Leader, Long-term care
  - Michelle Porter RN, BScN, GNC(C), Residential Care
  - Susan Brown
  - Jim Oldnall RN, BSN, GNC(C)
  - Colleen Bowers, RN, BSN, Cancer Care Coordinator, Northern Health
  - Megan Hiltz RN MHS GNC(C), Clinical Nurse Specialist – Dementia Care/ Clinical Nurse Leader, The Veterans Memorial Lodge at Broadmead

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  - Giselle Reyes RN, BSN, Home Care Nurse
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  • Ashley Heaslip, MD CCFP MPH, Family Physician
  • Elizabeth Bastian, MD, General Practice in Oncology, Palliative care, Northern Health
  • Dr. Nick Petropolis

Academic and professional practice partners

• Dr. Rick Sawatzky, RN, PhD and his Masters of Science in Nursing class, Trinity Western University
• Helena Daudt, PhD, Director, Education & Research, Victoria Hospice
• Karen Levy RN MSN, Clinical Practice Lead, Vancouver Home Hospice
• Susan Brown, R.N., BScN., MScN., GNC (C), Clinical Nurse Specialist, Residential Care and Assisted Living, Gerontology, Fraser Health Authority
• Coby Tschanz, RN, MN, PhD (c), CHPCN(C)
• Dr. Sukaina Kara, MD, CCFP (Palliative Care)
• Dr. Charlie Chen, M.D., CCFP-PC, Program Director: UBC Adult Palliative Medicine Residency Programs

Specific patient populations

• Camara van Breeman - RN, MN, CHPCN (C), NP (F)
• Sarah Leung, B.Sc.(Pharm.), ACPR, Clinical Pharmacist, Children’s & Women’s Health Centre of B.C.
• Charmaine Ngo, B.Sc.(Pharm.), ACPR, Clinical Pharmacist, Children’s & Women’s Health Centre of British Columbia
• Dr. Philippa Hawley, B.Med., FRCPC, Head of UBC Division of Palliative Care, and Director, Pain and Symptom Management/Palliative Care Provincial Program, B.C. Cancer Agency
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- Dr. Sandra Lee, MD, Medical Consultant, Guidelines and Protocols Advisory Committee, B.C. Ministry of Health
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 website. 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 standards.

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.

3 BC Center for Palliative Care Strategic Plan 2015
**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 Scale\(^4\) 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.

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

The literature review included sources from 2012-2016, utilizing a modified GRADE\textsuperscript{5} methodology to determine the strength of practice recommendations. Each guideline 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.

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Figure 1: Phase 2 process summary

Writing team: Literature review and synthesis. Writing of 15 guidelines
=> DRAFT 1

Clinician Review Panel (clinicians experienced and specialized in palliative care)
provides feedback on content to the writing team. Feedback is considered, incorporated and decisions are documented
=> DRAFT 2

Relevant sections of all guidelines
Relevant sections of some guidelines
One sample guideline

Patient Voices Network: Patient and family perspective
First Nations Health Authority nurses for cultural sensitivity review
Expert palliative physicians: Review of recommendations which may be a change from current practice

General care Clinicians: Usability testing for content and format of interactive pdf and printable pdf with the intended

Academic and professional practice Partners:
Rigor testing using AGREE II

Project lead and writing team: Feedback is considered, incorporated and decisions are documented. Links to additional resources added. Edited for grammar, formatting etc.
=> DRAFT 3

All reviewers to provide feedback on DRAFT 3 and documentation of decisions made. Will be posted on Sharepoint with private access July-Aug

Project lead and writing team: Incorporation of feedback (early Sept)
=> FINAL DRAFT
completion of phase 2

To each health authority for endorsement (phase 3)

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

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 non-pharmacological 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. The intended audience is inter-professional health care clinicians working with adults living with advanced life-limiting illnesses. Though these guidelines were created for adults, the symptoms may also be experienced by children. See additional resources within each guideline specific to pediatrics, illnesses such as cancer, and your organization/region.

5. While we anticipate that allied health professionals will find these guidelines useful, they were written with physicians and nurses in mind.

6. 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
4. Standard of care

Step 1 | Goals of care conversation

Step 2 | Assessment
Using Mnemonic O, P, Q, R, S, T, U and V
Physical assessment
Diagnostics

Step 3 | Determine possible cause (s)
Principles of management (a summary of key items in the guideline)

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6 Health F. Symptom Guidelines: Hospice Palliative Care, Clinical Practice Committee; 2006 [Available from: http://www.fraserhealth.ca/health-professionals/professional-resources/hospice-palliative-care/]
The standard format continued

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

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
INCORPORATION OF FIRST NATIONS PERSPECTIVE ON HEALTH AND WELLNESS INTO THE B.C. PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES

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 First Nations perspective on health and wellness 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.
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.