



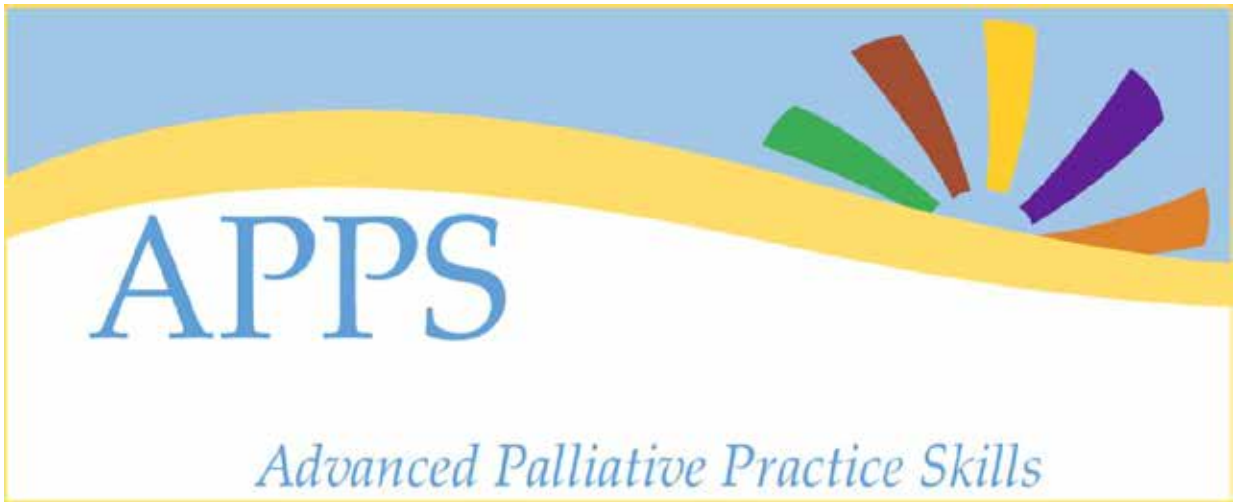
APPS

Advanced Palliative Practice Skills

# Facilitator Guide

A Resource Guide for APPS Facilitators





Revised: May 2017

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**HPC Consultation Service**  
Waterloo Region  
Wellington County

## INTRODUCTION

The Advanced Palliative Practice Skills (APPS) program is an educational opportunity for Personal Support Workers (PSWs), Health Care Aides and Hospice Volunteers who are graduates of the Core Fundamentals of Hospice Palliative Care Program and who are currently working or volunteering in palliative care.

The APPS program is comprised of three in-class sessions with additional reading, reflections and e-Learning modules. Course content includes:

- Role of PSW/volunteer in providing a palliative approach
- Self-Awareness in Providing Hospice Palliative Care (HPC)
- Loss and Grief
- Symptom Identification and Management Strategies
- Comfort Measures at End-of-Life (EOL)
- Ethical challenges in End-of-Life.

*Note: The Core Fundamentals of Hospice Palliative Care program is a prerequisite for the APPS program.*

### Note to Facilitators:

This program currently does not have a specific facilitator guide for each session. Notes for the facilitator to facilitate each class session are included in the notes below each PPT. It will be helpful to have the PPT on presenter view when teaching the class session. In preparation facilitators will need to review the PPT's, handouts and learner materials to develop your comfort with presenting as is. You will need to walk learners through the materials (as we do in the Core Fundamentals program) at the start of the first session.

We are using the Waterloo Wellington APPS program for this pilot. You will note that the ESAS-r tool is the Edmonton program version and not the version we typically use in our service area. Facilitators may choose to print and share the ESAS-r version that our program currently uses.

In your materials and in the learner package there are print copies of the e-Learning modules that learners are expected complete between the class sessions. It has been noted by previous facilitators of this course that participants can be confused between the copy of the PPTS for the sessions and the modules they will do online. At the end of each session, please review where they are in their learning materials and that the print copy is for note taking purposes.

The e-Learning modules do include voice over and video clips and they are required to complete the modules on line. The link for the modules are sent to learners by the administrative support person at St. Joseph's Healthcare as appropriate after each class session.

- Session 1 - Modules A and B link
- Session 2 - Modules C and D link

Learners are expected to find a way to complete the e-Learning modules even if they do not have the internet capacity at home. (i.e. library, work, colleague)

For the reflective activity, at the end of each e-Learning module there are *Reflection* note pages. After each module, learners can complete that activity.

Finally, at the end of the last session (Session 3), the participants have a print version of a *Workshop Evaluation* and will complete this in class. These evaluations are to be collected by the facilitator. Participants have the evaluation in their Learner Guide, and facilitators do not need to print them. Leave sufficient time to complete and collect the evaluations.





# Facilitator Tools

## TOOLS

- APPS Kit Checklist
- APPS Timeline: Sample
- Norms of Practice
- Peer-to-Peer Sign-Up Sheet: Sample
- Workshop Evaluation

## APPS Kit Checklist

(#)	Item	Notes
<b>General Handouts</b>		
1	Checklist	
1	Attendance Sheet	
24	Receipt (For those paying at the door)	
24	Blank Tent Card	
24	Timeline/Schedule	
1	Peer-to-Peer Signup Sheet	
24	PPS/ESAS	
24	Norms of Practice	
24	APPS Participant Binder	
24	Journal	
24	A Caregiver's Guide	
1	Door Sign	
<b>Session 1 Handouts</b>		
24	<b>Notes: Foundations of APPS</b>	
24	Domains of Issues Worksheet	
24	SBORS	
24	<b>Notes: e-Learning Module A: Self Awareness/ Self Care</b>	
24	Self-Assessment on Dying and Death	
24	Self-Care Inventory	
24	Compassion Fatigue and Vicarious Trauma – Signs and Symptoms	
24	<b>Notes: e-Learning Module B: Loss &amp; Grief</b>	
24	A letter of Condolence	
<b>Session 2 Handouts</b>		
24	<b>Notes: Tools for Symptom Management with a Focus on Pain</b>	
24	Domains of Issues Worksheet	
24	DOS (Documenting Observable Symptoms)	
24	PSW Fact Sheet	
24	<b>Notes: e-Learning Module C: Delirium, Dyspnea &amp; Nausea</b>	
24	Delirium, Dementia & Depression	
24	Confusion Assessment Method (CAM)	
24	Factsheet: Breathlessness	
24	<b>Notes: e-Learning Module D: ACP, Ethics &amp; Nutrition</b>	
24	Conversations Worth Having	
24	Ethical Decision Making: A Framework	
<b>Session 3 Handouts</b>		
24	<b>Notes: Last Hours</b>	
24	Steps to Perform a Gentle Hand Massage	
4	Closing Exercise for APPS (Facilitators Only)	
<b>Final Handouts</b>		
24	Final Evaluation	
24	Certificate of Completion	
24	When Someone is Dying (Community)	

**APPS Timeline: Sample (page 1)**

## Advanced Palliative Practice Skills (APPS) Timeline

<b>Location:</b>		
<b>Facilitator:</b>	<b>Email</b>	<b>Phone</b>
<b>Admin/Tech Support:</b>	<b>Email</b>	<b>Phone</b>

**APPS Program Components:**

- **Reading Requirements:**
  - Fundamentals Participant Resource Guide
  - A Caregiver’s Guide
- **E-Learning Modules:** to be completed throughout the course
- **Peer to Peer Exchange:** two opportunities for learners to connect with each other to enable collaborative learning and shared solution-finding
- **Reflective Activities:** ongoing
- **In-Class Learning Sessions:** three facilitated in-class sessions
- **Post-Session Online Reflections:** a brief survey is to be completed after each of the 1<sup>st</sup> and 2<sup>nd</sup> in-class sessions
- **Post Course Evaluation:** to be completed and submitted during the final in-class session

**In-Class Learning Sessions:**

Date	Time	Location
1.		
2.		
3.		

**Criteria for Certificate of Completion**

Your certificate will be issued pending completion of the following:

- 100% attendance at the three, in-class **Learning Sessions**
- Completion of two post-session **Online Reflections**
- Completion of the assigned **E-learning Modules**
- Reading of the **Fundamentals Resource Guide and A Caregiver’s Guide**
- Engagement in **Reflective Activity** throughout the program
- Participation in two **Peer-to-Peer Exchanges**
- Participation in **Classroom Discussions**
- Completion of the **Final Course Evaluation**

*If you have missed a component, it is YOUR responsibility to arrange to make it up. Please contact your course facilitator.*

**APPS Timeline: Sample (page 2)**

**APPS Course Schedule**

		Readings	Online Learning	Activity	Date Completed
<b>Week 1</b> Date: <input type="text"/>	In Class Session #1 (3 Hours)	<b>Resource Guide</b> Classic (Pgs. 178-188) Core (176-181) <b>A Caregiver's Guide</b> (Pgs. 8-26)			
<b>Week 2</b>		<b>Resource Guide</b> Classic (Pgs. 154-175) Core (Pgs. 154-169) <b>A Caregiver's Guide</b> (Pgs. 125-131)	Module A	Peer-to-Peer Exchange before next in-class session (In person or teleconference) Engage in reflective activities weekly	
<b>Week 3</b>		<b>Resource Guide</b> Classic (Pgs. 68-76) Core (Pgs. 64-79) <b>A Caregiver's Guide</b> (Pgs. 70-79; 82-85)	Module B	Engage in reflective activities weekly	
<b>Week 4</b> Date: <input type="text"/>	In Class Session #2 (3 Hours)	<b>Resource Guide</b> Classic (91-101) Core(Pgs. 86-94) <b>A Caregiver's Guide</b> (Pgs. 91-95; 99-100)		Engage in reflective activities weekly	
<b>Week 5</b>		<b>Resource Guide</b> Classic (104-114 & 138-139) Core (Pgs. 114-121 & 138-139) <b>A Caregiver's Guide</b> (Pgs. 51-59)	Module C	Peer-to-Peer Exchange Before next in-class session, (In person or teleconference) Engage in reflective activities weekly	
<b>Week 6</b>		<b>Resource Guide</b> Classic (140-150) Core (Pgs.140-148) <b>A Caregiver's Guide</b> (Pgs. 109-123)	Module D	Engage in reflective activities weekly	
<b>Week 7</b> Date: <input type="text"/>	In Class Session #3 (3 Hours)				

**Peer Partner Information**

Name	Phone	Initial Connection Date	Final Connection Date

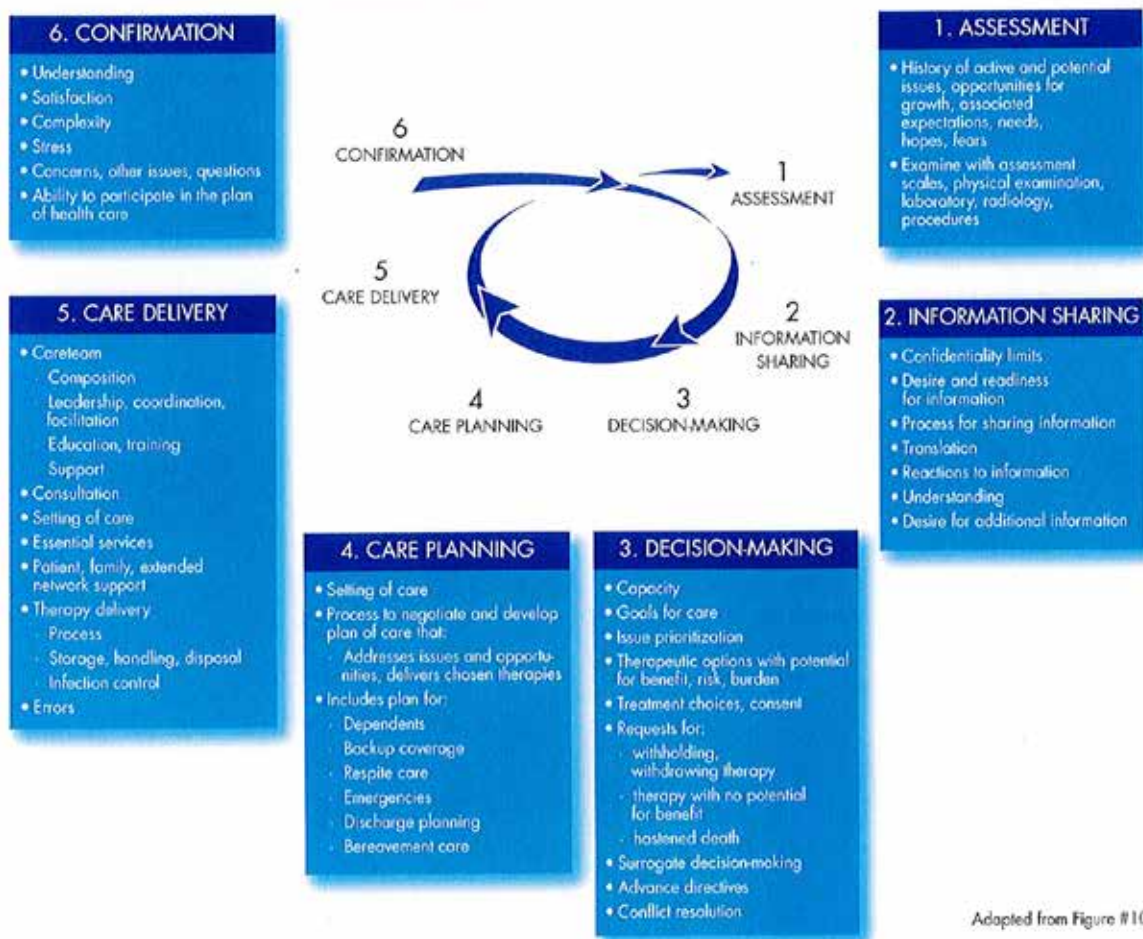
Norms of Practice (page 1)



# NORMS of PRACTICE

## *The Process of Providing Care*

### ESSENTIAL AND BASIC STEPS DURING A THERAPEUTIC ENCOUNTER



Adapted from Figure #10

*"While hospice palliative care has grown out of "care for the dying," the concepts can now be used to guide care at any point during an acute, chronic, or life-threatening illness, or bereavement." p.53*

Source: A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice.  
Canadian Hospice Palliative Care Association (CHPCA), March 2002, 131C — 43 Bruyère Street, Ottawa, Ontario, Canada K1N 5C8.

Visit [www.chpca.net](http://www.chpca.net) to view this document in its entirety.

Norms of Practice (page 2)



DOMAINS OF ISSUES ASSOCIATED WITH ILLNESS AND BEREAVEMENT



\* Other common symptoms include, but are not limited to: **Cardio-respiratory:** breathlessness, cough, edema, hiccups, apnea, agonal breathing patterns. **Gastrointestinal:** nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia. **Oral conditions:** dry mouth, mucositis. **Skin conditions:** dry skin, nodules, pruritus, rashes. **General:** agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo.

Adapted from Figure #7

*Providing a Shared Vision*

*"so that patients and families can realize their full potential to live even when they are dying." p.87*

**Hospice palliative care** 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; promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization. **Hospice palliative care** 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 needs, and are prepared to accept care. **Hospice palliative care** may complement and enhance disease-modifying therapy or it may become the total focus of care. p. 17

**Peer-to-Peer Sign-Up Sheet: Sample**

**Advanced Palliative Practice Skills (APPS)  
Peer-to-Peer Sign-Up Sheet**

Advanced Palliative Practice Skills (APPS)	Name	Phone Number	Initial connection date planned
<b>Session:</b> _____			
Group 1			
Group 2			
Group 3			
Group 4			
Group 5			
Group 6			
Group 7			
Group 8			
Group 9			
Group 10			





### Advanced Palliative Practice Skills (APPS) Final Workshop Evaluation

Dates: \_\_\_\_\_

Thank you for taking the time to provide us with your feedback about the APPS Course!

1. What did you like about the course?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

2. What surprised you?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. What didn't you like about the course?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. To what extent did this course meet your expectations?

- Exceeded     To a great extent     To some extent     Did not meet

5. How confident do you feel about applying APPS knowledge to your job? (please circle)

0%   10%   20%   30%   40%   50%   60%   70%   80%   90%   100%

6. Please list the barriers to applying APPS knowledge to your job:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

7. Do you have an action plan for applying APPS knowledge to your job?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

8. Please list supports that would help you to apply APPS knowledge to your job:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## APPS Workshop Evaluation (page 2)

The next two charts focus on your perceptions of the last in-class session:

Overall, how would you rate the following aspects of the last in-class session?  
(Please check )

	Poor	Good	Excellent
• Pace of activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Opportunities to participate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Volume of material covered	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Overall, how would you rate this session?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please indicate the extent to which you agree with each statement below. (Please check )

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
• The facilitator was effective in presenting information in a way that facilitated my learning.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The facilitator was knowledgeable in the subject matter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The facilitator was able to create a positive learning environment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I have the supports in my workplace to apply the new knowledge I learned in this session.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Overall Course Evaluation

Please take an addition moment to provide feedback on the APPS Program:

Course Components  
(Please check )

	Not at all Helpful	Helpful	Extremely Helpful
• Fundamentals Program Guide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• The Caregiver's Guide	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Four E-Learning Modules	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Three In-Class Sessions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Two Peer-to-Peer Exchanges/ Learning Debriefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Online Reflections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Timeline/Course Schedule	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Additional Comments:

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# Session 1

## SESSION 1: FOUNDATIONS OF APPS

- Session 1 Power Point Presentation (Copy)
- Domains of Issues Worksheet
- SBORS Tool

### **Note to Facilitator:**

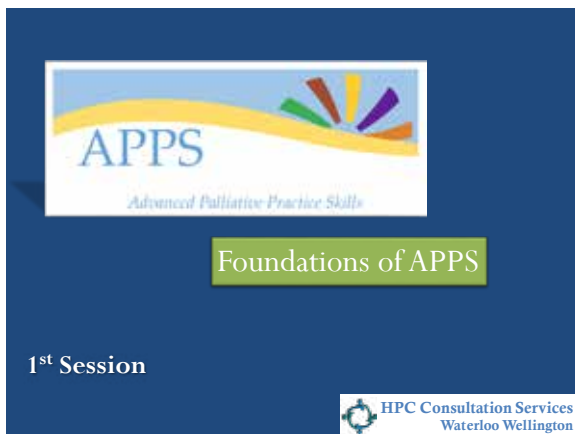
For the welcoming exercise, the activity involves having jujube candies as part of the exercise. Facilitators are to provide or replace the welcoming activity with one of your own.

Throughout the materials, for the learning sessions and e-Learning modules, mention is made of writing in their journals. For this pilot we have not supplied journals but have alternative options. Instruct learners to record their thoughts or notes when instructed to write in their journals either on the note pages beside the power point handouts or to use the Reflection pages provided after each e-Learning module. Learners may also add their own notepaper to their materials if they so desire. Facilitators will need to mention this when reviewing materials together on the first night and may need to remind in subsequent sessions.

When reviewing their materials with learners at the first session please note that the materials were originally focused on the PSW role and is now expanded to include volunteers, but they will still notice that much of the resources mention the PSW's more frequently. Facilitator will also need to remain aware of being inclusive of volunteers; adapting language and adding 'volunteer' role and conversation throughout the program.

In the material review when speaking to the e-Learning modules, facilitators should mention that worksheets and handouts related to activities they will do in the modules are included in their materials just after the e-Learning modules themselves.

# Foundations of APPS




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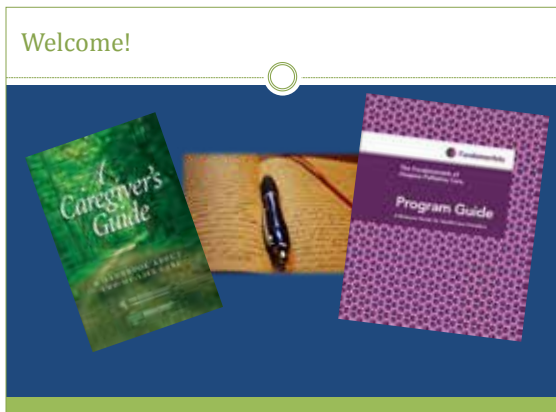
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### Overall APPS Objectives

- Demonstrates a growing sensitivity, understanding and respect for the individuality of the person, family and team/caregivers involved in the palliative illness experience
- Builds upon the learning concepts from the Fundamentals of HPC to effectively communicate with the person, family and team
- Identifies strategies for both individual as well as organizational opportunities to enhance the palliative philosophy into care delivery; and
- Actively contributes to the team approach to HPC

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### Program Expectations

- 100% attendance is expected
- Active participation is expected within the 3 in class sessions
- Completion of the self direction learning modules
- Completion of the Peer to Peer interactions
- Commitment to ongoing self reflection with practical application activities

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### Session 1 Objectives

Review:

- ROPES
- Domains of Issues
- Palliative Performance Scale
- Edmonton Symptom Assessment Scale

Role of PSW on HPC Teams

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R.O.P.E.S.

- R** – Respect and Responsibility
- O** – Open mindedness
- P** – Participation
- E** – Experiment & Enthusiasm
- S** – Sensitivity & Support

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Domains of Issues

The diagram 'Domains of Issues' is a grid with 10 boxes. The top row includes 'Physical', 'Psychological', and 'Social'. The middle row includes 'Spiritual', 'Cultural', and 'Ethical'. The bottom row includes 'Financial', 'Legal', and 'Religious'. Each box contains a list of specific issues related to that domain.

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“No human interaction is neutral. It is either healing or wounding”

Dr. Balfour Mount

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T

S1

eLA

eLA

S2

eLC

eLD

S3

### 3 Foundational Concepts of Hospice Palliative Care

- Effective Communication
- Effective Group Functioning
- Ability to Facilitate Change

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#### Palliative Performance Scale (PPSV2) version 2

PPS Level	Activities	Activity & Endorse of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable housework Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sillie	Unable to do any work Evident disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Evident disease	Mainly assistance	Normal or reduced	Full or Somnolent +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Evident disease	Total Care	Normal or reduced	Full or Somnolent +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Evident disease	Total Care	Normal to -	Full or Somnolent +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Evident disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

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### PPS Review Case Study

Mrs. L has been a resident of your LTCH for the past 3 years.  
 Her diagnoses include: end stage Dementia, Diabetes and Osteoarthritis.  
 She is w/c bound and a 2 person assist. She requires total care.  
 Although she drinks well, she is on thickened fluids because of some dysphagia and a pureed diet.  
 Her current conditions require that she is fed all meals by staff.

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### Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & none No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Normal activity & work	Full	Normal	Full
80%	Full	Normal activity with E/M Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal J/S/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Seated	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy or Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy or Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to None	Full or Drowsy or Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma or Confusion
0%	Death	-	-	-	-

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### Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & none No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Normal activity & work	Full	Normal	Full
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10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma or Confusion
0%	Death	-	-	-	-

Requires Total Care

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### Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & none No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Normal activity & work	Full	Normal	Full
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10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma or Confusion
0%	Death	-	-	-	-

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Victoria Hospice SOCIETY

**Palliative Performance Scale (PPSv2)**  
version 2

PPS Level	Amelioration	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with <i>Effort</i> Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly <i>Still</i> , <i>in</i>	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

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Victoria Hospice SOCIETY

**Palliative Performance Scale (PPSv2)**  
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90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
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0%	Death	-	-	-	-

? Consciousness Level

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Victoria Hospice SOCIETY

**Palliative Performance Scale (PPSv2)**  
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10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

? Consciousness Level

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### Your Assessment Findings:

Mrs. L.:

- Ambulation: Mainly Sit/ Lie 50%
- Activity: Unable to do most activity/ Has extensive disease 40%
- Self-Care: Requires total care 30%
- Intake: Normal or Reduced 30%
- LOC: Full or Drowsy +/- Confusion 30%

**PPS = 30%**

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### Making "Best Fit" Decisions

- Only use PPS in 10% increments (e.g. cannot score 45%)
- Sometimes it will be challenging to "fit" patient because s/he will be higher or lower on several columns

*Use clinical judgment & leftward dominance to determine most accurate score*




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### Review of how to complete the ESASr



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### Who Completes the ESASr?

- Ideally, the patient & family should be taught
- Gold standard for symptom assessment: the patient identifies issues and determines severity
- If person cognitively impaired, it is completed by caregiver, or:
- Last choice: health professional

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### Who is on your team?



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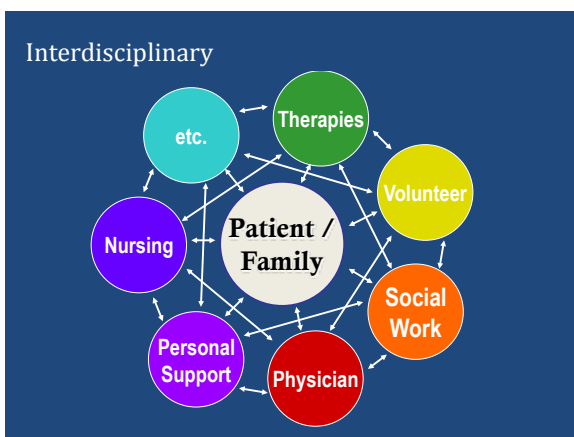
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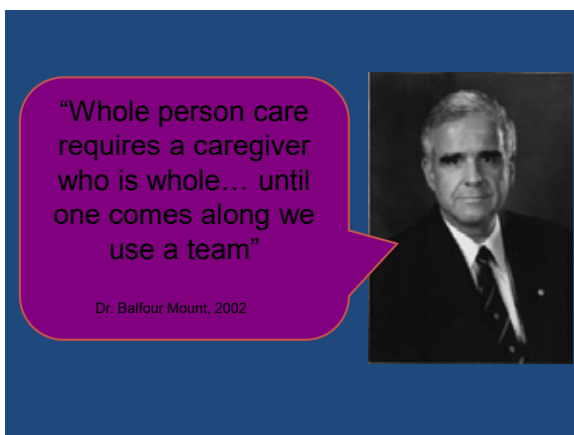
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T

S1

eLA

eLA

S2

eLC

eLD

S3

### Hospice Palliative Care

What is it?

Definition → Page 14 Fundamentals Resource Guide

“Aims to relieve suffering and improve the quality of living and dying”

(Ferris et al., 2002)

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### Barriers to Team Information Sharing

In small groups...

➤ Name one barrier to information sharing among caregivers on the team

➤ Name one successful or creative method for information sharing amongst your team

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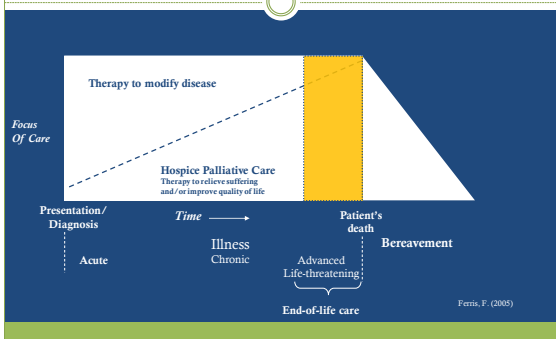
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### The Role of HPC During Illness



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**Handout:**

**Identifying the Issues in whole person and family care**

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**A Story About Care**

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**Handout:**

**Identifying the issues in person and family centered care**

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**SBOR**  
A  
Communication  
Tool



The SBOR form is a structured communication tool with four main sections: **S** (Situation), **B** (Background), **O** (Observations), and **R & S** (Review & Solutions). Each section contains specific prompts for the user to fill in.

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### Applying Learning to Practice

Considering the topics covered this evening please jot down in your journal:

- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing

As part of the interdisciplinary team, how will you as the PSW/ Volunteer work to communicate issues to your team?

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### e Learning Modules A & B

In preparation for **eLearning module A** please pre-read:

- Fundamentals of HPC: pg. 178-188 &
- A Caregiver Guide: pg. 8-26

In preparation for **eLearning module B** please pre-read:

- Fundamentals of HPC: pg. 154 - 174
- A Caregiver Guide: pg. 117 - 127

**Reflective Writing:**  
Complete your reflections within your journal or course note pages and use during you Peer to Peer interaction.  
Please remember to bring your journal to each in person session

Indicates this should be shared in your Peer to Peer meeting

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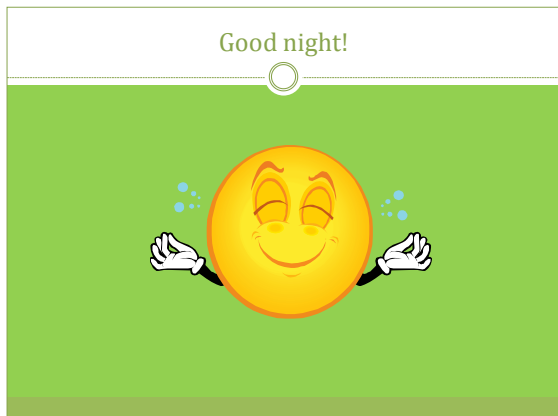
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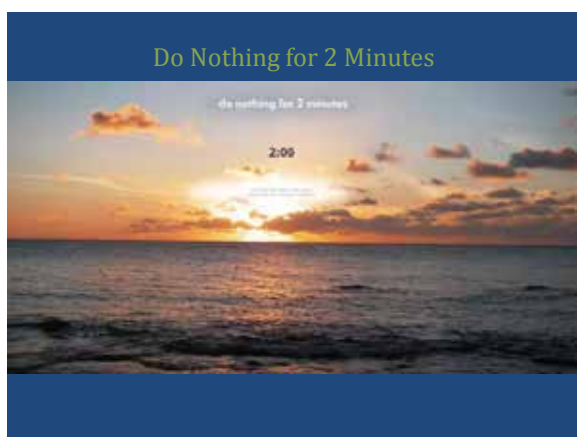
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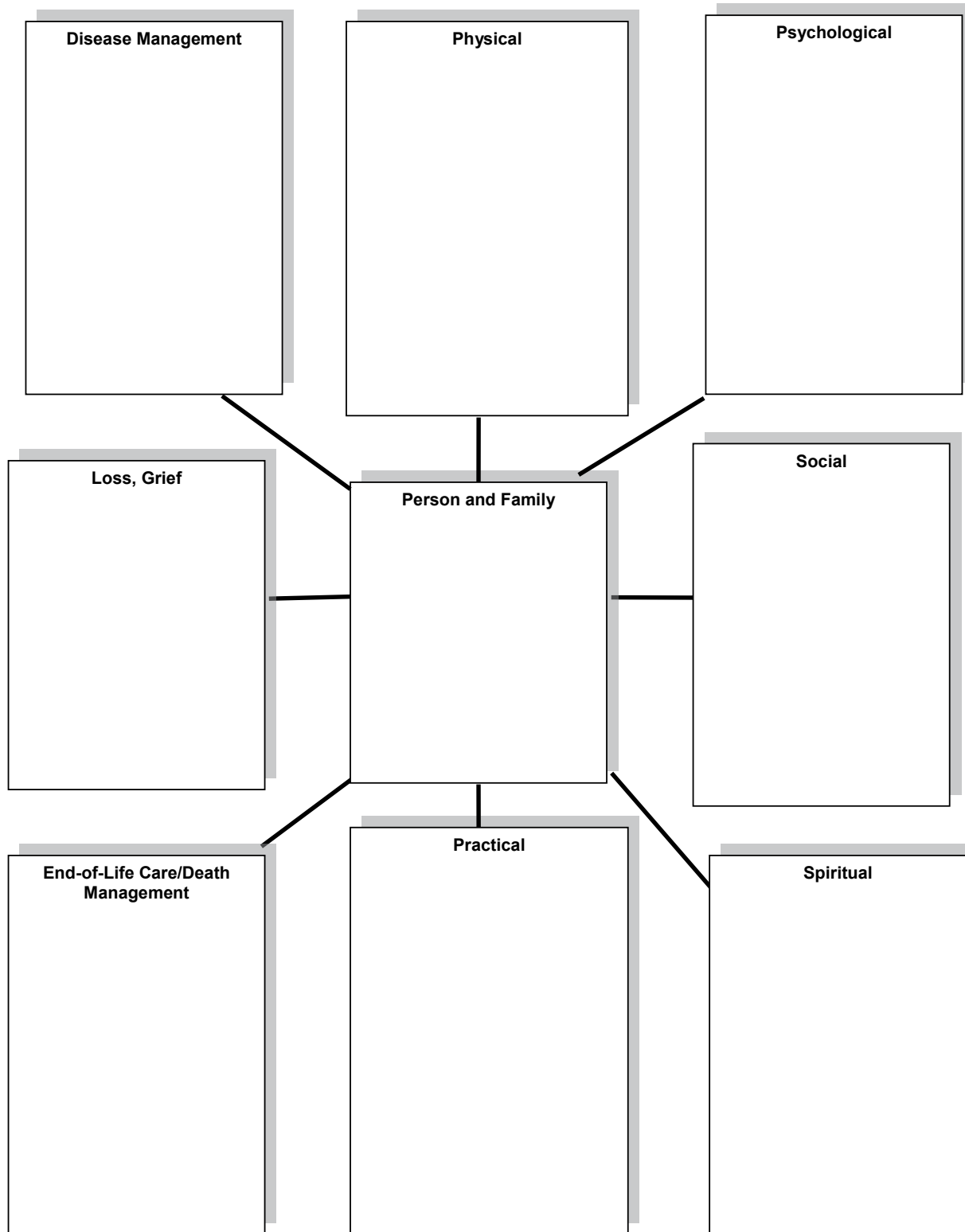
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### Domains of Issues WorkSheet



# SBORS TOOL FOR PSW OBSERVATION



Waterloo Wellington  
HPC Consultation Services

S

## SITUATION

- ✓ Your name and designation
- ✓ Who are you calling about? Include address or room number
- ✓ I am reporting that.....

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B

## BACKGROUND

- ✓ Briefly, explain what has been going on recently
- ✓ Include any incidents, such as falls, change in medical condition
- ✓ Explain what has changed with the care you provide

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O

## OBSERVATIONS

- ✓ Changes in self-report of a symptom?
- ✓ Changes in behavior?
- ✓ An incident?
- ✓ A new challenge or opportunity for care provision?

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R

## RESPONSE & SUGGESTIONS

- ✓ Does the RN/RPN need to come soon?
- ✓ Is there an intervention you would like to try (eg, to address a behavior?)
- ✓ How should we document this change ongoing?

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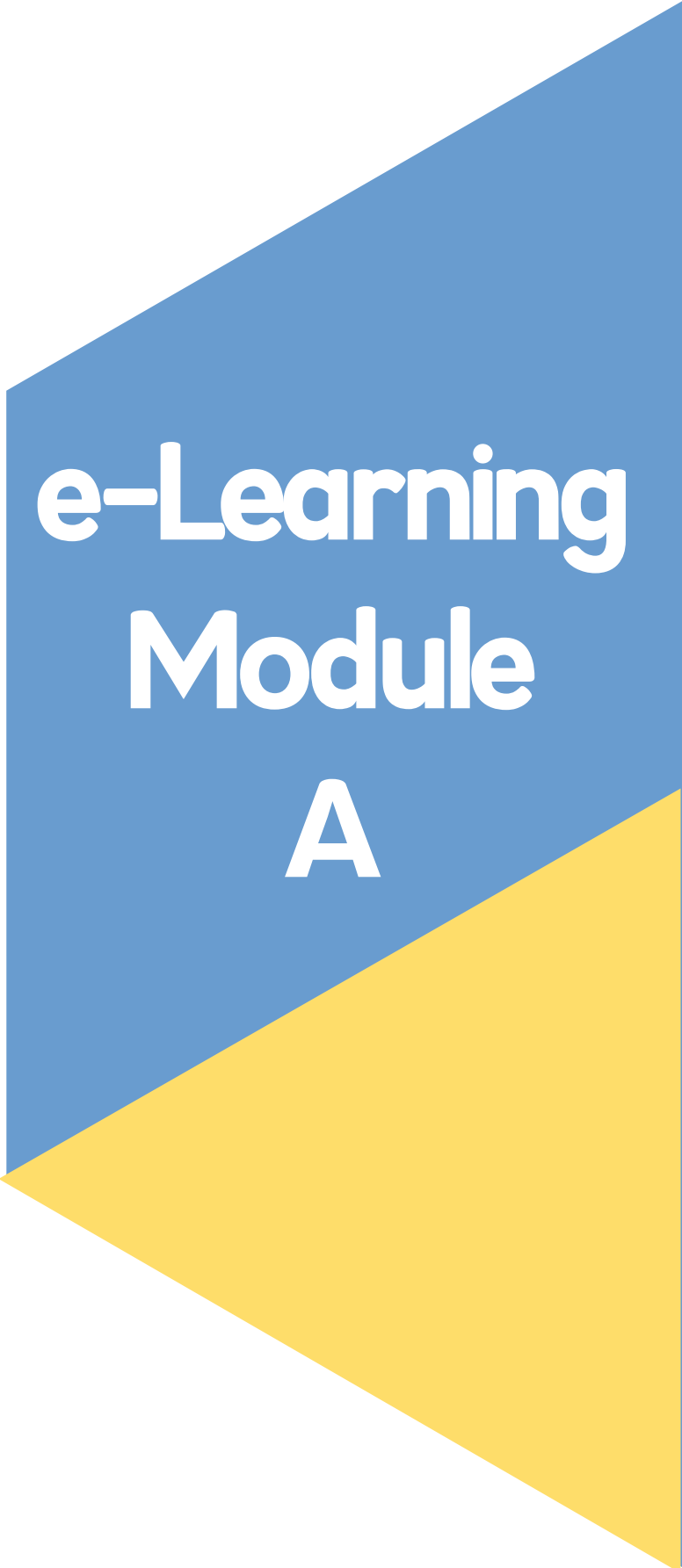
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S









# e-Learning Module A

## **E-LEARNING MODULE A: SELF-AWARENESS / SELF-CARE**

- Self-Awareness / Self-Care
- Self-Assessment on Dying and Death
- Self-Care Inventory
- Compassion Fatigue and Vicarious Trauma - Signs and Symptoms

*The learners will receive a link to the appropriate modules after Sessions 1 & 2.*

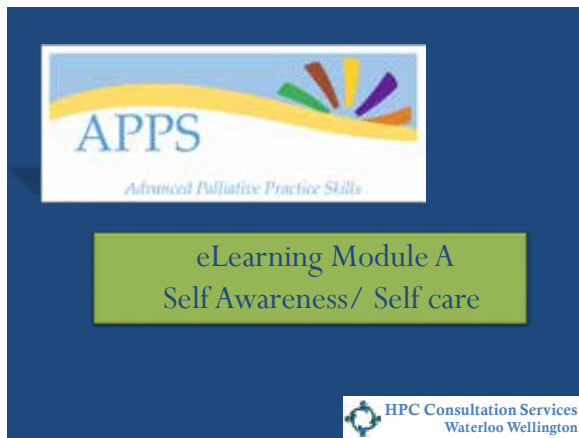
*Please remind the learners that a print copy of the module is in their materials for the purpose of facilitating note taking while do the on-line module.*

*There are videos and interactive pieces embedded in the modules that they will access via the link provided.*

*Review the e-Learning module process and requirement to complete at each of the appropriate session:*

- *Session 1: Modules A & B*
- *Session 2: Modules C & D*

### Self-Awareness / Self Care




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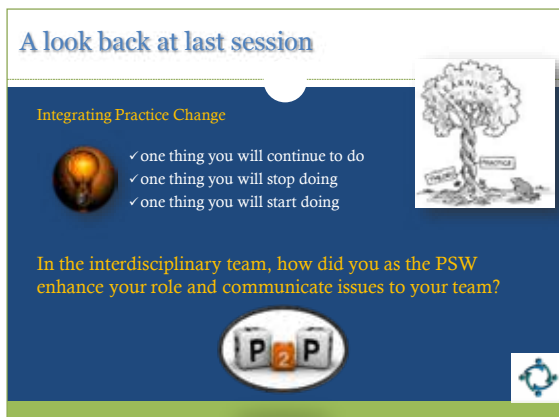
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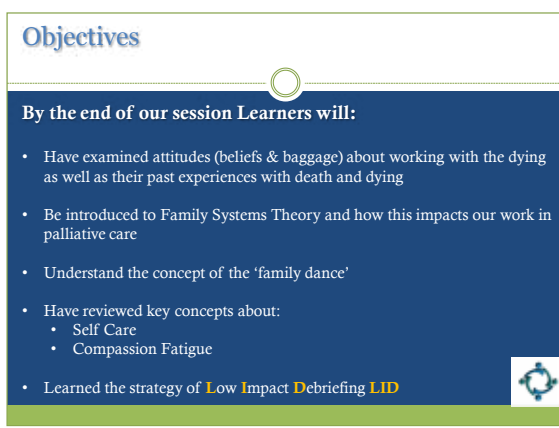
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### On Dying

*"The nature of dying is not medical; it is experiential. Dying is fundamentally a personal experience, not a set of medical problems to be solved."*

Dr. Ira Byock (1997)



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### Beliefs and Baggage

*"When I realize I will be working with people who are dying, I feel..."*

Unsure I might say something wrong

WORRIED

interested

scared

fascinated

Eager to learn

nervous

afraid

Glad I can offer help

apprehensive



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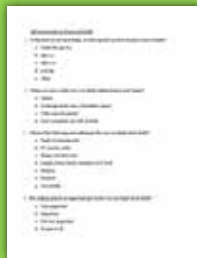
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### Self Assessment on Dying & Death

Please take a few minutes to complete the *Self Assessment on Dying and Death*



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More on the Bags we carry....



**What constitutes a “Good” or a “Bad” death?**




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More on the Bags we carry....



Good Death	Bad Death
Pain free	In pain
In my home	With no support
With my family	Alone
Alone	No time to say goodbye
Quick	Suffering
Time to get my affairs in order	Seeing my family suffer
With my pets at my side	In the hospital
At the cottage	In ICU




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**Family Systems**




Definition:  
*Those closest to the person in knowledge, care and affection.*

May include:

- the biological family
- The family of acquisition (related by marriage/ contract)
- The family of choice and friends (including pets)

**The person defines who will be involved in his or her care and/or present at the bedside.**




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## The Dance

- Every family has a dance
- Every family dance has a history and a reason
- Our role is to stand on the edge of the dance floor and observe, comment and normalize.
- We need to work from a 'therapeutic distance'

We can recognize we are on someone else's dance floor when we:

- Experience extremes of emotion
- Find it hard to share the care, using words like: 'my patients', 'my clients', 'my families'
- Try to control patients/ families....their decisions, behaviors and belief systems



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## Hooks

Hooks have a tendency to pull us onto the dance floor



To be clear about where we stand in our work we need to:

- Be clear and honest about our own needs
- Learn to see and value our dance
- Consciously strive to be in a dance that nurtures and supports us as individuals



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## Case Study

Mr. Fleming is moving towards the end of his life in hospital. His daughter Sarah (who lives in same town and has always been there to help her parents) and Mrs. Fleming are in his room. His other daughter Tracey (who moved back east to raise her family) has just arrived. Tracey wants to know what's happening and appears to be trying to take charge. The two sisters are arguing over their fathers bed while their mother sits quietly in the corner.



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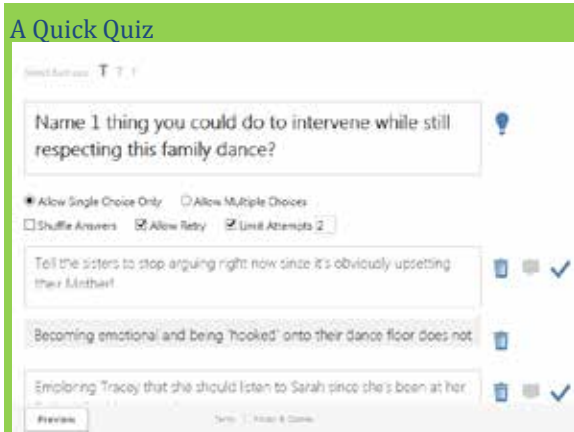
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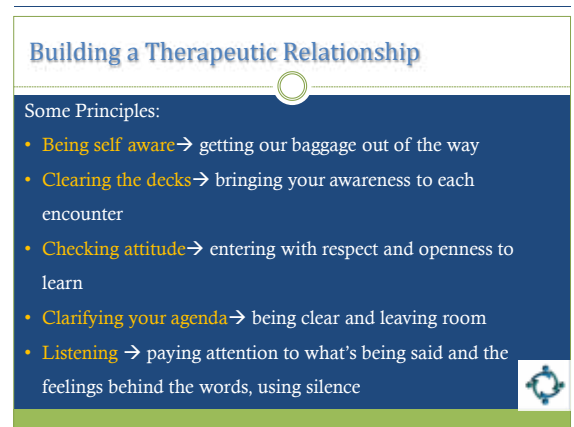
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### Compassion Fatigue: the cost of caring

**“The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet.”**

*Rachel Naomi Remen,  
Kitchen Table Wisdom 1996*



Mathieu, Françoise (2012) [www.compassionfatigue.ca](http://www.compassionfatigue.ca)



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### Compassion Fatigue

- A deep erosion of our compassion, of our ability to tolerate strong emotions/difficult stories in others
- Evident in helpers' professional and personal life
- Can also happen to caregivers (“caregiver fatigue”)

Mathieu, Françoise (2012) [www.compassionfatigue.ca](http://www.compassionfatigue.ca)



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### Vicarious Trauma

- Repeated exposure to difficult stories changes our view of the world (Saakvitne & Pearlman)
- Can cause nightmares, difficulty getting rid of certain images, an intense preoccupation with a particular story or event we've been exposed to.

Mathieu, Françoise (2012) [www.compassionfatigue.ca](http://www.compassionfatigue.ca)



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### Quick Review of the key elements of CF/VT

- CF and VT are normal, occupational hazards of the work: we get CF/VT because we care.
- Your signs and symptoms are your warning signs
- The solutions lie in reducing your isolation, taking a long hard look at your workload, managing stressful experiences with relaxation and breathing techniques and finally making self-care your number one priority.
- Not all workplaces are created equal. You could be experiencing job burnout due to an unsupportive workplace in addition to the challenging work that you do with clients/patients.

Mathieu, Françoise (2012) www.compassionfatigue.ca

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### Warning signs

- Signs and symptoms checklist
- Your S&S will be your **WARNING SIGNS**

Mathieu, Françoise (2012) www.compassionfatigue.ca

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### The Warning Signs Continuum

Mathieu, Françoise (2012) www.compassionfatigue.ca

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Strategy: Low Impact Debriefing

Low impact debriefing = LID  
(anti-sliming strategy)



Mathieu, Françoise (2012) www.compassionfatigue.ca

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Low Impact Disclosure  
and  
Debriefing

Françoise Mathieu, M.Ed., CCC.  
Compassion Fatigue Solutions Inc.  
[www.compassionfatigue.ca](http://www.compassionfatigue.ca)

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For More Resources/Information  
[www.tendacademy.ca](http://www.tendacademy.ca)



**WE TEND**  
to Organizational Health,  
Trauma, Compassion Fatigue,  
Burnout, Stress Management,  
Lifestyle Medicine and Conflict  
Resolution.

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### Applying Learning to Practice

Considering the topics covered throughout this eLearning Module - please jot down in your journal:



- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing



Review the Self Care Inventory Handout  
 Place a tick ✓ beside anything you currently do as part of your self care routine. Circle anything you'd like to add to your self care inventory

**In preparation for eLearning module B please pre-read:**

- Fundamentals of HPC: pgs. 154 - 174
- A Caregiver's Guide: pgs. 117 - 127

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- T
- S1
- eLA
- eLB
- S2
- eLC
- eLD
- S3

**Self-Assessment on Dying and Death (page 1)**

1. To the best of your knowledge, at what age did you first become aware of death?
  - a. Under the age of 3
  - b. Age 3-5
  - c. Age 5-10
  - d. 10 & up
  - e. Other
  
2. When you were a child, how was death talked about in your family?
  - a. Openly
  - b. As though death were a forbidden subject
  - c. With some discomfort
  - d. Don't remember any talk of death
  
3. Which of the following most influences the way you think about death?
  - a. Death of someone else
  - b. TV, movies, radio
  - c. Things you have read
  - d. Length of time family members have lived
  - e. Religion
  - f. Funerals
  - g. Own health
  
4. Has religion played an important part in the way you think about death?
  - a. Very important
  - b. Important
  - c. Not very important
  - d. No part at all

**Self-Assessment on Dying and Death (page 2)**

5. How often do you think of your own death?
  - a. At least once per day
  - b. Often
  - c. Not more than once per year
  - d. Never or almost never
  - e. Other
  
6. What does death mean to you?
  - a. The end of life
  - b. End of physical life, the spirit lives on
  - c. Endless sleep & peace
  - d. Don't know
  - e. A new beginning of life after death
  - f. Other
  
7. What thought about your own death bothers you the most?
  - a. I will no longer have any experiences
  - b. I am afraid of what may happen to my body after I die
  - c. I am not sure what will happen to me; if there is life after death
  - d. I will no longer be able to provide for my family
  - e. My relatives & friends will grieve
  - f. The process of dying may be painful
  - g. Other

## Self-Care Inventory

**SELF-CARE INVENTORY (Reprinted with permission)**

Organizational Solutions

<p><b>Physical Self-Care</b></p> <ul style="list-style-type: none"> <li>___ Eat regularly (e.g. breakfast, lunch, and dinner)</li> <li>___ Eat healthily</li> <li>___ Exercise</li> <li>___ Get regular medical care for prevention</li> <li>___ Get medical care when needed</li> <li>___ Take time off when sick</li> <li>___ Get massages</li> <li>___ Dance, swim, walk, run, play sports, sing or do some other physical activity that is fun</li> <li>___ Take time to be sexual – with yourself, with a partner</li> <li>___ Get enough sleep</li> <li>___ Wear clothes you like</li> <li>___ Take vacations</li> <li>___ Take day trips or mini-vacations</li> <li>___ Make time away from telephones</li> <li>___ Other:</li> </ul>	<ul style="list-style-type: none"> <li>___ Notice your inner experience – listen to your thoughts, judgments, beliefs, attitudes and feelings</li> <li>___ Let others know different aspects of you</li> <li>___ Engage your intelligence in a new area (e.g. go to an art museum, history exhibit, sports event, auction, theatre performance)</li> <li>___ Practise receiving from others</li> <li>___ Be curious</li> <li>___ Say no to extra responsibilities sometimes</li> <li>___ Other:</li> </ul>
<p><b>Psychological Self-Care</b></p> <ul style="list-style-type: none"> <li>___ Make time for self-reflection</li> <li>___ Have your own personal psychotherapy</li> <li>___ Write in a journal</li> <li>___ Read literature that is unrelated to work</li> <li>___ Do something at which you are not expert or in charge of</li> <li>___ Decrease stress in your life</li> </ul>	<p><b>Emotional Self-Care</b></p> <ul style="list-style-type: none"> <li>___ Spend time with others whose company you enjoy</li> <li>___ Stay in contact with important people in your life</li> <li>___ Give yourself affirmations, praise yourself</li> <li>___ Love yourself</li> <li>___ Reread favourite books, re-view favourite movies</li> <li>___ Identify comforting activities, objects, people, relationships, places, and seek them out</li> <li>___ Allow yourself to cry</li> <li>___ Find things that make you laugh</li> <li>___ Express your outrage in social action, letters, donations, marches, protests</li> <li>___ Play with children</li> <li>___ Other:</li> </ul>

## Compassion Fatigue and Vicarious Trauma - Signs and Symptoms

### Physical Signs and Symptoms

- Exhaustion
- Insomnia
- Headaches
- Increased susceptibility to illness
- Somatization and hypochondria

### Behavioural Signs and Symptoms

- Increased use of alcohol and drugs
- Absenteeism
- Anger and Irritability
- Avoidance of clients
- Impaired ability to make decisions
- Problems in personal relationships
- Attrition
- Compromised care for clients
- The Silencing Response
- Depleted parenting

### Psychological signs and symptoms

- Emotional exhaustion
- Distancing
- Negative self image
- Depression
- Sadness, Loss of hope
- Anxiety
- Guilt
- Reduced ability to feel sympathy and empathy
- Cynicism
- Resentment
- Dread of working with certain clients
- Feeling professional helplessness
- Diminished sense of enjoyment/career
- Depersonalization/numbness
- Disruption of world view/ Heightened anxiety or irrational fears
- Inability to tolerate strong feelings
- Problems with Intimacy
- Intrusive imagery – preoccupation with trauma
- Hypersensitivity to emotionally charged stimuli
- Insensitivity to emotional material
- Difficulty separating personal and professional lives
- Failure to nurture and develop non work related aspects of life

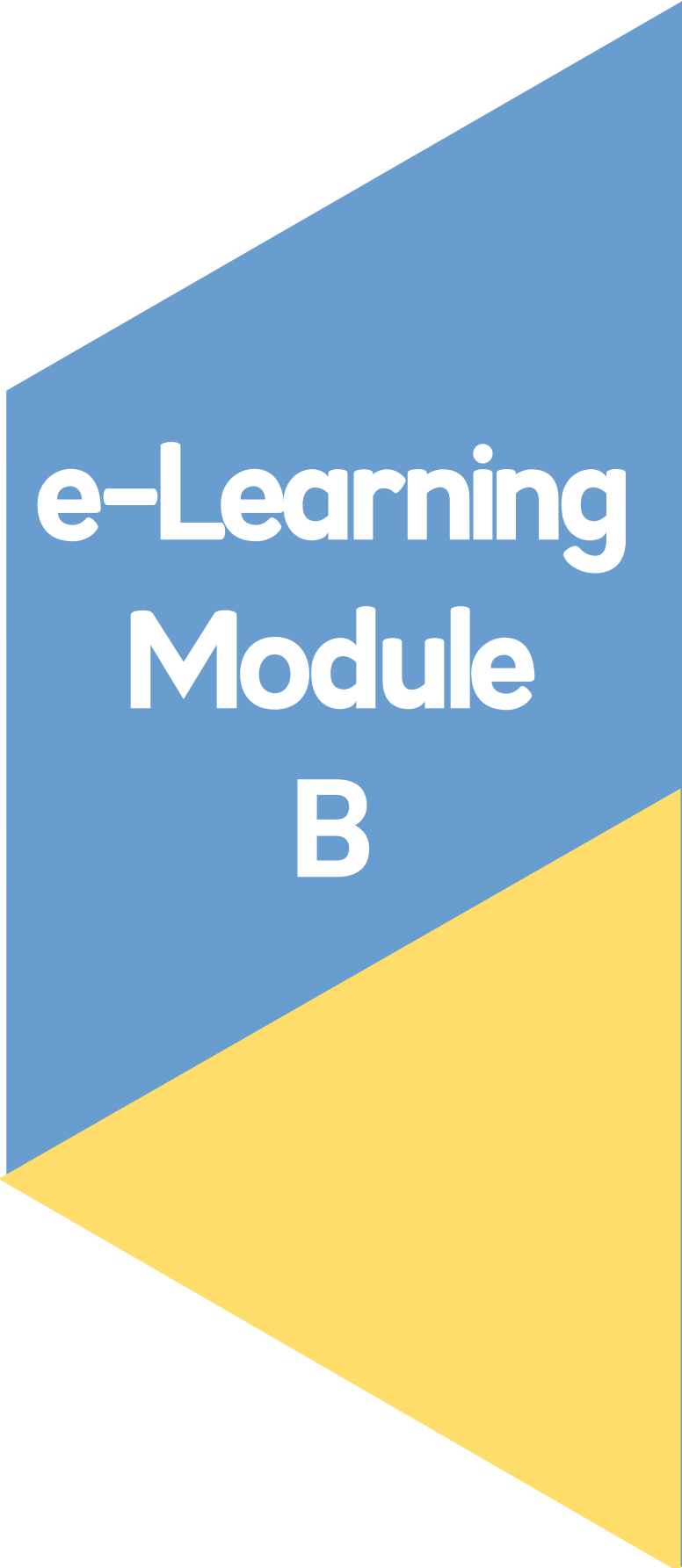
Sources: Saakvitne (1995), Figley (1995), Gentry, Baranowsky & Dunning (1997), Yassen (1995).

This sheet may be freely copied as long as (a) this box is left intact on the handout, (b) the author is credited, (c) no changes are made, and (d) it is not sold. Please be advised that compassion fatigue can lead to serious problems such as depression, anxiety and suicidal thoughts. The information contained on this sheet is not intended as a substitute for professional medical advice.

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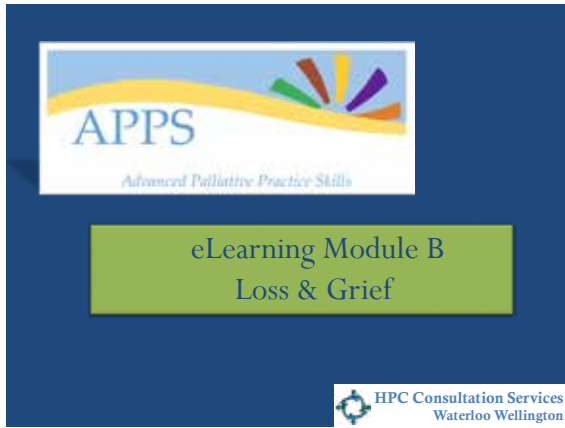


# e-Learning Module B

## **E-LEARNING MODULE B: LOSS & GRIEF**

- Loss & Grief
- A Letter of Condolence Handout

# Loss & Grief




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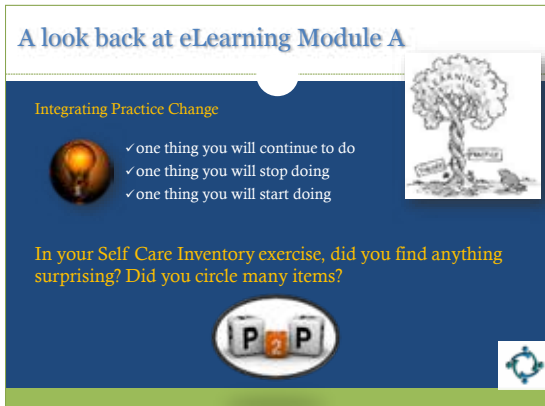
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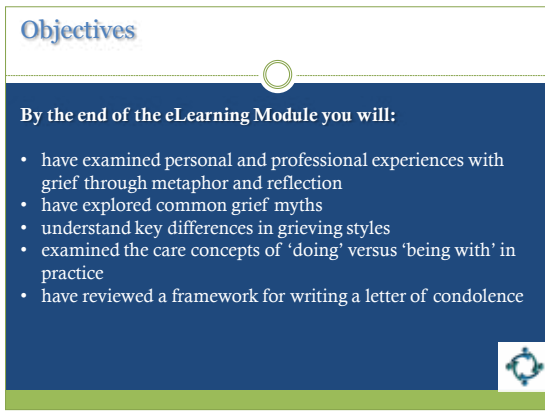
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### On Being up close with death and dying

It is a privilege to work up close and personal with the dying  
It is in this sacred space that we are taught by the masters...  
It is in this space we learn matters of life and death.

*Katherine Murray*



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### Grief Wounds



Sometimes grief is described as a wound

Thinking about our role?



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### Grief

- Remember – Grief is a natural and healthy response to any loss
- Every person grieves in a different way – each person in their family system may react and grieve distinctly



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### Exploring Grief Myths

- 1) Grief and mourning are the same experience
- 2) There is a predictable and orderly progression to the experience of grief
- 3) It is best to move away from grief and mourning instead of towards it.
- 4) Tears expressing grief are only a sign of weakness.
- 5) The goal is to “get over” your grief.

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### Grieving Styles

#### Instrumental Grievors

- Process grief through expression of thoughts and action
- Process feelings through cognition and activity
- How do you express - involved doing or thinking
- How do you experience grief – don't always identify it as grief
- How do you adapt to grief – doing: e.g. after death of teenage daughter in car accident that involved her driving into a fence = dad fixed fence on day of funeral

#### Intuitive Grievors

- Processes grief through feelings and expressing emotions – through verbal expression
- Experienced as Waves of emotions
- Expression of grief mirrors their inner experience
- Helps – time to get in touch with reaction/ feelings – support group/ confidantes etc.




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### Dying as a series of losses




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### Doing vs Being

**Doing is a skill**

- Skills are important
- Allow us to feel competent in our work
- Allow patients/ family to feel safe in our presence

**Being is an art**

- Just as important that we cultivate this ability
- It requires us to stop and pay attention to the whole human being with us



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### Health Care Providers Grief

*A patient you have been working with for a number of months died before your return. You never had a chance to say good-bye to him and you feel something is unfinished.*



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### Legacy Work



- ❖ Storytelling
- ❖ Scrapbooking
- ❖ Handprints /Footprints
- ❖ Dignity Therapy



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### Legacy Work: Dignity Therapy



Dr. Harvey Max Chochinov, MD, PhD, FRSC

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### Letter of Condolence



1. Acknowledge the death
2. Express your sympathy
3. Note special qualities of the deceased
4. Recount a memory of the deceased
5. Note special qualities of the bereaved
6. Close with a thoughtful word or phrase

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### Applying Learning to Practice

Considering the topics covered throughout this eLearning Module - please jot down in your journal:

- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing



In your journal, take the time to write a letter of condolence to someone you've cared for in your work or someone from your personal life.

**This is practice only; there is no expectation to send this letter**

In preparation for your 2<sup>nd</sup> in class session please pre-read:

- Fundamentals of HPC: pgs. 64 - 79
- A Caregiver's Guide: pgs. 70 -79; 91 - 95




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## A Letter of Condolence

Acknowledging when a nurse takes care of the whole person.

This framework can be used as a self-reflective exercise when a patient has died or as a way of letting the family or loved ones understand that we saw them as a person.

### Some general tips:

- writers should make every effort to write as if they were speaking to the bereaved
- Learners should express themselves in a simple, natural, direct way
- Ideally, the person who receives the letter should almost be able to see and hear the writer while reading it
- A good letter is a visit on paper

### The Framework

#### 1. Acknowledge the death

- Note how you came to hear of the news.

#### 2. Express your sympathy

- Express your sorrow sincerely to let the grieving person know you care.
- Don't hesitate to use the word death.

#### 3. Note special qualities of the deceased

- Mention the qualities you liked the most. This helps to remind the bereaved that the loved one's life was meaningful and was appreciated by others.

#### 4. Recount a memory of the deceased

- Relate a brief anecdote.
- Mention how the deceased touched and influenced your life.
- Do not avoid humorous incidents: laughter is a great healer.

#### 5. Note special qualities of the bereaved

- Remind the bereaved person of his or her other personal strengths such as resilience, courage, patience, competence, etc.

#### 6. Close with a thoughtful word or phrase









# Session 2


## SESSION 2: TOOLS FOR SYMPTOM MANAGEMENT WITH A FOCUS ON PAIN

- Session 2 Power Point Presentation (Copy)
- Domains of Issues Worksheet
- Dementia Observation Worksheet
- Fact Sheet - PSW Role

### Facilitator Reminders:

- Remember to be inclusive of the Volunteer role when presenting these materials.
- Allow opportunities for any questions that may have arisen from their Peer-to-Peer or e-Learning sessions.

### Tools for Symptom Management with a Focus on Pain



**Tools for Symptom Management with a Focus on Pain**

2nd Session

HPC Consultation Services  
Waterloo Wellington

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#### A look back at eLearning Module B

Integrating Practice Change

- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing

How did you find the experience of writing a letter of condolence?


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#### OBJECTIVES

The learner will:

- Have increased understanding of how tools guide the team in their care plan
- Have increased comfort in why screening is appropriate for the PSW or volunteer role
- Have examined Principles and Practices related to Pain:
  - Definitions & types of pain
  - Assessment of pain in the patient able to verbally communicate
  - Assessment of pain in the patient unable to verbally communicate
  - Strategies for pain management: pharmacological & non-pharmacological

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### Difference between screening and assessment



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### SCREENING vs ASSESSMENT

What's the difference?

- Screening is determining whether it is a problem, or not
- If it is a problem, then we are obliged to ASSESS or explore why it is a problem or what kind of problem it is.

If no, move on to next question.  
If yes, a full assessment is needed

What is your scope of practice as a PSW?

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### PSW Scope of Practice



PSW Scope of Practice, Lynelle Hamilton, Director, PSW Programmes, Capacity Builders, Ontario Community Supports Association (OCSA)

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### Case Study: Mr. Lewis

Mr. Lewis is a 70-year-old widower who lives alone in a one-bedroom apartment. He has been living on the second floor in the same apartment building for over 20 years. He was diagnosed with colon cancer a year ago. He has undergone extensive chemotherapy and radiation. He was recently told that there is no further therapy indicated and that the disease is spreading and progressing. Mr. Lewis used to be physically active and quite active socially. Since his illness, he has isolated himself from his friends at the local YMCA and no longer participates in bingo at his local parish. Mr. Lewis is on pain medication and he states he is still having pain. He has a colostomy. He has constant diarrhea and he finds the odour embarrassing. He needs to rely on help for personal care because his strength is failing. He is mentally alert but is often very anxious.



From AHPCE 2007

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### In small groups, visit each station

The diagram shows a grid of 12 boxes arranged in 3 rows and 4 columns. The top row is labeled 'Identifying Issues' and contains three boxes. The middle row contains three boxes. The bottom row contains three boxes. To the right of the grid is an illustration of a flipchart on a stand with a bar chart on it.

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### What about the other tools? What would you expect?

- ESAS?
- PPS?
- Pay attention to the ADL's...

*How would you communicate issues to your team?*




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eLC

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### From screening to assessment

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### Documenting Observable Symptoms (DOS)



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### Take a moment...

Think of one of your clients who was in pain

- Who was he/she?
- How did the pain affect
  - their activities?
  - their family
- How did you feel trying to help?




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### Pain

**MOST common problem we face  
and  
MOST significant fear people express**




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### What is Pain?

Pain is whatever the experiencing person says it is, existing wherever and whenever the person says it does

McCaffery, M., & Pasero, C. 1999

Pain is an unpleasant subjective experience that can be communicated to others either through self-report when possible or through a set of pain-related behaviours

Kaasalainen, S. 2007




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### Total pain is composed of:



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### Types of pain

#### What do these pains feel like?

- A toothache
- Giving birth to a baby, passing a kidney stone, or being constipated...
- A cold sore, shingles, a sunburn

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### Descriptors of Bone, Muscle & Organ Pain

- Squeezing
- Tender
- Throbbing
- Cramping
- Crushing
- Cutting
- Aching
- Lacerating
- Piercing
- Pinching
- Pounding
- Pressing
- Sharp



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### Descriptors common with nerve pain

- “A nerve not working right...”
- “burning” “numb”
- “shooting”, “zinging”,
- “electrical”
- “pins and needles”
- “stabbing”




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### Why do we assess pain?

- In order to:
- Understand the patient’s experience
  - Determine the cause
  - Manage pain



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### Pain assessment

What are the roles of the:

- Patient?
- Family?
- Personal Support Worker?
- Nurse?
- Physician?




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T

S1

eLA

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### Goals of pain assessment:

1. Determine the type, severity and causes of pain
2. Understand the meaning and impact of pain on the patient and family
3. Develop an individualized plan to manage the pain.



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### Symptom Assessment Acronym

Fraser Health Symptom Assessment Acronym



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### Pain Assessment: O

#### O – Onset

- o When did it begin?
- o How long does it last?
- o How often does it occur?



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**Pain Assessment: P**

**P - Provoking/Palliating**

- What brings it on?
- What makes it better?
- What makes it worse ?
- What do you think might help now?



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**Pain Assessment: Q**

**Q - Quality**

- What does the pain feel like?
- Can you describe the pain?



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**Pain Assessment : R**

**R - Region/Radiating**

- Where is the pain?
- Can you point to where it hurts?
- Does the pain move/radiate
- Mark on body map



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Body maps provide a great visual

Sharp, esp. with cough

Ache, constant esp. walking

Ache, numb esp. standing

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Pain Assessment : S

### S - Severity /Symptoms

- o 0-10 pain scales
  - o verbal
  - o faces
  - o colours
- o Are there other symptoms with the pain?



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Faces of Pain

### Used for measuring pain intensity in children

- It is supposed to be self-rated



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Pain Assessment: U

U - Understanding

- What do you believe is causing the pain?
- How is the pain affecting you and/or your family?




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Pain Assessment: V

V – Value

- How can I help you with this?
- What is the most important thing you want me to do right now?
- What information would you like me to pass on to the Nurse?




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But what about....



Assessing individuals with cognitive impairment?




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**A Quick Tally....**

Which residents in the next few pictures could be experiencing pain?



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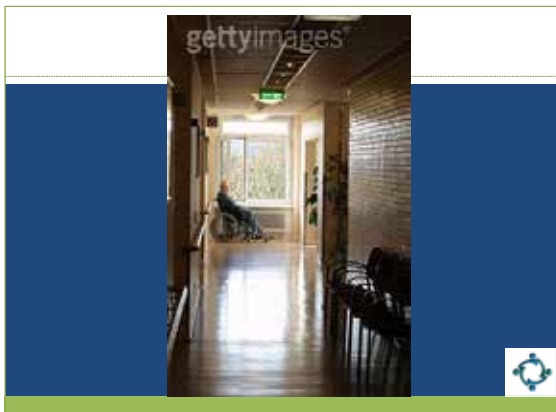
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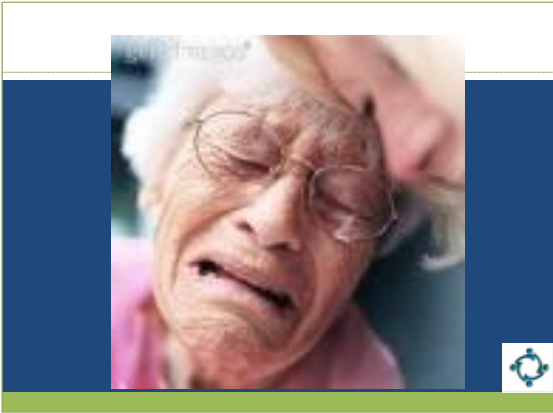
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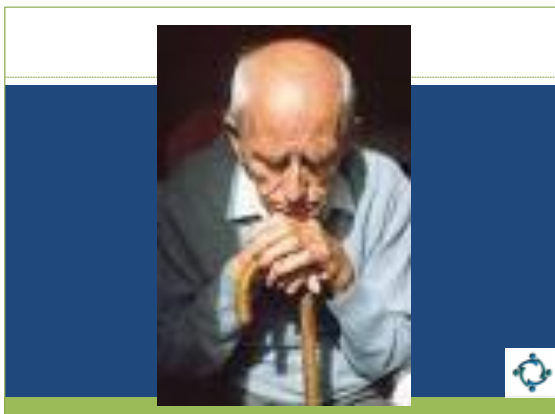
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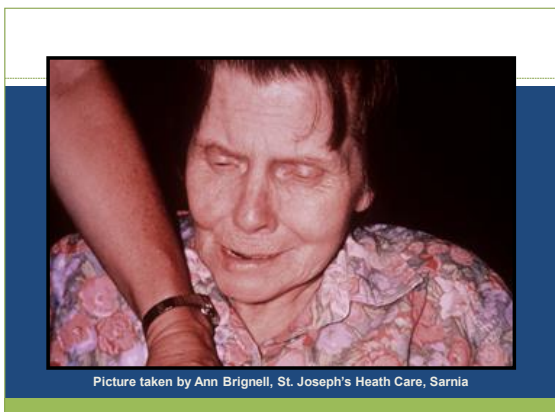
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Picture taken by Ann Brignell, St. Joseph's Health Care, Sarnia

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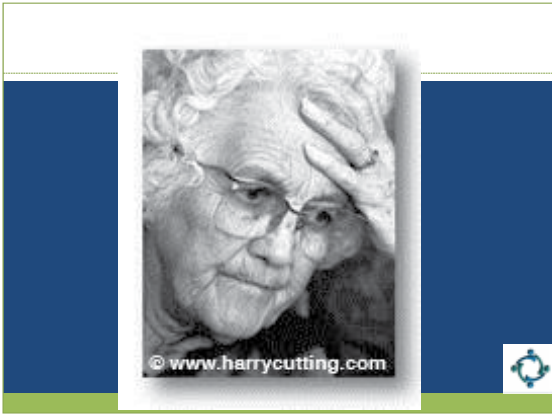
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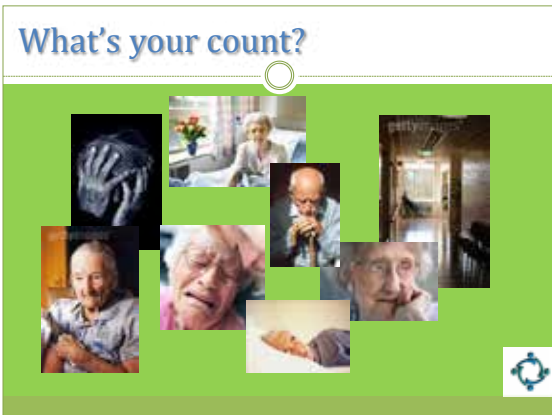
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### Potential Causes of Pain in Nonverbal Older Adults

- Conditions/ Diagnoses:
  - History of persistent pain
  - Osteoarthritis/ Rheumatoid arthritis
  - Low back pain
  - Osteoporosis and fractures
  - Degenerative disk disease
  - Peripheral neuropathies
  - Postherpetic neuralgia
  - Trigeminal neuralgia
  - Diabetic neuropathy
  - Peripheral vascular disease
  - Myofascial pain
  - Fibromyalgia
  - Gout
  - Bone pain
  - Cancer
  - Recent fall
  - Urinary tract infection
  - Pneumonia
  - Skin tear
  - constipation

Source: Pasero, C. & McCaffery, M. (2011). *Pain assessment and pharmacological management*, p. 124

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### Misconceptions



Caregivers might not believe what the resident is saying about their pain

Self report of pain is **often possible** in residents with mild to moderate cognitive impairment

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### Other behaviours indicating pain

- Decline in functioning
- Decrease in activity participation
- Noisy breathing
- Swearing
- Sad or frightened facial expression
- Tense body language
- Fidgeting
- Changes in mental functioning
- Falls
- Decreased appetite
- Calling out for help
- Rocking
- Pacing

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**Misconceptions**



Some family members and healthcare providers believe residents with cognitive impairment do not experience as much pain as those who are cognitively intact




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**Misconceptions**

Residents will always have **easily** observable signs to indicate they're experiencing pain


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**AGS Guidelines (2011)**

**Where do we start?**

Hierarchy of Pain Assessment Techniques

**Recommendations:**

1. Self report
2. Search for potential causes of pain
3. Observation of resident behaviors
4. Proxy reporting of pain
5. Attempt an analgesic trial




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**Common Pain Behaviours**

**AGS Guidelines (2011)**

- o Facial Expressions
- o Verbalizations, vocalizations
- o Body movements
- o Changes in interpersonal interactions
- o Changes in activity patterns or routines
- o Changes in mental status




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**Abbey Pain Scale**




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**PAINAD: Pain Assessment in Advanced Dementia Scale**




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**The assessment helps to**

Identify the cause and the type of pain



Understanding the cause helps to identify the best treatment!




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**Fears about managing pain with opioids**

Fears of addiction, tolerance, respiratory depression

Fear of Side Effects

- Constipation
- Nausea/vomiting
- Confusion
- Drowsiness

Fear of what using medications might symbolize - "It will kill him"




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**Medications**

1. Medications are **one set of tools** for managing pain
2. A combination of medications may be needed-
  - *Analgesics* – purpose of the medication is to reduce pain
  - *Adjuvants* – primary purpose of the medication is not pain relief, but may provide pain relief




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### Fear of addiction

#### Will my Dad become a drug addict?"

- It is very rare for an individual to become an addict when opioid use is managed responsibly in end of life care.



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### Fear of tolerance

#### “ Will my Dad need more medication over time?”

- Sometimes a person can develop a tolerance to the medication. If this occurs the medication can be increased or a different opioid can be used.



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### Fear of opioid side effects

- Constipation
- Confusion/ delirium
- Nausea and vomiting
- Drowsiness



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### Fear of constipation

Constipation is often a fear with opioids!

- We need to remember that anyone taking opioids needs to also be on a routine bowel medication



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### Drowsiness

Drowsiness is common in first few days – usually disappears

- Person may be catching up on sleep missed when in pain – this disappears
- Drowsiness may also be an indicator of dying process – this drowsiness will not disappear.



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### Fear - "It will kill him, when my friend started Morphine, he died"

- Opioids are no longer *saved* until the last moment of dying
- Opioids are useful early in the disease process
- Dose levels can continue to increase as individual needs increase



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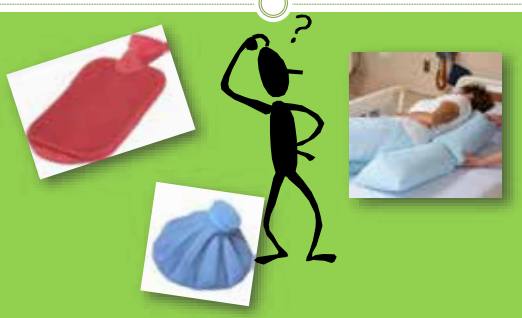
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### Non-pharmacological Measures



The slide features a green background with a white border. At the top, the title 'Non-pharmacological Measures' is written in blue. Below the title, there are four images: a red heating pad, a blue cooling pad, a black stick figure with a question mark above its head, and a photograph of a patient lying in a hospital bed.

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### Until next time....

Considering the topics covered this evening please jot down in your journal:

- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing



Using the information we discussed tonight about indicators of pain – identify a patient in your care that displays symptoms that may indicate to you that the person may have pain. Document your findings and what you were able to do in your role.

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### e Learning Modules C & D

**In preparation for eLearning module C:** please pre-read:

- Fundamentals of HPC: pg. p86 – 94 NEW or 91 to 102 OLD
- A Caregiver Guide: pgs. 82-85; 91-95; 99-100

**In preparation for eLearning module D:** please pre-read:

- Fundamentals of HPC: pgs. 114-121; 139-141 NEW or 103-115 & 127 to 135 OLD
- A Caregiver Guide: pgs. 50-53



Indicates this should be shared in your Peer to Peer meeting

**Reflective Writing:**  
Complete your reflections within your journal or course note pages and use during your Peer to Peer interaction  
Please remember to bring your journal to each in person session

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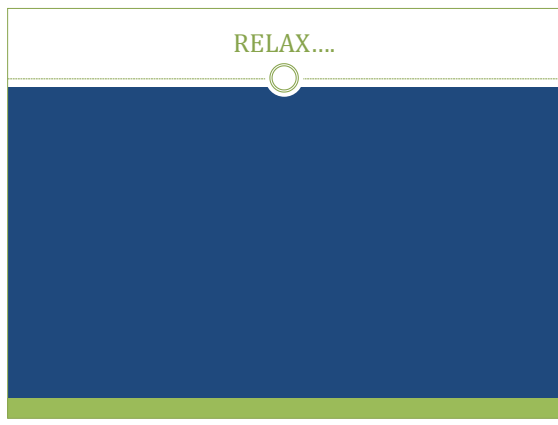
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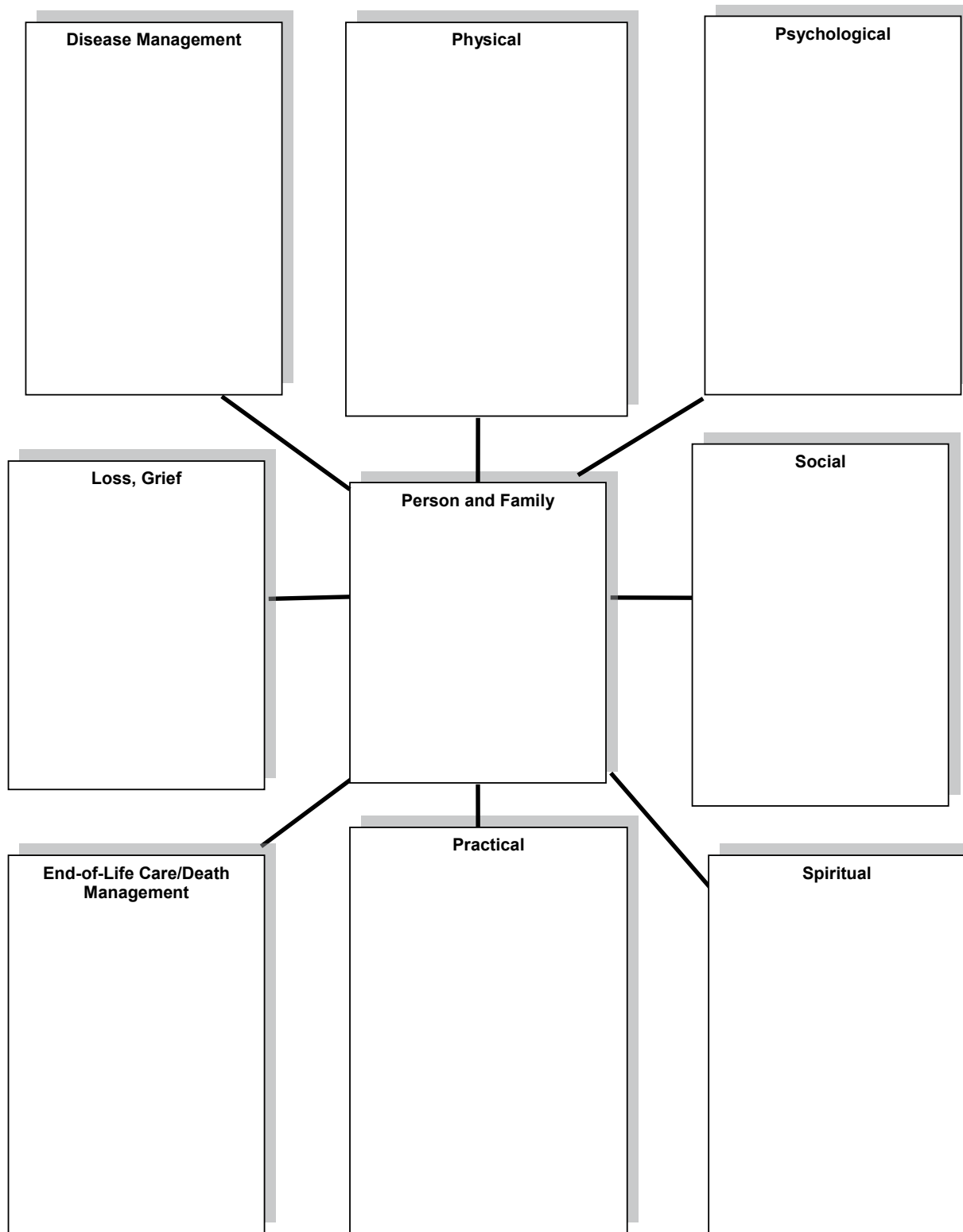
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### Domain of Issues Worksheet



## Dementia Observation Worksheet (DoS)

Use corresponding numbers to record in ½ intervals.

- |                      |                          |
|----------------------|--------------------------|
| 1. Sleeping in Bed   | 5. Restless, Pacing      |
| 2. Sleeping in Chair | 6. Exit Seeking          |
| 3. Awake/Calm        | 7. Aggressive -verbal    |
| 4. Noisy             | 8. Aggressive - physical |

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## Fact Sheet - PSW Role (page 1)



**P·S·N·O**  
PERSONAL SUPPORT  
NETWORK OF ONTARIO



**SENIORS HEALTH RESEARCH TRANSFER NETWORK**  
Linking Caregivers, Researchers & Policy Makers

# Fact Sheet

## What is a PSW's Role in Medication?

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The rules for a PSW monitoring and assisting their clients with medication are often misunderstood. This Fact Sheet provides information to help clarify the PSW role in medication administration.

As we'll discuss below, the setting will determine the extent of the PSW role. However, as a PSW, you should have been taught to do the following:

- ✓ Remind client to take medication when the client is physically able to do so
- ✓ Provide some help with physical tasks, such as helping the client to open a bottle or blister pack, when asked by the client
- ✓ Hand the client the contents of a dosette or individual-dose blister pack at the proper time, when asked by the client
- ✓ Apply topical medications, transdermal patches, administering eye, ear and nose drops
- ✓ Open a medication bottle, pour out the proper amount of liquid or oral pill medication, and give the medication to the client at their request or as instructed in the support plan.

There are 4 factors that determine if and how a PSW can assist a client in medication. We call these the "Four L's of Medication Assistance"

1. *Legislation*
2. *Location of Work* (community, LTC home, hospital, etc.)
3. *Local Employer Policy* (what the PSW's employer permits you to do)
4. *Liability* (The PSW's training, competencies and ethics)

### 1. *Legislation*

There is no law in Ontario that prohibits a PSW from administering a medication as part of her job, **unless**:

- S/He is working in a long term care home that falls under Ontario's *Long Term Care Homes Act*, or a facility governed by one of Ontario's hospital acts.
- The medication is
  - ✓ Injected
  - ✓ Inserted
  - ✓ Inhaled

## Fact Sheet - PSW Role (page 2)



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## Fact Sheet

Other than in the settings just described, the law does not prohibit any person from administering/assisting another with administration of:

- ✓ Oral pills/liquids
- ✓ Lotions and topical medications
- ✓ Eye drops
- ✓ Ear drops
- ✓ Nose drops
- ✓ Transdermal patches

Excepted Acts under the *Regulated Health Professions Act (RHPA)*:

Administration of a substance by injection or inhalation or by insertion into an opening of the body is a controlled act in Ontario. This means that these acts must be performed by a member of a regulated health profession permitted to perform the act, unless certain conditions apply.

The RHPA states that certain acts may be performed by another, if the act is routine for the person. (*RHPA, Section 29 (1) (e)*). The acts the RHPA permits a PSW to do are:

- Administering a substance by injection or inhalation.
- Putting an instrument, hand or finger,
  - i. beyond the external ear canal,
  - ii. beyond the point in the nasal passages where they normally narrow,
  - iii. beyond the larynx,
  - iv. beyond the opening of the urethra,
  - v. beyond the labia majora,
  - vi. beyond the anal verge, or
  - vii. into an artificial opening into the body.

The most common acts are those done by injection, insertion or inhalation. We call these the "Three I's."

## Fact Sheet - PSW Role (page 3)



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Linking Caregivers, Researchers & Policy Makers

# Fact Sheet

## *Routine Acts*

The RHPA states that the above acts may be legally performed by a PSW if the act is routine. RHPA does not define routine, but it is generally accepted that the following are key factors:

- ✓ The client's condition is stable
- ✓ The act is something that is regularly done (note that it does not have to be done *daily*..just routinely)
- ✓ The expected outcomes of the administration are known
- ✓ The PSW has been taught the procedure with the client by a member of the health profession permitted to perform the act, or the client.

In such cases, the PSW must have the agency's permission *before performing the act*. As well, the training is often client-specific, so the PSW cannot perform the act for another client unless s/he is trained with the new client.

## *2. Location of Work*

Where you work will affect what you can do. If you work in the community or in a retirement home, your employer will set the boundaries (within the range we discussed above) and you may well be asked to administer medications.

If you work in a long term care home that falls under Ontario's *Long Term Care Homes Act*, or a facility governed by one of Ontario's hospital acts, you cannot administer medications. There is one exception to this rule. Occasionally, a Registered Nurse or Registered Practical Nurse may delegate the application of topical medications (e.g. medicated lotions or ointments) to a PSW on a one time basis. Such delegation is legal, but must only be done in situations in which the delegation clearly benefits the client and does not pose undue risk. In such a case, the liability is with the regulated health professional who delegated the act, not with the PSW to whom the act was delegated.

## *3. Local Employer Policies*

Employers can and usually do set policies that limit a PSW's ability to administer medications. This may be a part of a contract the employer has with a third party. PSWs have an obligation to work within the agency's policy, even if the acts are legal or otherwise permitted activities. Permitted activities may vary from client to client or program to program.





## Fact Sheet

### 4. *Liability: Training, Competencies and Ethics*

Even if a PSW is permitted by legislation and the employer to administer medication, it is your responsibility to make sure that you have been taught the correct method and have had time to practice and gain skill and comfort. *No act is safe if you have not been trained, or do not have the required competencies, to do it!*

Ethics is a set of principles of right conduct. The principles that come most into play when a PSW is administering medications are:

1. *Client Safety* ("First, do no harm"). Medications can be harmful, and at times even fatal. Ensure that you know:
  - a. What your role is to be with the specific client
  - b. How to administer the medication if you are asked to do so
  - c. What to look for and what to look out for after the medication is administered
  - d. Who to call if there is a problem (in some cases, this is the client, but is usually your supervisor, a family member or a health professional)

Do not administer medication that is not part of your role, or appears to be altered or damaged, even if the client urges you to do so.

Remember that sometimes not taking medication can be harmful and even fatal. Medication refusals should be reported as per your agency's policy.

### 2. *High Quality Care*

Use best practices at all times. If you don't know the current best practice, ask for supervision, training, guidance or assistance before acting. If you are not the only person available to help in the administration of medication, make sure that the most qualified person administers the medication (unless you are being trained). If there is nobody else available, get whatever help you can find to ensure the best interest of the client is looked after in the best way possible.

## Fact Sheet - PSW Role (page 5)



## Fact Sheet

Before you Administer or Assist

When administering or assisting you must know:

- ✓ Any relevant information about the client, including allergies/health concerns that may be affected by the medication and what you should look out for
- ✓ Other medications the client is taking – when are they taken, do any of these medications affect the medication they are about to be given and observe for that
- ✓ Foods/beverages that may affect the drug or cause side effects
- ✓ The reason the client is taking the drug
- ✓ The effects that should happen and what action to take if the expected result does not appear.
- ✓ What side effects may arise and what to do if they do arise
- ✓ The time the drug is to be administered, the correct dosage and the method to be used to administer the medication
- ✓ What to do if the client refuses the medication or skips a dosage
- ✓ The person to contact if there are any problems
- ✓ The records to be kept and the procedure to be used for recording.

As a PSW, you should NEVER:

- Offer advice about taking or not taking a drug
- Share information about their personal medications
- Administer a medication when they are not authorized
- Fail to advise the appropriate person of concerns they have about a client's medication use.

For more information on personal support workers and PSNO, visit our website:

[www.psno.ca](http://www.psno.ca)



## PSW Scope of Practice

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### Introduction:

Personal care is service that is provided to a person(s), in a person's home, wherever home is, that meets the supportive, physical and psychosocial needs of that person(s).

Hands on personal care is provided by an appropriately trained "Unregulated Care Provider" and at times will require working as a member of a health care team under the supervision of either a Care Planner or a Registered Health Professional RHP. Supervision will be required when performing a designated task as delegated by an RHP under the *Regulated Health Professions Act*.

Personal Support Workers' provide care to person(s) who require personal assistance with activities of daily living. They may also provide additional care as delegated by an RHP as needed and when it can be performed safely and within Provincial legislation. PSW's provide personal care and related paraprofessional services in accordance with an established plan of care. PSWs also provide for the personal needs and comfort of all individuals in their homes or other environments. Typically involves both personal care tasks and incidental activities of daily living, such as housekeeping, meal preparation, socialization and companionship.

### The PSW:

- Can assist person(s) with activities of daily living such as feeding, lifts and transfers, bathing, skin care, oral hygiene, and toileting.
- Can perform delegated tasks which have been delegated by an RHP in compliance with the *RHPA* for which transfer of functional training has been completed, such as insertion of a digit or instrument into a body cavity, care or procedure under the dermis and any task or skill needing a physician's prescription.
- Can assist with medication and medication reminders to person(s) in accordance with established employer or government policy.
- Can perform light housekeeping duties such as sweeping and mopping floors, vacuuming, washing dishes, and laundry.

## PSW Scope of Practice ( page 2)

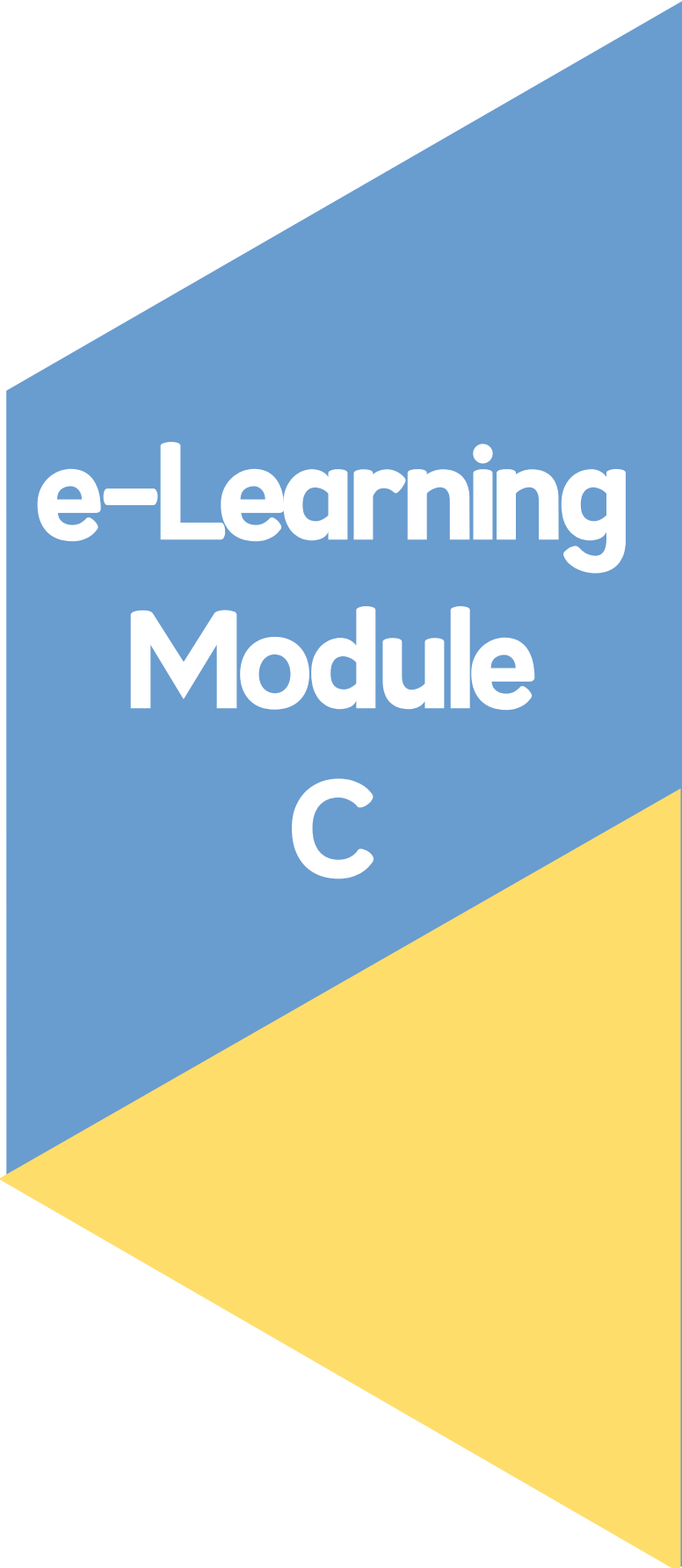
- Must continuously observe person(s) and their environments, and must report and document unsafe conditions and behavioral, physical, and / or cognitive changes to an appropriate supervisor; i.e. family member, employer, care coordinator etc.
- Must communicate and demonstrate basic information to person(s) in relation to activities of daily living, light housekeeping, meal planning and preparation, in accordance with pre-established Plan of Care.
- Must complete and maintain related records and documentation such as communication books and progress notes.

\*RHP- Regulated Healthcare Professional

\*PSW – Personal Support Worker



Completed in partnership with 

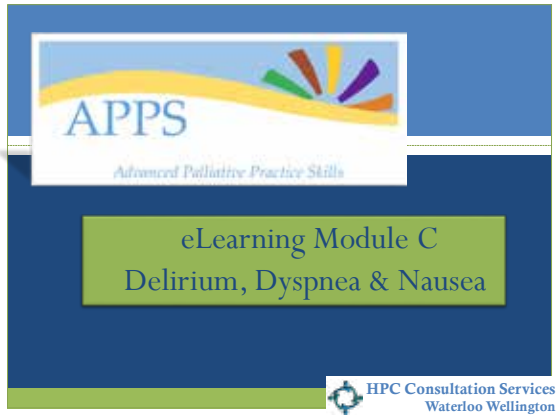


# e-Learning Module C

## **E-LEARNING MODULE C: DELIRIUM, DYSPNEA & NAUSEA**

- Delirium, Dypnea & Nausea
- 2 D's Chart
- CAM (Shortened Version)
- Breathless COPD

# Delirium, Dypnea & Nausea




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**A look back at Tools for Symptom Management with a Focus on Pain**

Integrating Practice Change

- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing

Identify a patient in your care that displays symptoms that indicate to you that the person may have pain. Document your findings and what you were able to do in your role.






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**Objectives**

By the end of this module Learners will:

- have reviewed key concepts about Delirium
  - learned about the Confusion Assessment Method (CAM)
- have examined Principles and Practices related to Dyspnea:
  - What is Dyspnea?
  - Potential causes
  - Assessment and management techniques
- have examined Principles and Practices related to N & V:
  - Understanding the potential causes
  - Assessment and management techniques
  - Important points to consider
- Explored essential tips, tools and techniques for providing mouth care

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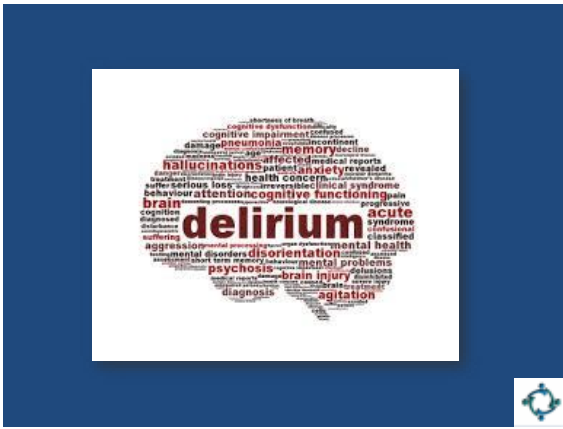
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**Definition of delirium**

Delirium is an *acute confusional state* that lasts from a few hours to a few weeks, which may last even longer in the older adult.

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### Delirium symptoms

Problems with...

- Attention
- Thinking
- Memory
- Psychomotor behaviour
- Sleep-wake cycle




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### Delirium

	Delirium	Dementia
ONSET	Rapid (hours, days)	Slow (months, years)
SYMPTOMS	Fluctuate over the course of the day	Relatively stable
DURATION	Days to weeks	Years
ORIENTATION	Disorientation and disturbed thinking are intermittent	Persistent disorientation
LEVEL OF CONSCIOUSNESS	Fluctuates, with inability to concentrate	Alert, stable
SLEEP/WAKE CYCLE	Sleep/ wake cycle may be reversed	Sleep may be fragmented




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### Causes of Delirium

- Medications
- Alcohol withdrawal
- Hypoxia
- Infection
  - chest or urinary
- Metabolic Abnormalities
- Constipation
- Urinary retention
- Pain
- Dehydration
- Sleep deprivation
- Changes in psycho-social environment
  - Relocation stress




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### Delirium and restlessness

- are **common** in last days and hours
- important to discuss with families if preparing them to care during that period.



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### Types of Delirium

<h4>Hypo-alert</h4> <p><i>Patient is:</i></p> <ul style="list-style-type: none"><li>○ hypoactive</li><li>○ quiet</li><li>○ sleeping ++</li><li>○ less conscious</li><li>○ but does not have a clear delirium.</li></ul>	<h4>Hyper-alert</h4> <p><i>Patient is:</i></p> <ul style="list-style-type: none"><li>○ hyperactive</li><li>○ more unsettled</li><li>○ delirium easier to identify, but a more difficult experience for family and patient.</li></ul>
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**Mixed type**  
Patient fluctuates from hypo-alert to hyper-alert.



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### Comfort measures:

- Environment
- Communication
- Familiarity
- Activity
- Safety



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### Comfort measures: Environment

- Provide calm, reassuring, protective environment
- Maintain adequate light
- Use radio or TV only if it provides relaxation or a familiar background noise
- Medication schedule should not interrupt sleep if possible
- Consider removing items that might be misinterpreted



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### Comfort measures: Communication

- Orient patient to reality when appropriate, otherwise allow patient to stay in his/her reality
- Try to understand the patient's reality
  - "What are you worrying about?"*
  - "Tell me how this is for you"*
- Reduce fear... "I am here with you"



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### Comfort measures - Communication

- Provide support during hallucinations
  - "I don't see the spiders, but I know that you see them and I am here to help make them go away"*
- Keep directions simple, clear, and concise
- Listen to what is being said
  - "What are you seeing, hearing?"*
- Verbally remind patient of time, day, and place



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### Comfort measures - Familiarity

- Keep person in familiar surroundings as much as possible
  - e.g. familiar routine, familiar caregivers
- Avoid room changes
- If possible, have a family member or friend sit with the person during their most disturbing periods, and during a medical procedure, so the patient feels safe



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### Comfort measures - Activity

- Allow free movement as long as the person is safe
- Give patient something soft and comforting to hold, such as a stuffed animal or soft fleece



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### Comfort Measures - Safety

- Keep the environment hazard-free:
- Remove unsafe items, such as scissors, canes on the floor, etc.
  - Avoid physical restraint
  - Keep side rails down and lower the bed if the person has a tendency to get out of bed on their own -- If necessary, place a mattress on the floor



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### Complementary therapies

- Music
- Aromatherapy
- Gentle massage
  - \*\*Guided imagery is not appropriate for a confused person




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### Interventions

- Delirium is likely to be *more reversible on the first occurrence*, and less likely on subsequent occurrences.
- Delirium is less likely to be reversible in the last days of life.




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### Confusion Assessment Method (CAM)


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What is shortness of breath or Dyspnea?

Remembering the straw exercise from Fundamentals



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The Reality of Dyspnea



It is the struggle to breathe!!



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### Physical Causes of Dyspnea

- Physical obstructions – like COPD
- Pneumonia
- Fluid collecting around/in the lungs or abdomen
- Weak heart
- Muscle weakness
- Anxiety and fear

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### Barriers to Managing Dyspnea



What are some of the barriers to dyspnea management?

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### Goals for Treating Dyspnea

- Patient will experience relief
- Patient will be able to continue with activities of daily living as long as possible
- Patient will feel supported by the Health Care Team

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S2

eLC

eLD

S3

### Case Study: Mr. Brown

Mr. Brown is a 65 year old man with Chronic Obstructive Pulmonary Disease (COPD) with a PPS of 30%. He is living at home with his wife. He has periods of extreme shortness of breath (SOB). At times he is very anxious and as a result has increased SOB.

1. What issues or domains might be affected by this symptom?
2. What can you do to support him to alleviate the SOB?
3. How would you measure the level of distress he has?
4. Who on the team needs to know about his anxiety and SOB?



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### Gathering Information about Dyspnea

ASK the Patient:

What do you observe about:

"Do you ever have trouble breathing?"

- Rate dyspnea with ESAS
- Always remember that what we observe may not tell the story of dyspnea

Respiratory rate  
Breath sounds  
Periods of shortness of breath  
Pauses for breath when talking?  
Shortness of breath on exertion?  
Does it settle with rest?  
Cough/congestion  
Skin color  
Fever  
Anxiety or fear

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### Medications to treat Dyspnea



There are many medications to help treat Dyspnea



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### Opioids

The best practice medication for dyspnea

- Decreases the sense of breathlessness
- Don't need to wait until last hours and last days to start!

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### Ways to comfort during acute episodes

- Acknowledge patient's  
*"I can hear that you are uncomfortable..."*
- Touch *may* help ground individual
- Provide a focus message (focused breathing technique)  
*"Look in my eyes..."*  
*"Breathe with me..."*
- Oxygen  
Use with discretion

**Remember: If this continues → CALL FOR HELP!**

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### Following an acute episode of Dyspnea

- Contact the nurse or supervisor and together with the patient you can develop a plan for the future that includes:
  - Medications as required
  - Comfort measures
  - Follow up procedures.

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### Prevention of Dyspnea

- No perfumes
- Avoid triggers such as smoke, smells, memories, anxiety
- Limit the number of people in the room
- Encourage fresh air with an open window or fan
- Loose clothing
- Sitting upright, with arms supported

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### Comfort measures

- Pace activities
- Provide breathing stations
- Air on face
- Damp cloth
- Window open
- Reposition for comfort
- Medications
- Be calm and supportive



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Comfort measures continued

- When SOB try:
  - focus breathing
  - progressive relaxation
  - guided imagery
  - limit visitors

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Comfort measures continued

Positioning

- Elevate head of bed
- Recliner
- Use of pillows

Loosen clothing around neck and chest

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Other troubling symptoms

Nausea & Vomiting

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### What is Nausea and Vomiting

**Nausea** is a sick or uncomfortable feeling in the stomach which is often described as an urge to vomit. Some people also describe nausea as an uncomfortable feeling at the back of the throat.

**Vomiting** is a strong tightening of the stomach muscles that forces whatever is in the stomach to come out through the mouth.



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### Assessing Nausea and Vomiting

What tools can we use to gather information about nausea?

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### Causes of N&V



List all of the possible causes of Nausea and vomiting you can

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### Possible causes of N&V

- Obstruction of GI tract
- Infection
- Medications
- Biochemical abnormalities
- Emotional upset
- Gastric irritation
- Cough
- Peptic ulcer
- Gastric distention
- Delayed gastric emptying
- High calcium levels in blood
- Fluid and electrolyte imbalance
- Liver and kidney failure
- Increased intracranial pressure
- Even just the memory of previous nausea

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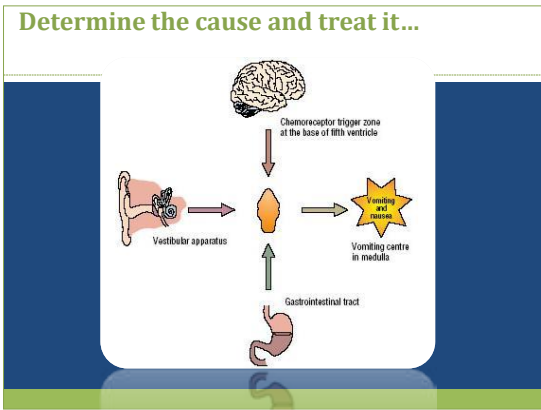
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### Comfort Measures for N & V

Need to be tailored for each individual

List all of the possible comfort measures for nausea and vomiting you can

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### Important points

- If vomiting occurs in bed, position the person on one side so that vomit will not be inhaled and cause choking
- Keep a record of how often and how much the person vomits
- **Ask for help and report if:**
  - Vomiting occurs more than 3 times an hour for 3 or more hours
  - Blood or material that looks like coffee grounds appears in the vomit
  - Medications are vomited
  - The person feels unusually weak, dizzy or becomes unresponsive

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### Make taking fluids easier

- Offer people fluids they enjoy – water, juice, jello, popsicles or ice chips. Avoid juices high in acid, such as orange juice, as they may irritate the mouth.
- Have a variety of fluids available. People may change their fluid preferences often.
- Offer a straw for drinking. → less likely to cause choking than cups & can more easily deliver small amounts.
- Do not give fluids to people who are not able to swallow safely → never force fluids
- Offer small, frequent sips of fluid rather than a whole cup at one time
- When someone is too weak to swallow, provide mouth care to keep the person's mouth moist and comfortable



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### Mouth care



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### Applying Learning to Practice

Considering the topics covered throughout this eLearning Module - please jot down in your journal:

- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing



watch "Managing an Acute Episode of SOB" at:  
<https://www.youtube.com/watch?v=wUr0YVZuM5M> Write about what you learned from watching this instructional video or from practicing the breathing techniques in your journal.

In preparation for eLearning module D please pre-read:

- Fundamentals of HPC: pgs. OLD 104-114, 138 & 139 NEW pgs. 114-121, 138&139
- A Caregiver's Guide: pgs. 51-59

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- eLA
- eLB
- S2
- eLC**
- eLD
- S3

### 3 D's Chart

Feature	Delirium/Acute Confusion	Dementia	Depression
Onset	<ul style="list-style-type: none"> <li>Acute/subacute depends on cause, often at twilight</li> </ul>	<ul style="list-style-type: none"> <li>Chronic, generally insidious, depends on cause</li> </ul>	<ul style="list-style-type: none"> <li>Coincides with life changes, often abrupt</li> </ul>
Course	<ul style="list-style-type: none"> <li>Short, diurnal fluctuations in symptoms; worse at night in the dark and on awakening</li> </ul>	<ul style="list-style-type: none"> <li>Long, no diurnal effects, symptoms progressive yet relatively stable over time</li> </ul>	<ul style="list-style-type: none"> <li>Diurnal effects, typically worse in the morning; situational fluctuations but less than acute confusion</li> </ul>
Progression	<ul style="list-style-type: none"> <li>Abrupt</li> </ul>	<ul style="list-style-type: none"> <li>Slow but even</li> </ul>	<ul style="list-style-type: none"> <li>Variable, rapid-slow but uneven</li> </ul>
Duration	<ul style="list-style-type: none"> <li>Hours to less than 1 month, seldom longer</li> </ul>	<ul style="list-style-type: none"> <li>Months to years</li> </ul>	<ul style="list-style-type: none"> <li>At least 2 weeks, but can be several months to years</li> </ul>
Awareness	<ul style="list-style-type: none"> <li>Reduced</li> </ul>	<ul style="list-style-type: none"> <li>Clear</li> </ul>	<ul style="list-style-type: none"> <li>Clear</li> </ul>
Alertness	<ul style="list-style-type: none"> <li>Fluctuates; lethargic or hypervigilant</li> </ul>	<ul style="list-style-type: none"> <li>Generally normal</li> </ul>	<ul style="list-style-type: none"> <li>Normal</li> </ul>
Attention	<ul style="list-style-type: none"> <li>Impaired, fluctuates</li> </ul>	<ul style="list-style-type: none"> <li>Generally normal</li> </ul>	<ul style="list-style-type: none"> <li>Minimal impairment but is distractible</li> </ul>
Orientation	<ul style="list-style-type: none"> <li>Fluctuates in severity, generally impaired</li> </ul>	<ul style="list-style-type: none"> <li>May be impaired</li> </ul>	<ul style="list-style-type: none"> <li>Selective disorientation</li> </ul>
Memory	<ul style="list-style-type: none"> <li>Recent and immediate impaired</li> </ul>	<ul style="list-style-type: none"> <li>Recent and remote impaired</li> </ul>	<ul style="list-style-type: none"> <li>Selective or patchy impairment, "islands" of intact memory</li> </ul>
Thinking	<ul style="list-style-type: none"> <li>Disorganized, distorted, fragmented, slow or accelerated incoherent</li> </ul>	<ul style="list-style-type: none"> <li>Difficulty with abstraction, thoughts impoverished, make poor judgments, words difficult to find</li> </ul>	<ul style="list-style-type: none"> <li>Intact but with themes of hopelessness, helplessness or self-deprecation</li> </ul>
Perception	<ul style="list-style-type: none"> <li>Distorted; illusions, delusions and hallucinations, difficulty distinguishing between reality and misperceptions</li> </ul>	<ul style="list-style-type: none"> <li>Misperceptions often absent</li> </ul>	<ul style="list-style-type: none"> <li>Intact; delusions and hallucinations absent except in severe cases</li> </ul>

Reprinted with permission. Adapted from: New Zealand Guidelines Group (1998). *Guideline for the Support and Management of People with Dementia*. New Zealand: Enigma Publishing.



## CAM (Shortened Version)



## Confusion Assessment Method (CAM)

Shortened version

The diagnosis of delirium by CAM requires the presence of <b>BOTH</b> features <b>A</b> and <b>B</b>		
<b>C A M</b> Confusion Assessment Method	<b>A.</b> <b>Acute onset</b>  <b>and</b>  <b>Fluctuating course</b>	Is there evidence of an acute change in mental status from patient baseline?  Does the abnormal behavior: <ul style="list-style-type: none"> <li>➤ come and go?</li> <li>➤ fluctuate during the day?</li> <li>➤ increase/decrease in severity?</li> </ul>
	<b>B.</b> <b>Inattention</b>	Does the patient: <ul style="list-style-type: none"> <li>➤ have difficulty focusing attention?</li> <li>➤ become easily distracted?</li> <li>➤ have difficulty keeping track of what is said?</li> </ul>
	<b>AND the presence of EITHER feature C or D</b>	
	<b>C.</b> <b>Disorganized thinking</b>	Is the patient's thinking <ul style="list-style-type: none"> <li>➤ disorganized</li> <li>➤ incoherent</li> </ul> For example does the patient have <ul style="list-style-type: none"> <li>➤ rambling speech/irrelevant conversation?</li> <li>➤ unpredictable switching of subjects?</li> <li>➤ unclear or illogical flow of ideas?</li> </ul>
<b>D.</b> <b>Altered level of consciousness</b>	Overall, what is the patient's level of consciousness: <ul style="list-style-type: none"> <li>➤ alert (normal)</li> <li>➤ vigilant (hyper-alert)</li> <li>➤ lethargic (drowsy but easily roused)</li> <li>➤ stuporous (difficult to rouse)</li> <li>➤ comatose (unrousable)</li> </ul>	

Adapted with permission: Inouye SK, vanDyck CH, Alessi CA, Balkin S, Siegel AP, Horwitz RI. Clarifying confusion: The Confusion Assessment Method. A new method for detection of delirium. *Ann Intern Med.* 1990; 113: 941-948.  
*Confusion Assessment Method: Training Manual and Coding Guide*, Copyright 2003, Hospital Elder Life Program, LLC.



## Factsheet: Breathlessness

## ASK THE BREATHWORKS COACH

**I'm often out of breath.  
How do I stop my breathlessness?**

Breathlessness – also known as shortness of breath, or dyspnea – is one of the main symptoms of COPD.

Many factors influence shortness of breath. Good nutrition, adequate sleep, anxiety control, regular physical activity, and a healthy environment help our breathing muscles and therefore decrease breathlessness. Laughing, coughing, and talking change the breathing pattern and therefore may bring on shortness of breath. Illnesses like chest infections can also cause breathlessness.

Some people with COPD become breathless with the slightest exertion and feel short of breath nearly all the time. Others only become breathless when walking or exercising. Sometimes, people become breathless just by worrying about their breathing.

Breathlessness resulting from effort is uncomfortable, but it isn't harmful or dangerous in itself. However, if you begin to experience new or worsening symptoms, contact your doctor.

If your COPD is even moderately advanced, you may not be able to completely get rid of your breathlessness. But there are ways of helping yourself. The first step? Learn techniques that control your breathing, and help your lungs and breathing muscles work more effectively.

### 1. Learn breathing exercises

Everyone knows how to breathe naturally, right? But most people with COPD can benefit from learning to breathe in a couple of new and different ways.

Two helpful methods are:

- pursed-lip breathing
- diaphragmatic breathing

Before you start, ask your doctor if these types of breathing can help you. Also ask whether you need to have your medications changed or the doses adjusted. It's also a good idea to have a physiotherapist or respiratory educator demonstrate these breathing techniques, to make sure you're doing them correctly.

### Pursed-lip breathing

In COPD, the airways tend to close before you're finished breathing out (exhaling). If you can't push the 'used' air out, it's hard to take in a deep breath of fresh, oxygen-rich air. This is why you feel breathless. Pursed-lip breathing helps keep the airways open so stale air can escape. It also helps slow down your breathing, especially when you're doing something that takes effort and uses extra oxygen, like lifting, bending or walking.

**Pursed-lip breathing isn't complicated. In fact, you may already be doing it unknowingly.**

THE  LUNG ASSOCIATION™  
When you can't breathe, nothing else matters.

B R E A T H W O R K S™

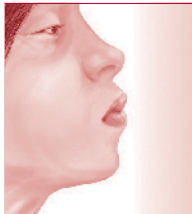
Fact Sheet

July 08

### Pursed-Lip Breathing



**STEP ONE**  
With your mouth closed, breathe in a normal amount of air through your nose.



**STEP TWO**  
Purse your mouth as if you're whistling or making a candle flame flicker gently.



**STEP THREE**  
Keeping your lips pursed, slowly blow the air out through your mouth. Do not strain yourself to force the air out.

**Try to breathe out (exhale) twice as long as you breathe in (inhale). Hint: It can be helpful to count to two as you inhale and to four as you exhale.**

You can use this type of breathing during activities that cause breathlessness, such as walking, or climbing stairs. You can also use pursed-lip breathing when you start feeling panicky and short of breath, to prevent your breathing from spiraling out of control. The trick is to practice when you're relaxed, so you find yourself doing it naturally as soon as you start becoming breathless.

### Diaphragmatic breathing

The diaphragm is the main breathing muscle. It sits at the base of your chest and separates your lungs from your abdomen. Learning to use this muscle more effectively may allow you to control your breathlessness. If you've ever watched a baby sleep, you've seen diaphragmatic breathing in action (babies and toddlers are natural 'belly-breathers') but we adults may

need a little practice to master the technique.

- STEP ONE Relax. Start by relaxing your shoulders. Try sitting comfortably in an easy chair.
- STEP TWO Place your hands lightly on your abdomen.
- STEP THREE Breathe in slowly through your nose. You want to feel your abdomen rise out under your hands.
- STEP FOUR Breathe out slowly through pursed lips. Your abdomen should fall inward.



### 2. Control rapid breathing

If you are short of breath, you automatically begin breathing faster, which in turn can make you panicky. Panic can send your breathing spiraling out of control. So how can you put on the brakes?

- Stop and rest in a comfortable position (see suggestions to follow).
- Breathe in through your mouth, blow out through your mouth.
- Breathe in and blow out as fast as necessary.
- Begin to blow out longer, but not forcibly. Use pursed-lip breathing if you find it works for you.
- Begin to slow your breathing.
- Begin to use your nose when breathing in.
- Once your breathing is under control, start diaphragmatic breathing (but only if you know it works for you).
- When you feel less short of breath, stay in this position, and continue pursed-lip breathing for five minutes, or until you feel your breathing is under control.

### 3. Practice proper positioning

Positioning your body properly can help reduce breathlessness. For instance, leaning forward slightly eases pressure on the diaphragm, allowing it to move more easily.

Keeping your arms, shoulders and neck loose and relaxed rests other muscles that help you breathe. (Tight muscles also keep you feeling tense and anxious.) Get into one of the following positions when you're trying to take control of your breathing.

### Sitting

- Place both feet on the ground.
- Lean your head and shoulders forward slightly.
- Rest your arms on your knees, or rest them lightly on a table or chair.
- Keep your arms relaxed. Pushing or grabbing at the table overworks some of smaller breathing muscles. (Hint: Letting your hands rest palms-up may help prevent you from tightening your arm muscles.)



### Standing

- Lean your back against a wall, pole, chair or counter.
- Place your feet slightly apart, and a comfortable distance away from the wall
- Relax and lean your head and shoulders forward slightly.
- Rest your hands lightly on your thighs, or a piece of furniture: Don't lean your weight on your arms.



### 4. Straighten up

Poor posture can make it difficult to breathe. Standing or sitting with your back bent, or shoulders slumped prevents the chest from expanding fully. Concentrate on keeping your spine straight (apart from the natural dip at the base of your back) to give yourself more 'breathing room'. Relaxing your shoulders (no hunching!) also gives some of your breathing muscles a break.

### 5. Exercise control

Many people with COPD find it difficult to exercise – some even avoid normal activities to avoid breathlessness. But that strategy is bound to backfire. The less physically active you are, the weaker your muscles become, so you actually have to work harder to do day-to-day things like lifting a bag of groceries, or taking a few steps. Staying as active as possible can help break this 'vicious cycle of breathlessness'.

Specially-designed exercise programs, tailored to your needs and abilities by a physiotherapist, are also very helpful. Check out The Lung Association factsheets **Exercise** and **Pulmonary Rehabilitation**, or call your local Lung Association office for more information.

### 6. Budget your energy

Learning how to 'budget' your energy can help you bring your breathlessness under control. Pacing and planning your activities, and re-organizing your home can allow you to accomplish your tasks without breathlessness. Sitting to dress yourself, allowing dishes to air dry, and economizing on stair climbing are all simple ways of saving energy. For more 'energy conservation' techniques, see The Lung Association's **Energy Management** factsheet.

### 7. Ease anxiety

Emotional stress can make you breathe more rapidly. This in turn, can trigger breathlessness. So how can you cope with anxiety? Here are a few ideas:

- Think ahead and avoid situations that cause stress.
- Make plans for situations you can't avoid, but which might cause you to become breathless. If you're traveling by air, for example, arrange for a wheelchair so you won't get winded walking from one part of the airport to another.
- If you start feeling anxious, sit down and collect your thoughts. Practice pursed-lip breathing. Remind yourself of the last time pursed-lip breathing and relaxation eased your breathlessness. Sit still for a few minutes while you calm down.
- Talk about your anxieties with your family and friends. If they're aware of emotional triggers, they can help you deal with them.
- Consider using a walker in situations where you experience breathlessness – long walks in the mall, for example.
- Consider therapy for your anxiety. Talk to your doctor about possible choices.
- Relax and try your best to remember that most things can wait. You don't have to do everything in one day, and you can ask for help.

**If I learn to control my breathing, do I still need to take my medications?**

Yes! Continue taking all medications as prescribed by your doctor, even if you feel you have better control of your breathing.

**Will oxygen help control my breathlessness?**

Oxygen therapy is not a cure-all. It's only helpful if you have critically low levels of oxygen in your blood (hypoxemia). If your doctor suspects you have hypoxemia, you will be sent for a blood test that measures how much oxygen is in your blood. For more information on oxygen therapy, check out The Lung Association's factsheet

**What you need to know about oxygen.**



All images, except 'coach', used with permission from **Living Well with COPD™** - A plan of action for life self-management education program.

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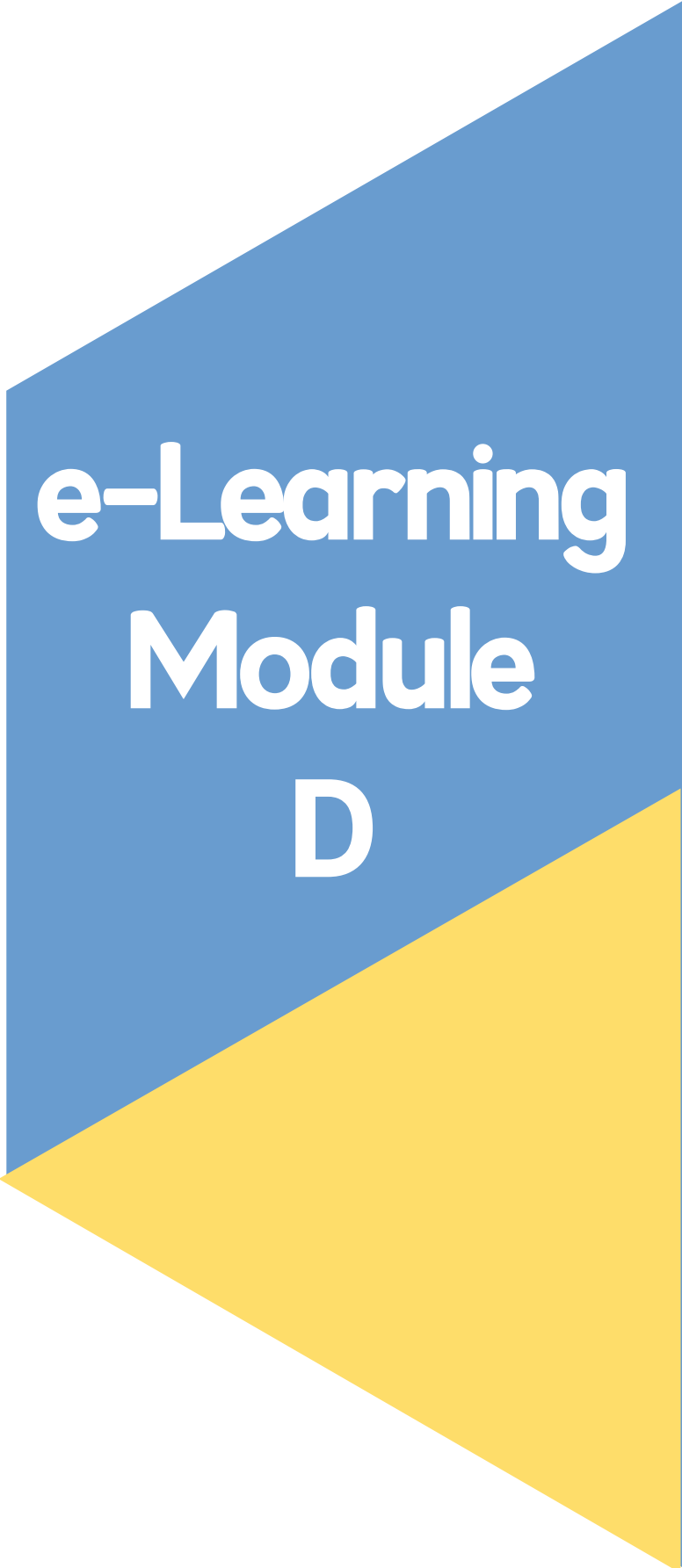
Get the information and support you need from one of our  
**Breathworks COPD educators.**

Phone **1-866-717-COPD (2673)** or visit us online at  
**[www.lung.ca/breathworks](http://www.lung.ca/breathworks)** .

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B R E A T H W  R K S <sup>™</sup>





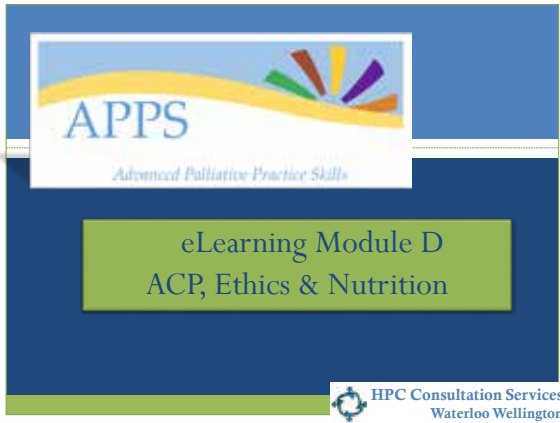
# e-Learning Module D

## **E-LEARNING MODULE D: ACP, ETHICS & NUTRITION**

- ACP, Ethics & Nutrition
- Conversations Worth Having
- Ethical Decision Making: A Framework



# ACP, Ethics & Nutrition



**APPS**  
Advanced Palliative Practice Skills

eLearning Module D  
ACP, Ethics & Nutrition

HPC Consultation Services  
Waterloo Wellington

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**A look back at Delirium, Dyspnea & Nausea**

Integrating Practice Change

- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing

You either watched the YouTube "managing an acute episode of SOB" or practiced Pursed Lip breathing. How you might apply it to a patient suffering from this symptom?




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**Objectives**

The learner will:

- Review and consider key concepts about advance care planning
- Review loss of appetite and anorexia as a symptom and decision making point
- Discuss decision making, the considerations, and one ethical framework for approaching difficult issues
- Apply the ethical decision framework to a case study.

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## What is “Advance Care Planning” in Ontario?

1. **IDENTIFYING** the capable patient's future **Substitute Decision-Maker (SDM)**, by either
  - a) confirming that the patient is satisfied with their default SDM in the Hierarchy list that is in the *Health Care Consent Act*  
OR
  - b) choosing someone else to act as SDM by preparing a Power of Attorney for Personal care (a formal written document)
2. **Wishes, Values, and Beliefs** – discussing with the capable patient about his/her wishes, values and beliefs, and more generally how he/she would like to be cared for in the event of incapacity to give or refuse consent

Advocacy Centre for the Elderly - May 2014

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## Difficult Decisions

Henry is an 89 year old widowed gentleman living with advanced dementia in your LTCH. Henry has diabetes and had a stroke several years ago that left him wheelchair dependant and requiring much assistance with all ADLs. He has recently returned from hospital after receiving treatment of aspiration pneumonia for the second time in the past 6 months.

You notice, on return to your LTCH that Henry has lost weight and is not interested in eating. Henry has 3 daughters who ask you to make sure and 'get him eating'. They bring in his favorite foods but he turns his head away when they're offered. Now his daughters are requesting Henry return to hospital to have a feeding tube inserted. His PPS is currently 30% but was 40% prior to his last hospitalization.

What do you do?




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## Decreased Nutritional Intake Contributing Factors

- Uncontrolled symptoms (pain, dyspnea, nausea)
- Fatigue
- Dry and/or sore mouth
- Difficulty/pain with swallowing
- Aversion to food odors/tastes
- S/E of meds - N/V, Constipation
- Psychological factors: depression, anxiety, stress
- Cognitive impairment

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**Important to remember....**

- Food can cause conflict and frustration... for family, staff... and for the dying person

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**Thinking about Nutrition at EOL**

- What a patient can eat and drink will become less.
- Eventually both eating and drinking will become zero.
- Stopping eating and drinking is natural to the dying process.

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**Thinking about Nutrition at EOL**

- What is nutritionally right at one stage may be very wrong at another.
- Aggressive nutritional therapy in advanced disease often contributes to difficulty in symptom control.
- Food can cause more discomfort than pleasure.

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### Thinking about Nutrition at EOL

- What a person likes is more important than what is 'right' or 'of value'.
- The atmosphere around eating is more important than what is ingested.
- excellent mouth care is essential!

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### Conclusion

- Nourishment needs change throughout our life
- Nourishment needs change when we are approaching end of life...

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### Anorexia

- Anorexia is the loss of appetite, the decreased interest in food and eating.
- (Today's discussion only addresses anorexia at end of life)

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### Is he starving?

- Cachexia (involuntary weight loss) is different from starvation.
- In starvation, the body seeks to conserve energy and nutrients.
- In cachexia, the body uses energy and nutrients even faster than usual.

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### “Would “Ensure” or a feeding tube, an IV or medications help?”

Unfortunately, not much.

- Supplemental artificial nutrition (e.g. feeding tube) causes at least as much harm as good.

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### “Is he dying because he’s not eating?”

No,  
He is not eating because he is dying.

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### Improving Decision Making about Feeding Options in Dementia



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### Case Study...Claire

Claire is 64 years old and is living with ALS. At present, she is having difficulty swallowing but is still capable of making decisions about her care. Her PPS is 30%

Claire has expressed clearly that she does not want a feeding tube – but her daughter, Erin, is having a baby in 3 months and Claire may die before that time if she does not receive nutrition.

Erin wants her mom to meet the baby and be there with her when she delivers, so she would like her mom to reconsider having a feeding tube.

The visiting nurse/ PSW have ethical distress because they want to honor Claire's wishes and they are feeling torn.

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### The Importance of Empathy



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### Understanding Potential Risks for Conflict

**Sources of Conflict in Patient Care:**

- Complex healthcare information
- Different cultures, professional training, bylaws, practices, experience, perceptions
- Large Healthcare Team
- Rotation schedules (introduction and exiting of new team members and learners)
- Emotional complexity of illness experience
- Prognostic Uncertainty

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### Let's use the ethical decision making tool....

- Claire is a 64 year old living with ALS has a PPS of 30%. Here ESAS scores are as follows:
  - Pain 3/10
  - Anxiety 1/10
  - Appetite 10/10
  - Depression 2/10
  - Drowsiness 0/10
  - Well being 5/10
  - Nausea 3/10
  - Tiredness 8/10
  - Shortness of breath 6/10
- Her medications are managing her symptoms fairly well, but she doesn't want a feeding tube but is worried if she can't eat she will die before she gets to see her new grandbaby born

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**Ethical Decision Making: A Framework**

**Sources of Conflict in Patient Care:**

- Complex healthcare information
- Different cultures, professional training, bylaws, practices, experience, perceptions
- Large Healthcare Team
- Rotation schedules (introduction and exiting of new team members and learners)
- Emotional complexity of illness experience
- Prognostic Uncertainty

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### Summary

- Early identification of a plan of care including wishes, values and goals of treatment are critical to the delivery of excellent care.
- Exquisite communication is required between all team members to avoid client/family confusion
- Early choice of a SDM and having conversations about your wishes and values can reduce conflict and indecision at end of life.
- Loss of appetite is a common symptom as people near end of life and eating will not prolong life but quite possibly make it very uncomfortable.

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### Applying Learning to Practice

Considering the topics covered throughout this eLearning Module - please jot down in your journal:



- ✓ one thing you will continue to do
- ✓ one thing you will stop doing
- ✓ one thing you will start doing



What strategies and techniques might you offer families struggling with not feeding their loved ones at end of life?



**In preparation for the 3<sup>rd</sup> in class session please pre-read:**

- Fundamentals of HPC: OLD pgs. 140-150 NEW 140- 148
- A Caregiver's Guide: pgs. 109-123

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## Conversations Worth Having



*When it comes to your health care, who will speak for you if you cannot speak for yourself?*

### The Waterloo Wellington Advance Care Planning (ACP) Education Program “Conversations Worth Having” is...

A three year initiative funded by the Waterloo Wellington Local Health Integration Network. This program is designed to engage the general public, community professionals and health care providers to build understanding and capacity for correct ACP practices across Waterloo Region and Guelph/Wellington.

*92% of local Waterloo Wellington residents believe Advance Care Planning conversations will make it easier for loved ones (Community Survey 2015).*

### WHAT is Advance Care Planning in Ontario?

**Deciding** who will make future health care decisions for you if you are unable to. This will be your substitute decision maker (SDM) and in Ontario there are two ways to determine your SDM:

1. Confirming your automatic future SDM from the hierarchy (see back of page for ranking list) found within the Ontario legislation under the Health Care Consent Act **OR**
2. Choosing someone else to act as your future SDM by preparing a Power of Attorney for Personal Care (a legal document).

**Discussing** with your SDM (and loved ones) your wishes, values and beliefs, and anything else that will help your SDM understand how you would like to be cared for in the event you are mentally incapable of making health care decisions for yourself.

### WHY is ACP important?

Before providing treatment, health practitioners must get informed consent from the patient or from their SDM (if patient is not mentally capable).

Studies have shown that ACP conversations can improve the quality of care and have a lasting positive impact on the entire family.<sup>1</sup> ACP conversations are not consents BUT do provide important information about your patient’s wishes and preferences that will guide the future SDM in making health care decisions when your patient is not mentally capable of making health care decision for themselves.

### WHAT is your role as a professional?

1. Encourage your patients to DECIDE who their future SDM will be.
2. Encourage your patients to DISCUSS with their SDM and loved ones about their wishes, values and beliefs.

*95% of local Waterloo Wellington residents believe having Advance Care Planning conversations make good sense (Community Survey 2015).*

### HOW can we help?

The **Conversations Worth Having Program** is available to provide you with the resources, support and education needed to build your capacity for ACP conversations as an individual, a potential SDM and/or as a professional. We are working with key stakeholders and influencers in both the community and health care sectors to inform the strategies and resources needed to increase understanding and build the skills to ensure correct advance care planning practices.

## The Hierarchy of Substitute Decision Makers (SDMs)

Health Care Consent Act s.20

A patient's SDM is the person(s) in that particular patient's life who is the *highest* ranking in the hierarchy and meets the *requirements* to act as an SDM.

1. **Guardian of the Person**
2. **Attorney named in Power of Attorney for Personal Care**
3. **Representative appointed by the Consent and Capacity Board**
4. **Spouse or partner**
5. **Child or Parent or CAS (person with right of custody)\***
6. **Parent with right of access**
7. **Brother or sister\***
8. **Any other relative\***
9. **Office of the Public Guardian and Trustee**

\*When a person has multiple family members at the same level on the hierarchy (e.g., several children) health care providers cannot choose or require that only one act as the SDM. Equally ranked SDMs may amongst themselves choose to have one or more of them act as the SDM. If more than one person wants to act as SDM they must agree on any decisions for patient. If they cannot agree, then the health care provider would turn to the Public Guardian and Trustee for the patient's healthcare decisions.

### When do SDMs make health care decisions?

SDMs only make health care decisions for a patient if the patient is deemed mentally incapable by the health care professional offering the treatment.

### Requirements to be an SDM

The person(s) highest in the hierarchy can act as an SDM only if he/she is:

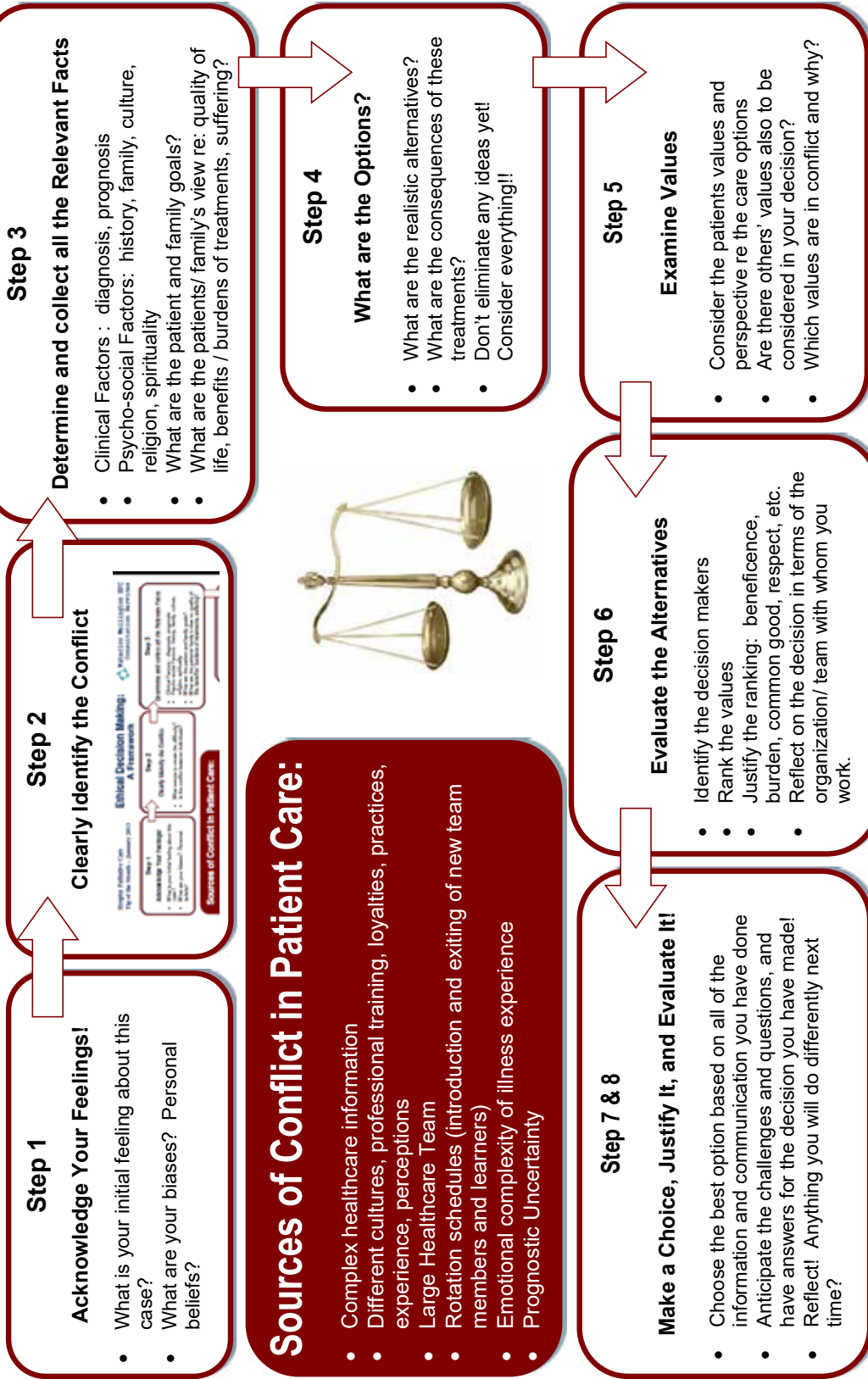
- a. Mentally capable with respect to treatment proposed,
- b. 16 years of age unless he/she is the parent of the incapable person,
- c. Not prohibited by court order or separation agreement from having access to the incapable person or giving or refusing consent on his/her behalf,
- d. Available, and
- e. Willing to assume the responsibility of giving and refusing consent

# Ethical Decision Making: A Framework



## Ethical Decision Making: A Framework

Hospice Palliative Care  
Tip of the Month – January 2013



References:  
Frolic, Andrea. Hamilton Health Sciences Ethical Decision Making Toolkit: 2007.  
St. Joseph's HealthCare (St. Mary's General Hospital): An Ethical Framework for Decision Making. 2008.





# Session 3

## SESSION 3: LAST HOURS

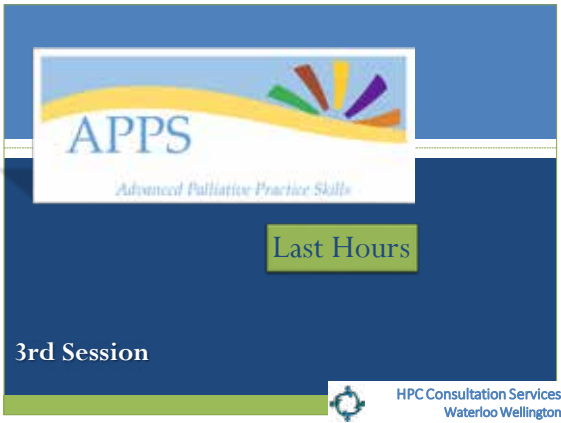
- Session 3 Power Point Presentation (Copy)
- Closing Exercise
- Steps to Perform a Gentle Hand Massage

### **Facilitator Reminders:**

- Remember to be inclusive of the Volunteer role when presenting these materials.
- Allow opportunities for any questions that may have arisen from their Peer-to-Peer or e-Learning sessions.



# Last Hours




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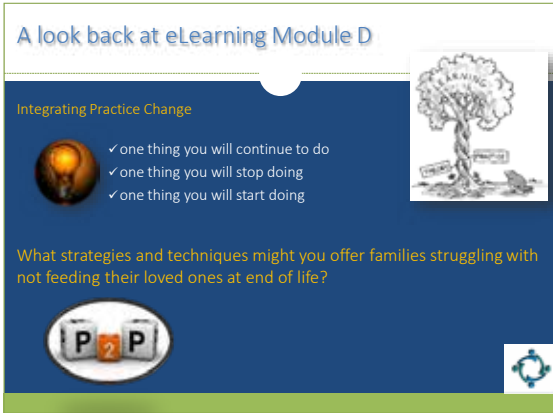
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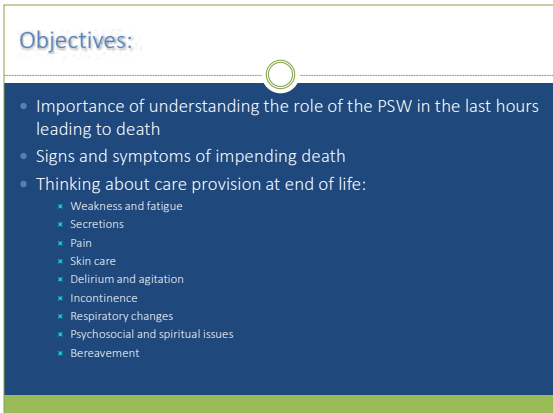
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*What is the hardest part for patients and families going through the dying process?*



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What is the hardest part ***for you*** in working with patients and families going through the dying process?



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*What comes to mind when you think of*

*A Good Death*



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Things to consider...

- The care plan must respect the client and family's rights to self determination
- Agreement that death is an acceptable outcome
- Hope shifts from cure to peaceful death
- Acceptable setting for death to occur
- Knowledge about what to expect in the dying process

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Care Considerations




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Absolute Necessities for Care

- Family and care provider education
- Pain and symptom control
- Written care plan and good communication tools for staff
- Prevention of family exhaustion

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What Matters Most in End-of-Life Care: Perceptions of Seriously Ill Patients and Their Family Members

- To have relief of symptoms
- Trust and confidence in the doctors looking after them
- Not to be kept alive on life support when there is little hope for meaningful recovery
- Information about their disease be communicated to them in an honest manner
- Complete things and prepare for life's end
- To not be a physical or emotional burden on their family

Daren Heyland et al. CMAJ 2006;174:627-33

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What we know:

- Careful management leads to smooth passage
- Careful management leads to healthy grief and bereavement
- Leads to personal & family growth

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What are the signs of impending death?



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### Signs of Impending Death

- Increasing weakness & fatigue
- Decreasing intake of food and fluids
  - Decreased urine output and dry membranes
- Difficulty swallowing & loss of gag reflex
  - Increasing rattling secretions
- Decreasing or altered level of consciousness
  - Drowsiness
  - Decreased blinking and drying of conjunctivae
  - Coma
  - Reflex activity: grasping, clenching, moaning
  - Terminal delirium
- Respiratory Changes – especially apneic spells
- Cardiovascular changes

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### Weakness & Fatigue

#### Positioning

- Positioning--propped up & slightly on side
- Change of position q 2 hrs. if appropriate
- **Very last hours** might change position q 8-12 hrs
- Draw sheet to turn or move patient




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### Weakness & Fatigue

#### Skin Care

- Avoid shearing and friction forces
- Gentle cleansing
- Manage incontinence to avoid skin irritation
- Decubitus Ulcers: minimize dressing changes
- Regular position changes
- Avoid massage over reddened areas

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### Gentle Hand Massage



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### Incontinence

- Dry, clean skin is helpful
- water repellent creams may be available
- In the home: incontinence pads on the bed
- Consider Incontinence products
- Catheters may be best for urine incontinence

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### Cardiovascular changes

- Heart pumping out less volume
- Blood does not reach limbs
  - ✦ Peripheral cyanosis (blue tinged skin colour), cooling & mottling
- Increased heart rate
- Low Blood Pressure
- Venous blood pools in dependent areas

IV fluids will not reverse this circulatory shutdown

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### Nutrition & Hydration

- Family concerns re: starving to death
- Need for education & counseling
- Hydrate sc/iv only if there is a good medical reason
- Keep lips, nares, conjunctivae moist
- Swallowing problems:
  - Educate about the dangers of aspiration

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### Mouth Care

- Maintain good oral hygiene
- Dentures clean, moist or removed
- Regular oral hydration hourly
- Do not use lemon glycerin swabs / commercial mouthwashes
- Use simple solutions:
  - 1 litre water, 1/2 tsp salt, 1 tsp baking soda
  - Biotene or Oral Balance

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### Terminal Delirium & Agitation

- Confusion, restlessness, agitation, day-night reversal
- May be very distressing to family & caregivers
- Poor management may destroy the good care earlier and leave family with fearful memories
- Observable Symptoms:
  - Moaning, restlessness, confusion
  - Treat to prevent agitation & family distress
  - **Do not use opioids for sedation**

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### Breathing Patterns

#### Respiratory changes

- Shallow
- Apnea (periods of no breathing)
- Cheyne-Stokes respirations
- Change in pattern is not usually dyspnea
- Oxygen is rarely necessary
- Room fan

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### Respiratory Congestion

- Pooling of secretions = gurgling
- Family suspect difficulty breathing
- Educate about why it's happening
- Positioning is vital
- Avoid suctioning

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### A look back at pain

- Rarely increases in last hours
- Assessment challenging if drowsy or reduced consciousness
- Moaning : different meanings → may be related to delirium
- Remind families that opioids do not hasten death
- Alternate routes of administration for necessary medications

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### Frequent Reassessment

- Rapid changes in condition
- Frequent presence of multidisciplinary team members is comforting and reassuring for the family

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### Transitioning to End of Life

- Focus of care on the family & the patient
- Education to reduce fear & promote involvement
- Educate away from the bedside




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### What we've learned...

- Patients are often aware
- Encourage them to communicate feelings
- Talk about death if they wish
- Advise the team members if questions or issues arise
- The nurse will arrange for alternative administration of medications if needed

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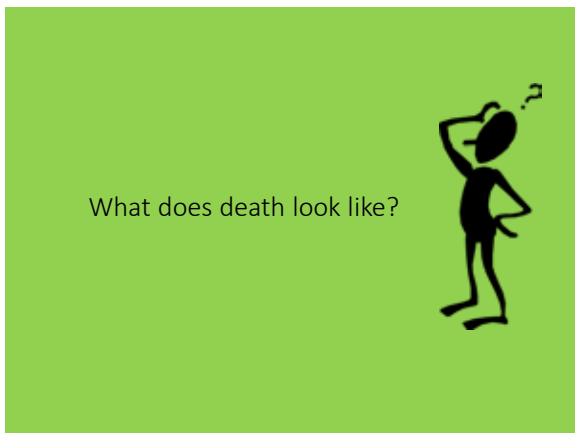
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**At the time of Death**

Educate family beforehand to avoid panic as to what physical changes will become apparent:

- Color of skin, and mottling
- No breathing
- No pulse
- Eyes fixed in one direction
- Eyelids may be open or closed
- Possible loss of bowel or bladder control
- No discomfort/ pain.



*Emphasize the peace and comfort attached to the death*

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**At the time of death....**

- Remain calm
- Notify the nurse
- Honor any rituals
- Offer nourishment, space and privacy
- Say your own good-bye

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How do you feel when your patient dies?



- Failure?
- Relief?
- Guilt?
- Satisfaction?
- Other?

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Our Closing Ritual




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Please remember to fill in your evaluation form!

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## Closing Exercise

### Closing exercise for APPS session 3

*Set up: chairs in a circle surrounding stones/candle on a small table*

As a way of closing this experience of shared learning I would ask everyone to find a comfortable way of being in their chair and just take a moment to return to your breath and be in the moment before we share a few minutes of reflection together.

With your feet uncrossed and planted gently on the ground – your hands relaxed and settled in your lap – your back straight and supported – just allow your chair to fully support your weight – lowering your gaze or gently closing your eyes if it feels comfortable to do so – just taking a few deep cleansing breaths together – breathing deeply in through your nose and out through your mouth – saying a quite ‘sigh’ as you exhale if it feels good to do so – breathing in peace and calm and breathing out tension and stress – anything that does not serve you in this moment

Just taking a few breaths together and sending your calming breath to any areas you notice hold tension and allowing your breath to soften them

*Allow a few breaths / moments for folks to settle*

Now returning our attention gently back to our circle – we are going to spend a few minutes in reflection as a way of honoring our shared learning – realizing that this learning has value to the way we practice – the way we care for our residents and families and ourselves

Honoring that our residents and families are often our greatest teachers – perhaps calling to mind some individual or a family that has touched you – perhaps offered an experience that has left you more aware than you were before – sometimes the learning comes in the form of a wonderful experience – sometimes the learning arrives as a very challenging lesson – and I would invite you to offer a silent thank you for that experience

Now just taking a few moments to consider the learning opportunities we’ve had together in this course – reflecting on what you will carry forward with you as will close this circle – perhaps it was something from one of our 3 class sessions – a learning from the online education modules – something that became clearer or more distinct when speaking to your peer to peer partner or even became more present to you when writing your personal reflection.

The light at the center of our circle represents the individuals and families we care for – some perhaps still living – others living on in our memories. I’m now going to invite you when ready to go to the table and select a stone – a touch stone to serve as a tangible way of remembering what you’ve learned – or have been reminded of – a gentle reminder to ourselves about what we’d like to move forward with as we leave the circle. If it feels comfortable, I invite you to name the learning – you’re going to remember with the help of your touchstone.....please know that it is fine to simply take a stone and know in your own mind and heart what you will carry forward with you as a result of the learning we’ve shared....

*Often a good idea is for you as facilitator to set the tone and go up first....but not always necessary*

## Steps to Perform a Simple Hand Massage

- Wash your hands and gather lotion or oil if desired.
- Apply massage oil or lotion to your hands. This will help your hand glide over the other person's skin better. Use approximately 1/4 to 1/2 teaspoon of massage oil per hand, or a coin-sized dollop of lotion. You can always apply more oil or lotion as needed during the massage.
- Gently smooth the massage medium (oil or lotion) over the person's hand. Use smooth, gentle strokes (called "effleurage") to apply the oil or lotion and warm and relax the muscles of the hand.
- Apply the lotion using your palm in several (3-6) long smooth strokes to the back of the fingers and hand.
- Flip the hand over and smooth more medium into the palm and fingers. Work from the tips of the fingers to the wrist, and then back down to the fingers.
- Massage the fingers. Hold the person's hand, palm down. Beginning with the pinky finger, pinch the tip of the finger firmly for a moment. Then using firm, short strokes with your thumb, massage up the finger towards the knuckle. Finally, squeeze the finger all over.
- Repeat the process with each finger, and finish with the thumb.
- Be sure to ask the person you are massaging if the pressure feels right, and remind them to speak up if they would like more or less pressure at any time
- Massage the back of the hand. Hold the person's hand in your hand, palm down and use your thumb to massage the back of the hand.
- Massage the back of the wrist. With the hand still face down, use both of your thumbs to massage the wrist using a small, circular motion. Focus first on the middle of the wrist, and then move out the sides.
- Massage the palm of the hand. Turn the person's hand over, and cradle it in both hands. Then massage the palm in small, circular movements using your thumbs. Begin in the middle of the palm, and work your way towards the sides, and then up towards the wrist.
- Stretch the fingers. Hold the person's hand palm down, and then interlace your fingers with hers to stretch the fingers apart. Grasp the whole hand in yours, and gently push back to stretch the wrist a bit. Then slowly and carefully turn the wrist from right to left, and then left to right.
- Finish the first hand. Hold the hand in yours, palm down, and give several long strokes with your palm and fingers. Begin at the back of the wrist, and smooth your hand down towards the fingers.
- Massage the second hand. Use the same steps, and massage the person's other hand. Try to be consistent in the motions you use, and the amount of time you spend on each hand.





