Hospice Palliative Care Program

Symptom Guidelines
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Fraser Health
Suite 400, Central City Tower, 13450 – 102nd Avenue
Surrey, BC
V3T 0H1

www.fraserhealth.ca
feedback@fraserhealth.ca
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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 ten years. We are greatly indebted to each and every one of these dedicated professionals (see The Authors).

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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.

Barbara McLeod, RN, BSN, MSN, CHPCN(C)
Clinical Nurse Specialist, End of Life Care
Fraser Health

Project Coordinator, Fourth Edition
Hospice Palliative Care Symptom Guidelines
December 5, 2006
Introduction

The Authors - revised January 2016

Shervin Communications Inc.
Revision: Opioid Principles - Appendix A Fentanyl Transdermal
Bruce Kennedy, B.Sc. (Pharm.), M.B.A. Clinical Pharmacy Speciality Palliative Care Fraser Health, BC
New: Refractory Symptoms and Palliative Sedation Therapy
Tammy Dyson, MSW, RSW. Clinical Social Worker, Fraser Health, BC
Bruce Kennedy, B. Sc. (Pharm.), M.B.A. Clinical Pharmacy Specialist Palliative Care, Fraser Health, BC
Nicola Macpherson, MD FRCP (Anaesth.), DABHPM. Hospice Palliative Care Physician, Fraser Health, BC.
Della Roberts, RN, MSN, CHPCN (C). Hospice Palliative Care Clinical Nurse Specialist - White Rock, South Surrey, South Delta, BC

Contributing Authors:
Doris Barwich, MD, CCFP. Program Medical Director, Fraser Health End of Life Care, BC
Ed J. Dubland, AA, MD, DABHPM Medical Coordinator Burnaby Tertiary Hospice Palliative Care, Fraser Health, BC.
Lynn Potter – MD, Palliative Care Physician, Fraser Health
Lucille Taylor, RN, MSN, CHPCN (C); Hospice Palliative Care Clinical Nurse Specialist – Abbotsford and Mission, BC
2011/2007 - Barbara McLeod, RN, BSN, MSN, CHPCN (C), Hospice Palliative Care Clinical Nurse Specialist, Fraser Health, BC.
2007 - Gloria J. Woodland, M.A.; Regional Coordinator, Spiritual Care, Fraser Health, BC.
2007 - B. Lynn Kobierski, MD, CCFP, FCFP, Hospice Palliative Care Physician, Abbotsford, BC.
2007 - Colleen Sheriff, RN, Systemic Therapy, Fraser Valley Cancer Center, BC.

Reviewers Fourth Edition:
Susan M. F. Breiddal, Masters of Transpersonal Psychology; Victoria, Hospice, BC.
Glenda Christie, MSW, RSW; Patient & Family Counselling Services, BC Cancer Agency, Vancouver Centre, BC.
Lottie Cox, RN, BSN, MHS, GNC (C); Clinical Nurse Specialist, Residential Care and Assisted Living Program, Fraser Health, BC
Nicole Dahlen, Pharmacist Lead, Northern Health Hospice Palliative Care Program, BC.
Dr. Mervyn M. Dean, MB, ChB, CCFP, Palliative Care Physician. Western Memorial Regional Hospital, Cornerbrook, NL, Canada.
Barbara Eddy, BSN, MN, NP(F), CHPCN (C) Family Nurse Practitioner, Vancouver Coastal Health, Vancouver, BC.
Bob Gillies, BSc(Pharm), PharmD, BCPS Clinical Pharmacy Specialist, Critical Care, Clinical Assistant Professor, Fraser Health, BC.
Cari Hoffmann, BA, BSW, RSW. Project Implementation Coordinator Advance Care Planning, Fraser Health
Bashir Jiwani, PhD; Ethicist and Director, Fraser Health Authority Ethics Services, BC.

Aynharan Sinnarajah, MD, Consultant, Palliative & End of Life Care, Alberta Health Services - Calgary Zone
Consultant, Section of Palliative Medicine, Department of Family Medicine, University of Calgary
Clinical Lecturer, Section of Palliative Medicine, Department of Oncology, University of Calgary

Fourth Edition – May 2009
Revision: Dyspnea
Doris Barwich MD, CCFP. Medical Director, Hospice Palliative and End of Life Care, Fraser Health, BC
Bruce Kennedy, B. Sc. (Pharm.), M.B.A. Clinical Pharmacy Specialist, Palliative Care, Fraser Health, BC
Barbara McLeod, RN, BSN, MSN, CHPCN (C); Hospice Palliative Care Clinical Nurse Specialist, Fraser Health, BC

Fourth Edition – April 2009
Shervin Communications Inc.
New: Psychosocial Care
Tammy Dyson, MSW, RSW. Clinical Social Worker, New Westminster Hospice Palliative Care Program, Fraser Health, BC
Mary-Ann Statton, BSW, RSW. Clinical Social Worker, Tri-Cities Hospice Palliative Care Program, Fraser Health, BC
Lisa Sutherland, MSW, RSW. Clinical Social Worker, Abbotsford and Mission Hospice Palliative Care Program, Fraser Health, BC

Contributing Authors:
Janet Coghlan, MSW, RSW, Clinical Social Worker, Tri-Cities Hospice Palliative Care Program, Fraser Health, BC
Michele Martin, MSW, RSW. Clinical Social Worker, Surrey Hospice Palliative Care Program, Fraser Health, BC.

Reviewers Fourth Edition
Mike Burpee, Consumer Representative, Coquitlam, BC
Barbara McLeod, RN, BSN, MSN, CHPCN(C) Clinical Nurse Specialist, Burnaby Hospice Palliative Care, Fraser Health, BC
Reverend David Musser, M. Div., Spiritual Care Coordinator, Queens Park Care Centre and Hospice, New Westminster, Fraser Health, BC
Sue North, BSc(Pharm), ACPR, Clinical Pharmacy Specialist, Hospice Palliative Care, Fraser Health, BC
Della Roberts, RN, MSN, CHPCN(C), Clinical Nurse Specialist, End of Life Care, Hospice Palliative Care, Fraser Health, BC
Sarah Sample, MSW, RSW, Oncology Social Worker, Vancouver Cancer Centre, BCCA
Kevin Sclater, MD, Hospice Palliative Care, Port Coquitlam, Fraser Health, BC.
Introduction

Hospice Palliative Care Program • Symptom Guidelines

Shervin Communications Inc.

Doris Barwich, MD, CCFP, Medical Leader, Hospice Palliative Care and End of Life Care, Fraser Health, BC
Pippa Hawley, B.Ed, FRCP, Palliative Medicine Specialist, BC Cancer Agency
Bruce Kennedy, B.Sc.(Pharm.), M.B.A. Clinical Pharmacy Specialist - Palliative Care, Fraser Health, BC
B. Lynn Kobierski, MD, CCFP, FCFP, Hospice Palliative Care Physician, Fraser Health, BC
Barbara McLeod, RN, BSN, MSN, CHPCN(C) Clinical Nurse Specialist, End-of-Life Care, Fraser Health, BC
Della Roberts, RN, MSN, CHPCN(C), Clinical Nurse Specialist, Hospice Palliative Care, Delta and White Rock/South Surrey Health Services, BC
Colleen Sherriff, RN, Systemic Therapy, Fraser Valley Cancer Center, BC
Ann Syme, RN, MSN, Provincial Leader, Pain and Symptom Management/Palliative Care, BC Cancer Agency
Carolyn Taylor, RN, BN, MSN, CON(C), Director Hospice Palliative and End of Life Care, Fraser Health, BC
Laura Tremblay, BSc(Pharm), Pain & Symptom Management / Palliative Care Team, BC Cancer Agency, Fraser Valley Centre.

Production Support and Review
Coordination Fourth Edition
Barbara McLeod, Project Coordinator
Carolyn Taylor
Colleen Sheriff, Researcher
Ann Syme

Contributors Third Edition – Oct 2005
Maureen Adamson, BSc, MD, CCFP, FCFP, Hospice Palliative Care Physician, Fraser Health, BC
Alexandros Alexiadis, MD, DABHPM, Palliative Consultant, Fraser Health, BC
Brenda A. Bailey, RN, MSN, CHPCN(C), Clinical Nurse Specialist, Hospice Palliative Care, Tri-Cities, BC
Shelley Briggs, RN, MN, CHPCN(C), Clinical Nurse Specialist, Hospice Palliative Care, Maple Ridge, BC
Janet Coghlan, MSW, RSW, Clinical Social Worker, Hospice Palliative Care Consultation Team, New Westminster, BC
Ed Dubland, AA, MD, DABHPM, Hospice Palliative Care Physician, Fraser Health, BC
Tammy Dyson, MSW, RSW, Clinical Social Worker, Hospice Palliative Care Consultation Team, Tri-Cities
Chris Emery, RN, MSN, CON(C), CHPCN(C), Clinical Nurse Specialist, Hospice Palliative Care, New Westminster, BC
Joan Goossen, RN BSN, Clinical Research Nurse, Home Health, Abbotsford/Mission, BC
Roxana Ho, B.Sc. (Pharm.), Clinical Pharmacist, Chilliwack Palliative Care Program, BC
Maureen Homemike, B.Sc. (Pharm.), Pharmacist, M.S.A. Hospital, Abbotsford, BC
Bruce Kennedy, B.Sc. (Pharm.), M.B.A. Clinical Pharmacy Specialist – Palliative Care, Fraser Health, BC
B. Lynn Kobierski, MD, CCFP, FCFP, Hospice Palliative Care Physician, Fraser Health, BC
Jennifer McMillan, B.A., MSW, Clinical Social Work Specialist, Hospice Palliative Care, Burnaby, BC
Alan J Nixon, MD DABHPM, Hospice Palliative Care Physician, Fraser Health, BC
Sue North, B.Sc.(Pharm), ACPR, Clinical Pharmacy Specialist, Hospice Palliative Care, Fraser Health, BC
David Ng, B.Pharm., MSc,RPh,MRPharms,RPEBC, Clinical Pharmacist, Oncology and Palliative Care, Surrey Memorial Hospital, Honorary Clinical Tutor, Faculty of Pharmaceutical Sciences, University of British Columbia
Cheryl Olma, B.Sc. (Pharm.), Pharmacist, Peace Arch Hospital, White Rock, BC
Lynne Potter, MD, Hospice Palliative Care Physician, Mission, BC
Della Roberts, RN, MSN, CHPCN(C), Clinical Nurse Specialist, Hospice Palliative Care, Delta Health Services, BC
Nancy Runzer, RN MSN Candidate - UBC, Clinical Nurse Leader Ambulatory Chemotherapy Unit / Day Care, Vancouver Cancer Centre
Eve S Sample, B.Sc. (Pharm.) Clinical Pharmacy Specialist, Hospice Palliative Care, Fraser Health, BC
Ruth Scott, RN, Hospice Photos
Farimah Shakeri, MSW, RSW, Clinical Practice Leader, Royal Columbian Hospital, New Westminster
Randi Soverby, B.Sc. (Pharm.), Clinical Pharmacist, Mission Memorial Hospital, Mission, BC
Mary-Ann Statton, BSW, RSW, Clinical Social Worker, Hospice Palliative Care Consultation Team, Tri-Cities, BC
Pieter R. Strauss, MBChB, MMEd[Psych][UOF], FRCP, Psychiatrist, Abbotsford, BC
Lucille M. Taylor, RN, BA, BSN, MSN, CHPCN(C), Clinical Nurse Specialist, Hospice Palliative Care, Abbotsford / Mission Health Services
Ruth Topolnicky, Clinical Nurse Specialist
Vancouver Coastal Health ALS Centre, GF Strong Rehabilitation Centre
Gloria J. Woodland, MA, Spiritual Care Practitioner-Regional Coordinator, Spiritual Care, Fraser Health, BC

Contributors Second Edition - Dec 1999
Ron Bull, MD, Hospice Palliative Care Physician, Chilliwack, BC
Beverly Gibbs, Secretary, MSA General Hospital, Abbotsford, BC
B. Lynn Kobierski, MD, CCFP, FCFP, Medical Director, Abbotsford Palliative Care Program, Abbotsford, BC
Karen LaPointe, Pharmacist, Abbotsford Palliative Care Program, Abbotsford, BC
Clay Marco, MD, Family Physician, Hope, BC
Karen Moore, RN, Manager, Medicine & Geriatrics, Mission Memorial Hospital, Mission, BC
Lynne Potter, MD, Hospice Palliative Care Physician, Mission, BC
Randy Smith, Pharmacist, Chilliwack Palliative Care Program, Chilliwack, BC
Jill Taylor, RN, Coordinator, Fraser Canyon Hospice Society, Hope, BC
Joan Weir, RN, BSN, Nurse Clinician/Coordinator, Chilliwack Palliative Care Program
Maureen Wilde, RN, BSN. Palliative Care Coordinator, Abbotsford, BC

Contributors First Edition - June 1996
Anthony D. Costantino, MD, FRCP[C] Neurologist, Abbotsford, BC
Martin Enig, Pharmacist, MSA General Hospital, Abbotsford, BC
Peggy Goertzen, Secretary, MSA General Hospital, Abbotsford, BC
B. Lynn Kobierski, MD, CCFP, FCFP, Medical Director, Abbotsford Palliative Care Program, Abbotsford, BC
Maureen Wilde, RN, Palliative Care Coordinator, Abbotsford Palliative Care Program, BC
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.
Introduction

Textbooks


References


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. (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.
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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. 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.

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: ➊ ‘strongly recommend,’ ➋ ‘recommend (with provisos and alterations);’ ➌ ‘would not recommend’ and ➍ ‘unsure.’ A summary of the quality of the Symptom Guidelines is included (see Appendix A).
Introduction

References


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

Under Development
### 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**

<table>
<thead>
<tr>
<th>O</th>
<th>Onset</th>
<th>When did it begin? How long does it last? How often does it occur?</th>
</tr>
</thead>
<tbody>
<tr>
<td>P</td>
<td>Provoking / Palliating</td>
<td>What brings it on? What makes it better? What makes it worse?</td>
</tr>
<tr>
<td>Q</td>
<td>Quality</td>
<td>What does it feel like? Can you describe it?</td>
</tr>
<tr>
<td>R</td>
<td>Region / Radiation</td>
<td>Where is it? Does it spread anywhere?</td>
</tr>
<tr>
<td>S</td>
<td>Severity</td>
<td>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?</td>
</tr>
<tr>
<td>T</td>
<td>Treatment</td>
<td>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?</td>
</tr>
<tr>
<td>U</td>
<td>Understanding / Impact on You</td>
<td>What do you believe is causing this symptom? How is this symptom affecting you and/or your family?</td>
</tr>
<tr>
<td>V</td>
<td>Values</td>
<td>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?</td>
</tr>
</tbody>
</table>

* Physical Assessment (as appropriate for symptom)
References


