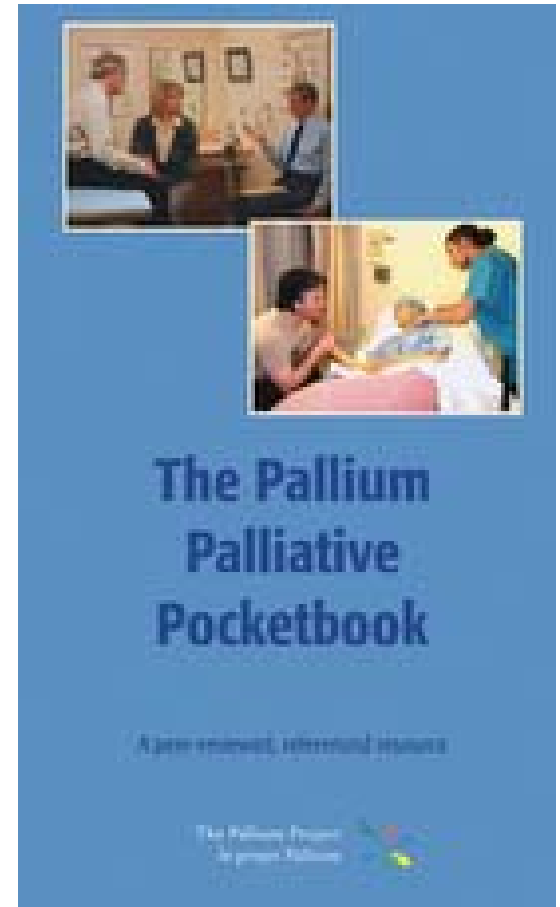


An Orientation to the Pallium Palliative Pocketbook (PPP)

First Canadian Edition

Information at

www.palliativetools.info



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with community colleagues in Newfoundland & Labrador (version - 17
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Introduction

- Written as a tool to help address practical clinical issues about quality end of life care in everyday practice.
- Supports practitioners who have a range of experiences, work in diverse settings and who desire to work in ways which are safe, effective, ethical and accountable.
- An evidence-informed (848 references), pan-Canadian inter-disciplinary, peer-reviewed, practical and accessible companion to complement, support and reinforce other practice tools and learning and development activities.
- Contains guidelines and general suggestions for treatment that must be individualized with professional judgment and adapted for a local service delivery context.



Chapters

1. Principles of Palliative care
2. Decision Making and ethics in Palliative Care
3. Communication
4. Estimating Life Expectancy
5. Pain
6. Cardiopulmonary Symptoms
7. Delirium
8. GI Problems
9. Hematological Problems
10. Metabolic, Electrolyte and Endocrine Problems
11. Neurological problems
12. Psychological and Psychiatric Distress
13. Total suffering, Spirituality, Hope, Dignity and Spiritual Care
14. Palliative Emergencies
15. Non-cancer: Select Issues
16. Miscellaneous Problems
17. Miscellaneous interventions
18. Palliative sedation
19. Last days and Hours
20. Grief and Bereavement



Comprehensive Assessment Focus

On all issues around palliative care service and in the PPP, comprehensive assessment is emphasized as a requirement to decide appropriate interventions and evaluation in order to provide quality palliative care.

“Despite this, many clinicians continue to take “short cuts”, resulting in inadequate and sometimes inappropriate care.”

PPP page 5-4



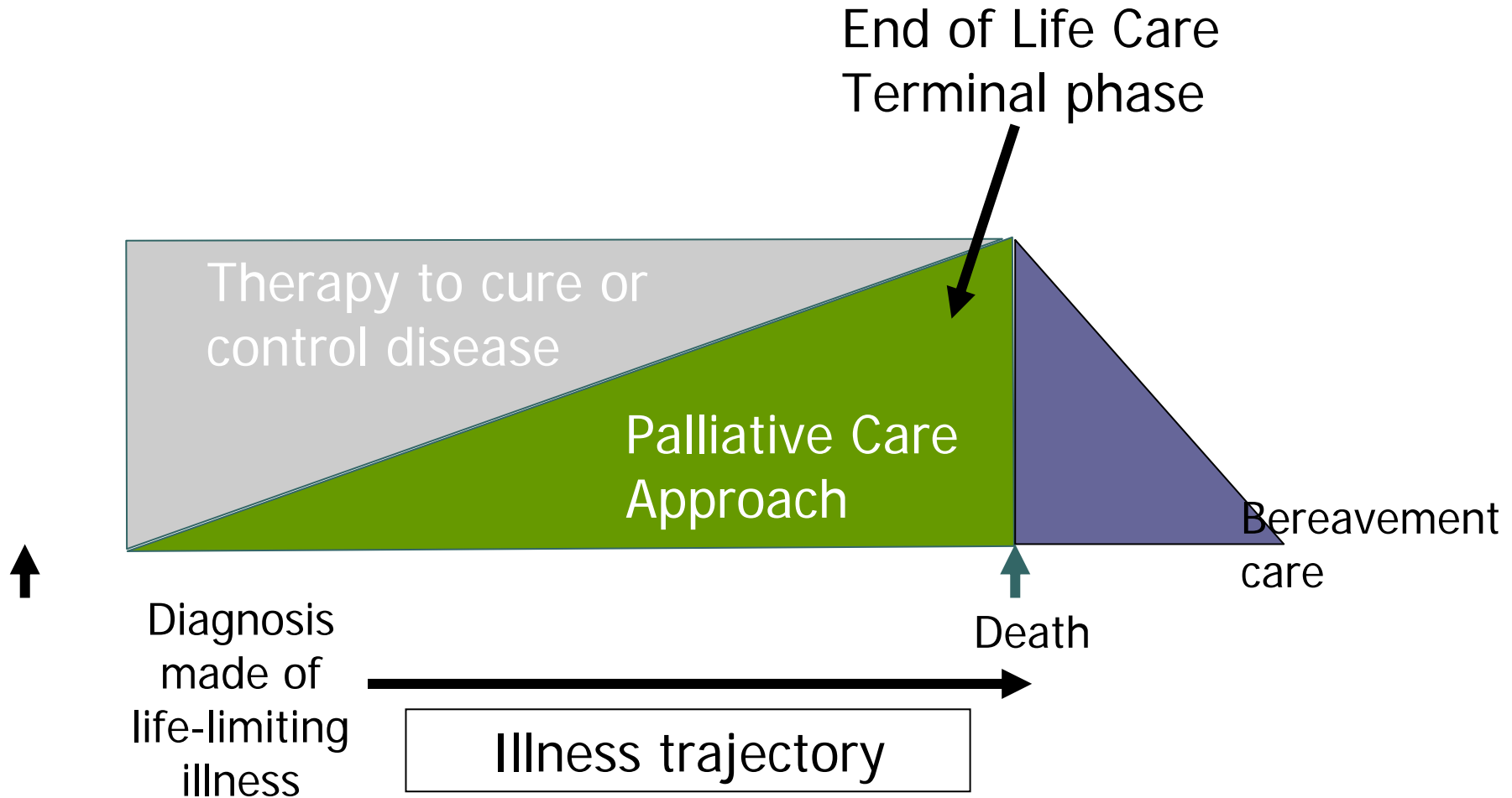
The Convention

- Alerts users new to evidence-based palliative care services about specific content they may wish to carefully review before undertaking tasks and interventions.
- Serves as a prompt/flag to seek out appropriate guidance/consultative support as a user gains palliative experience.
- A placeholder and prompt for short audio/ video tips in future e-book versions.



Hospice Palliative Care

(Scope - Canadian Approach)



A Phased Approach

PPP uses a practical, phased approach to care

Early palliative phase

- Soon after diagnosis
- Patient usually ambulatory and functioning relatively well
- Life expectancy may still be many months or more

Advanced palliative phase

- Level of functioning is reduced
- Assistance to maximize independence is often required
- May still be ambulatory at times
- Life expectancy is weeks to many weeks

Terminal palliative phase

- Patients are mainly bed-bound and require total care
- Life expectancy is days to perhaps a few weeks at most

PPP Pg. 1-5 to 1-6



Patient Realities

Within early, advanced and terminal phases patients may experience:

- **Acute periods** - acute crisis and complex symptom problems
- **Stable periods** - Symptoms and problems under relatively good control or tolerable
- **Bereavement** - Progressive losses, multiple losses, transitions



Decision Making and Ethics

(Chapter 2)

Guides practitioners about key questions, including:

- What are the GOALS of CARE?
- What are patient's/family's wishes?
- What is the current quality of life (QOL) and how will treatments under consideration potentially impact QOL?

PPP, Pgs 2-1 to 2-6



Decision Making and Ethics

(Chapter 2)

- What is the patient's estimated life expectancy?
- Is this an “acute reversible event” or is it a “terminal irreversible event?”
- What is the ratio of the potential benefits versus burdens of the proposed treatment?
- What is the preferred setting of care?

PPP, Pgs 2-1 to 2-6



An 'ethical grid' to assist in decision making

Medical Considerations <ul style="list-style-type: none">- Facts of the medical history- Prognosis- Treatment options, risks vs. benefits- Are treatments being considered consistent with goals of care?	Patient (and Family) Factors and Preferences <ul style="list-style-type: none">- Patient/family understanding of illness- Patient capacity to make decisions- Patient goals
Quality of Life Issues <ul style="list-style-type: none">- What does quality of life mean for the patient (and family)?- What gives meaning and brings dignity to their life?	Contextual Considerations <ul style="list-style-type: none">- Whose interests are affected?- What are societal norms and expectations?- What are the thoughts of the caregivers?

Adapted from Kuhl D, Wilensky P. J Pall Med. 1999; 2: 75-86.



Communication

(Chapter 3)

Communication is goal-focused, guided by ethical practice:

- Disclosure – truth telling
- Breaking bad news with **SPIKES**
- Initiating end of life discussions
- Establishing Goals of care (e.g . ACP)
- Eliciting concerns (FIFE approach)



SPIKES

1. **S** - Setting
2. **P** - Patient perception
3. **I** - Invitation
4. **K** - Knowledge
5. **E** - Exploring and Empathy
6. **S** - Strategy and summary

PPP Pages 3-6 to 3-11



FIFE to Elicit Concerns

F- Function “How is the Illness affecting you and your family?”

I - Ideas “What concerns you most now?”

F- Feelings “How do you feel about what is happening to you?”

E- Expectations “What are your hopes and wishes?”

PPP pages 3-14



Discussing Code Status

Persistent CPR Requests

PPP pages 3-18 to 3-21

Discussing Advanced Care Planning

PPP page 3-17

The Family Conference (14 steps)

PPP pages 3-23- to 3-28



Estimating Life Expectancy

(Chapter 4)



Palliative Performance Scale (PPSv2)

<i>PPS</i>	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal Activity Some Disease	Full	Normal	Full
90%	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
80%	Full	Normal Activity <i>with Effort</i> Some Disease	Full	Normal or Reduced	Full
70%	Reduced	Unable Normal Job/Work Some Disease	Full	Normal or Reduced	Full
60%	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance	Normal or Reduced	Full +/- Confusion
50%	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance	Normal or Reduced	Full +/- Confusion
40%	Mainly in Bed	Unable to Do Any Work Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
30%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Reduced	Full or Drowsy +/- Confusion
20%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Minimal Sips	Full or Drowsy +/- Confusion
10%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma
0%	Death	x	x	x	x

The Palliative Project
The Palliative Project



Palliative Prognostic Index (PPI)

(designed for cancer patients only)

3 Groups	Mean survival
A PPI < 2.0	134 ± 11 days
B PPI 2.0 - ≤ 4.0	89 ± 7 days
C PPI > 4.0	23 ± 3 days

Factor	Normal		Max. Poss.
PPS	10-20	4.0	4.0
	30-50	2.5	
	≥ 60	0	
Oral Intake	Sev. Reduced (< mouthfuls)	2.5	2.5
	Mod. Reduced (> mouthfuls)	1.0	
	Normal	0	
Edema	Present	1.0	1.0
	Absent	0	
	Refers to Peripheral bilateral edema due to low alb. Not DVT		
Dyspnea at rest	Present	3.5	3.5
	Absent	0	
Delirium	Present	4.5	4.0
	Absent	0	
	Rule out reversible cause		
Total			15



Guidelines for prognostication in non cancer end-stage illness

Including...

- Congestive Heart Failure (CHF)
- Chronic Obstructive Pulmonary Disease (COPD)
- Dementia
- Hepatic Disease
- Renal Disease
- Stroke

PPP pages 4-5 to 4-8



Pain – Assessment & Management

(Chapter 5)



Pain Assessment

- Regular Screening
- History
- Physical examination
- Investigations
- Poor prognostic factors of pain control
- Pain assessment in the cognitively impaired



Validated Assessment Tools

Local and regular proper use of validated pain assessment instruments/tools in daily practice is supported by appendices courtesy of tool copyright holders

Appendix A-5 to 6

PPP page 5-6



Edmonton Symptom Assessment System (ESAS)

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible Pain
Not Tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible Tiredness
Not Nauseous	0	1	2	3	4	5	6	7	8	9	10	Worst possible Nausea
Not Depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible Depression
Not Anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible Anxiety
Not Drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible Drowsiness
Best Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible Appetite
Best Feeling Of Wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible Feeling
No Shortness Of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible Shortness of Breath
Other Problems	0	1	2	3	4	5	6	7	8	9	10	

ESAS completed by:

Patient

Health professional

Family

Assisted by family or health professional



Management of Pain

- **Basic principles** (p 5-10)
 - ❖ **Selecting an analgesics regime-use WHO ladder and 8 process steps** (pages 5-11 to 5-33)
- **Opioid Neurotoxicity** (p 5-30 to 5-33)
- **Titration-3 methods** (p 5-34 to 5-36)
- **Opioid rotation/switching (6 steps)** (p5-44 to 5-48)
- **Opioid management in the elderly** (p 5-53)
- **Management of Pain types** (p 5-54 to 5-70)
- **Other Adjuvant analgesics** (p 5-71 to 5-75)



Pain Management – Points

- Comprehensive assessment required
- Individualize pain management
- Constant pain needs regular medication
- Titrate opioids to the best analgesia with fewest side effects
- Use adjuvant medications and treatments when necessary
- Educate the patient and family
- Recognize the concept of total suffering and total pain



Cardiopulmonary Symptoms

(Chapter 6)

Shortness of Breath (Dyspnea)

- causes, aggravating factors, treatment,

Assessment (4 steps)

Management (5 steps)

- Includes Non- pharmacological and pharmacological measures, Oxygen,
- Pleural effusions, tracheobronchial obstruction



Cardiopulmonary Symptoms

- Pericardial Effusion and tamponade
- Superior Vena Cava Syndrome (SVCS)
- Cough
- Bronchorrhoea
- Hemoptysis
- Terminal respiratory congestion(“death rattle”)
- Hiccups
- Pulmonary Embolism
- Edema



Delirium

(Chapter 7)

- **General**

- **Caregivers may mistake the manifestations of opioid-induced delirium (such as agitation, moaning or groaning) for uncontrolled pain and respond by rapidly increasing the doses of opioids and other analgesics, only to aggravate the delirium**
- **Delirium may be misdiagnosed as depression or anxiety disorder**

PPP page 7-1



Delirium

May be referred to in different terms such as “agitation” and “terminal restlessness”

***Many episodes of delirium are reversible.**

Discerning when to intervene with delirium reversing treatments and when to focus therapy on controlling the symptoms is an IMPORTANT decision-making process in managing delirium in the palliative setting



Delirium

- Causes
- Clinical presentation
- Screening
- Assessment
- Management (Includes non-pharmacological and pharmacological)

PPP pages 7-2 to 7-16



Delirium

- Blessed Orientation Memory Concentration Test (BOMC)
- The Nursing Delirium Screening Scale (NuDESC)

Appendix 12 and 13



Gastrointestinal (GI) Problems

(Chapter 8)

- Nausea and Vomiting
- Constipation
- Diarrhoea
- Malignant Bowel Obstruction
- Cachexia syndrome, anorexia, weight loss, artificial nutrition (5 steps to management)

PPP pages 8-1 to 8-48



Gastrointestinal Problems

- Ascites
- Dyspepsia
- Dysphagia (3 phases)
- Esophageal obstruction by tumor
- GI Bleeding
- Fistulas
- Hepatic Failure

PPP pages 8-36 to 8-44



Hematological Problems

(Chapter 9)

Management

- Anemia
- DVT in palliative care
- Thrombocytopenia (Platelet < 120)
- Leucocytosis (Elevated WBC)
- Leucocytopenia (Decreased WBC)
- Thrombocytosis
- DIC
- Bleeding

PPP page 9-1 to 9-3



Metabolic, Electrolyte and Endocrine Problems

(Chapter 10)

Hypercalcemia

- Is in many cases reversible with treatment that carries a relatively low risk of serious adverse effects (hydration and bisphosphonates).

Hypoalbuminemia

- Causes include cachexia syndrome and liver failure
- In most cases irreversible.

Hypocalcemia, Hyponatremia, Hypercalemia,
Hypokalemia, Hypomagnesemia, Adrenal Insufficiency

Hyperglycemia (diabetes mellitus) in the palliative setting



Neurological Problems

(Chapter 11)

- Seizures
- Spinal Cord Compression (SCC)
- Cerebral Metastases
- Leptomeningeal Involvement

PPP pages 11-1 to 11-6



Psychological & Psychiatric Distress

(Chapter 12)

Adjustment disorder, Demoralization Syndrome, Insomnia

Major Anxiety disorders

- Pharmacologic management
- Panic disorder
- Drugs for the Pharmacologic Management of Anxiety Disorder in Palliative care)

Major depression disorder

- Useful interview questions
- Suggested Antidepressant doses in the palliative setting
- Factors to Consider in Selecting an Antidepressant in Palliative Care)

Indications for a referral to a psychiatrist or palliative care specialist

PPP pages 12-1 to 12-26



Total Suffering, Spirituality, Hope, Dignity and Spiritual Care (Chapter 13)

- Total Suffering
- Spirituality, religion and existential distress
- Dignity and Dignity conserving Care
- Hope
- Appendix - Major faith traditions, beliefs and customs, considerations

PPP pages 13-1 to 13-16



Palliative Emergencies

(Chapter 14)

- Pain Crisis
- Psychospiritual crisis
- Delirium
- Dyspnea crisis
- Spinal Cord Compression (SCC)
- Massive Bleeding
- Seizure
- Superior Vena Cava Syndrome (SVC Syndrome)

PPP pages 14-1 to 14-8



Non-cancer: Select Issues

(Chapter 15)

- Amyotrophic Lateral Sclerosis (ALS)
- End-Stage Multiple Sclerosis (MS)
- End-Stage Heart Failure (CHF)
- End-Stage Chronic Obstructive Pulmonary Disease (COPD)

PPP pages 15-1 to 15-12



Miscellaneous Problems

(Chapter 16)

- Pruritis
- Fever and sweats
- Hot Flashes
- **Infections**
 - Antibiotic guidelines
- Urinary Tract Infection (UTI)
- Lower respiratory tract infections
- Wound care

PPP pages 16-1 to 16-18



Miscellaneous Interventions

(Chapter 17)

- Establishing Brain Death
- Withdrawing respirator support
- Subcutaneous (sc) injections: Guidelines
 - Table 17-1 Medications commonly used sc in Palliative are...
- **Artificial Hydration**
 - When should Artificial Hydration be withheld or withdrawn?
 - When should Artificial Hydration be considered?
 - Key issues to be considered when determining the role of non-oral hydration
 - When is withdrawal of hydration appropriate?
 - When is artificial hydration appropriate?
 - Hypodermoclysis (artificial sc hydration)
- Reviewing Hydration



Palliative Sedation

(Chapter 18)

- Definition of “palliative sedation”
- Indications for palliative sedation
- Incidence of palliative sedation
- Ethical considerations
- Initiating palliative sedation
 Calgary Guidelines (5 Steps)
- Pharmacological agents

PPP pages 18-1 to 18-10



Last Days and Hours (Terminal Phase) (Chapter 19)

- Signs that death is approaching
- Signs that death is imminent
- Preparing the patient when death appears imminent
- Managing airway secretions
- Preparing the family
- Pronouncement of death
- Death certification



Grief and Bereavement

(Chapter 20)

- Definitions
- Anticipatory grief
- Chronic phase
- Resolution phase
- Management of uncomplicated grief
- Communication
- Complicated grief



Evaluation Instruments

(Appendices)

- Edmonton Symptom Assessment System (ESAS)
- Palliative Performance Scale (PPS v2)
- Blessed Orientation Memory Concentration Test (BOMC)
- The Nursing Delirium Screening Scale (NuDESC)

A 1 to A 13

