Palliative Care…IT TAKES A VILLAGE…..

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PHC IGSI: College of Family Physicians Canada Conflict of Interest slide

Faculty/Presenter Disclosure

- **Faculty/Presenter:** Pam Cummer, Pansy Angevine, Maureen McCall

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Dementia and Palliative Approach

- Dementia is a progressive life limiting condition with increasing prevalence and complex needs.
- The disease course that dementia usually follows is one of prolonged & progressive disability.
- When the Palliative Approach is initiated, the baseline function is often already low.
- As dementia is often diagnosed in older adults, clients often have existing co-morbidities.
- “Typical” palliative client (cancer) follows decline from “high” functioning, rapid, predictable terminal phase where there is time to anticipate palliative needs & plans for end of life care.

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Clients with dementia often die:

- with inadequate pain control
- with feeding tubes in place
- without the benefits of hospice care

Barriers to quality end of life care in dementia patients include:

- dementia not being viewed as a terminal illness
- nature of the course & treatment decisions in advanced dementia
- assessment & management of symptoms
- caregiver experience & bereavement
- health system issues

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LIVING WITH DEMENTIA VS. *DYING* WITH DEMENTIA

Specific predictors: Dementia

Months to several months of life expected
(all predictors should be present)

- MMSE less than 12
- Unable to ambulate without assistance
- Unable to dress without assistance
- Unable to bathe without assistance
- Urinary and fecal incontinence
- Unable to speak or communicate meaningfully
- Unable to swallow
- Increasing frequency of medical complications
  (e.g. aspiration pneumonia, UTI's, decubitus ulcers

The Pallium Palliative Pocketbook, First Edition, Third Printing (2013)

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That's What I Mean…

Palliative Care: focuses on improving or maintaining quality of life for an individual with a non-curative illness; not time-limited but focused on benefit to the client and family

End-of-Life Care: during last days or weeks of life.

Hospice: A facility which provides inpatient end-of-life care.

Hospice Palliative Care: Terms used interchangeably

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Who **provides** palliative care?

We all do!

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Introducing the Palliative Care Approach

Appropriate model: Palliative care "early"

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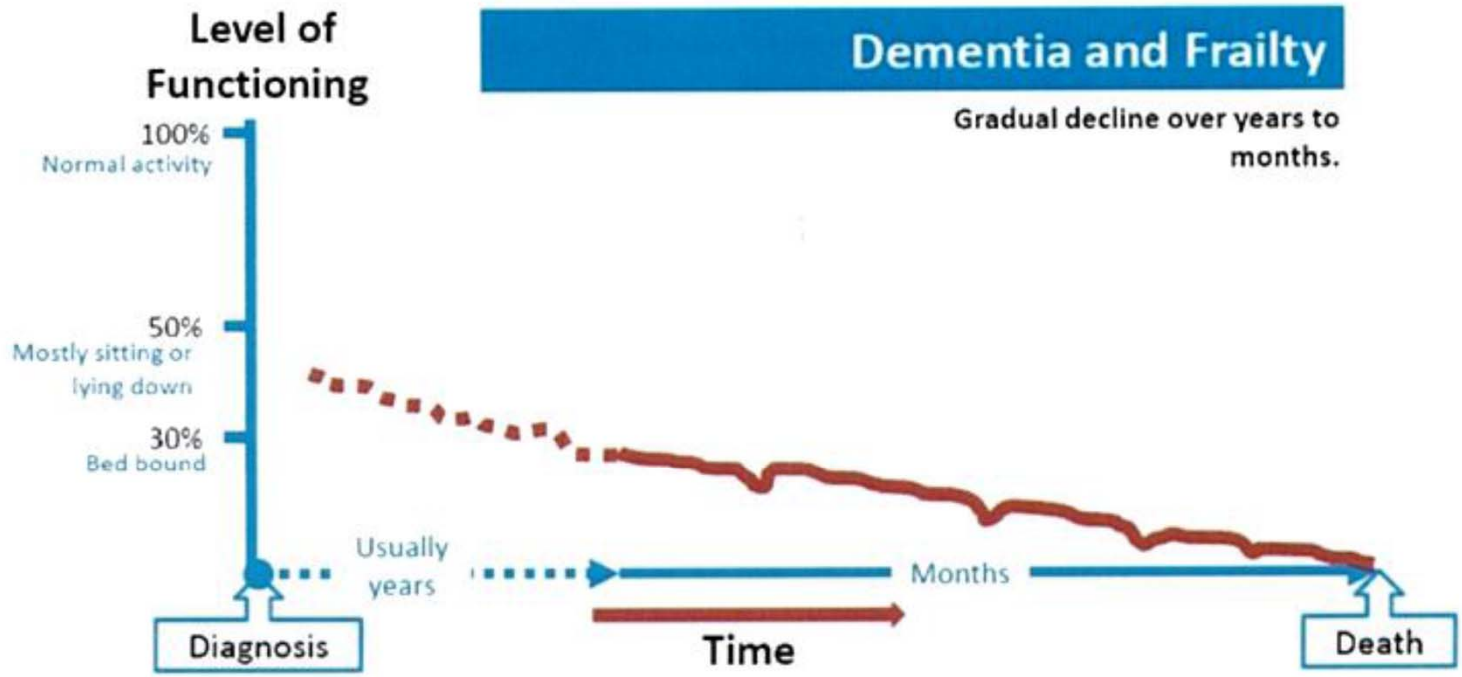
Illness trajectories: Dementia & frailty



Adapted from Gold Standards Framework and Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. *J Am Geriatr Soc* 2002;50:1108-12

The British Journal of Nursing reminds us that:

"Clearly the dignity of individuals suffering from dementia is at risk as they become less able to care for themselves, however it is unacceptable that loss of dignity is inevitable."

"Paying attention to the care environment, careful planning involving relatives and carers, and gentle but regular engagement with the individual can all make a difference."

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Dignity and the End of Life

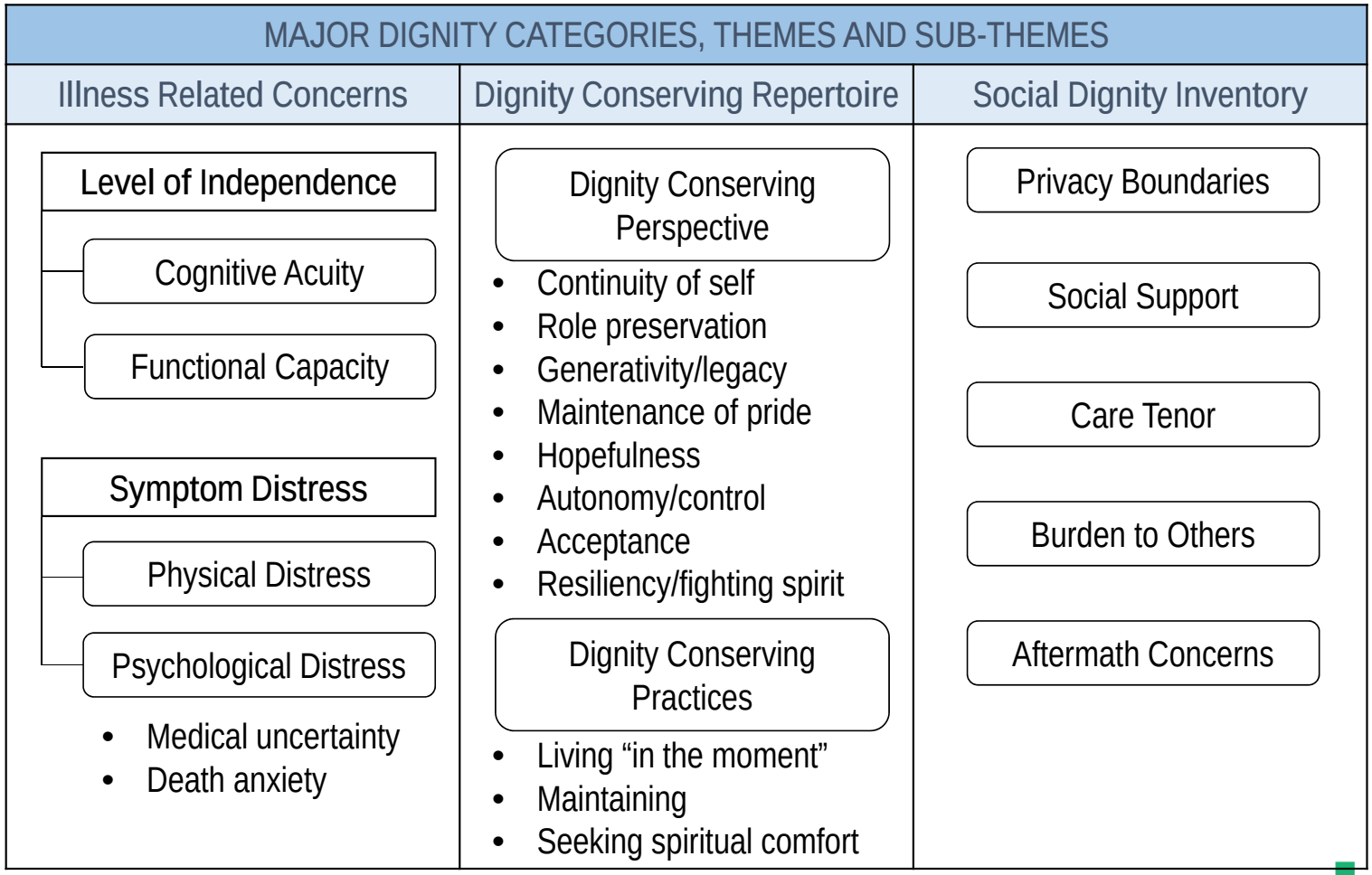

FIG 1.1 Model of dignity in the Terminally Ill. Reprinted with permission of Social Science & Medicine

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When do we know “Now” is the time?”

- Recognition of increased needs
- Increased frequency of critical incidents
- More frequent interventions required to manage symptoms
- Less positive response to interventions and
- treatments
- These are all indicators and it is now time to utilize available tools and assessments

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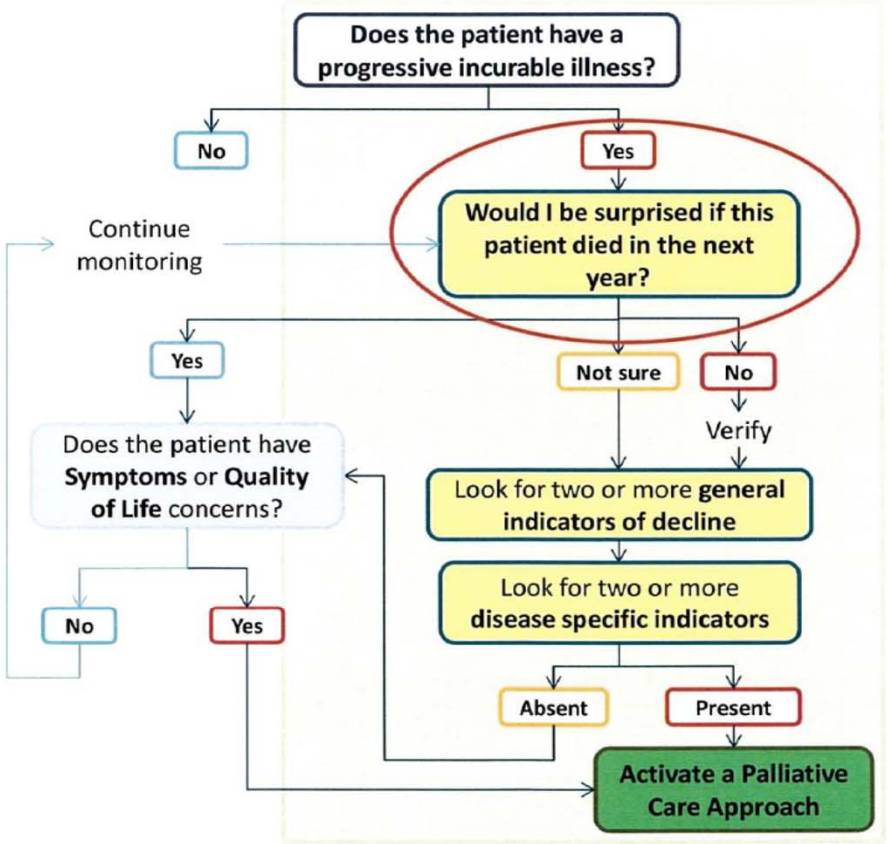
"Ask the question"



Adapted from GSF

What Can You Do?

Identify: Those patients who may *benefit* from palliative care early.

Assess: Clients/families understanding of illness
- symptoms
- quality of life
- psychosocial/spiritual needs/values

Plan: Advanced care planning/Goals of Care, Power of Attorney

Manage: Symptoms
- essential conversations

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Time to Assess and Monitor

- Why?
- How?
- How Often?

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Name

HCID #

PHN

DOB

Edmonton Symptom Assessment Scale (ESAS) Numerical

Please circle the number that best describes:

No Pain	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Pain**
Not Tired	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Tiredness**
Not Nauseated	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Nausea**
Not Depressed	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Depression**
Not Anxious	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Anxiety**
Not Drowsy	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Drowsiness**
Best Appetite	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Appetite**
Best Feeling of Well-being	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Feeling of Well-being**
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Shortness of Breath**
Other Problems	0	1	2	3	4	5	6	7	8	9	10	**(ie, constipation, diarrhea, urgency, etc)**

Date_____ **Time** _____

Completed by_____

Patient ☐

Caregiver ☐

Caregiver Assisted ☐

Body Diagram on Reverse

*ESAS

Edmonton Symptom Assessment Scale

PainAd

Pain Assessment in Advanced Dementia – PAIN AD (Warden, Hurley, Volicer, 2003)

ITEMS	0	1	2	Score
Breathing: Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventiliation	Noisy labored breathing, Long periods of hyperventilation, Cheyne stokes respirations	
Negative vocalizaiton	None	Occasional moan or groan Low level speech with a negative or disapproval quality	repeated troubled calling out, Loud moaning or groaning, Crying	
Facial Expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimacing	
Body Language	Relaxed	Tense, Distressed, pacing, fidgeting	Rigid, Fists clenched, knees pulled up. Pulling or pushing away, Striking out	
Consolability	No need to console	Distracted or reassrued by voice or touch	Unable to console, distract or reassure	

Total Score range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (“0” = no pain to “10” = severe)

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Wong-Baker FACES Pain Rating Scale

From Wong D.L., Hockenberry-Eaton M., Wilson D., Winkelstein M.L., Schwartz P.: Wong's Essentials of Pediatric Nursing, ed. 6, St. Louis, 2001, p. 1301. Copyrighted by Mosby, Inc. Reprinted by permission.

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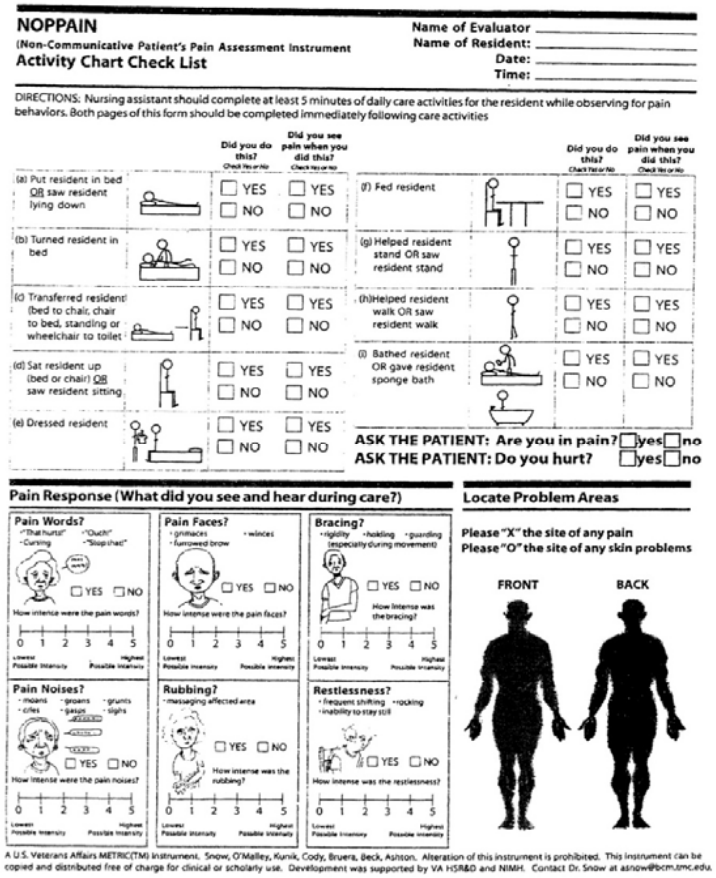
Module 2
Figure 8: NOPAIN



NOPPAIN
(Non-Communicative Patient's Pain Assessment Instrument
Activity Chart Check List

Name of Evaluator _____
Name of Resident: _____
Date: _____
Time: _____

DIRECTIONS: Nursing assistant should complete at least 5 minutes of daily care activities for the resident while observing for pain behaviors. Both pages of this form should be completed immediately following care activities

	Did you do this?	Did you see pain when you did this?
(a) Put resident in bed OR saw resident lying down	☐ YES ☐ NO	☐ YES ☐ NO
(b) Turned resident in bed	☐ YES ☐ NO	☐ YES ☐ NO
(c) Transferred resident (bed to chair, chair to bed, standing or wheelchair to toilet	☐ YES ☐ NO	☐ YES ☐ NO
(d) Sat resident up (bed or chair) OR saw resident sitting	☐ YES ☐ NO	☐ YES ☐ NO
(e) Dressed resident	☐ YES ☐ NO	☐ YES ☐ NO
(f) Fed resident	☐ YES ☐ NO	☐ YES ☐ NO
(g) Helped resident stand OR saw resident stand	☐ YES ☐ NO	☐ YES ☐ NO
(h) Helped resident walk OR saw resident walk	☐ YES ☐ NO	☐ YES ☐ NO
(i) Bathed resident OR gave resident sponge bath	☐ YES ☐ NO	☐ YES ☐ NO

ASK THE PATIENT: Are you in pain? ☐yes ☐no
ASK THE PATIENT: Do you hurt? ☐yes ☐no

Pain Response (What did you see and hear during care?)

Pain Words? · "That hurts!" · "Ouch!" · Cursing · "Stop that!" — ☐ YES ☐ NO — How intense were the pain words? 0 1 2 3 4 5 (Lowest Possible Intensity … Highest Possible Intensity)

Pain Faces? · grimaces · winces · furrowed brow — ☐ YES ☐ NO — How intense were the pain faces? 0 1 2 3 4 5

Bracing? · rigidity · holding · guarding (especially during movement) — ☐ YES ☐ NO — How intense was the bracing? 0 1 2 3 4 5

Pain Noises? · moans · groans · grunts · cries · gasps · sighs — ☐ YES ☐ NO — How intense were the pain noises? 0 1 2 3 4 5

Rubbing? · massaging affected area — ☐ YES ☐ NO — How intense was the rubbing? 0 1 2 3 4 5

Restlessness? · frequent shifting · rocking · inability to stay still — ☐ YES ☐ NO — How intense was the restlessness? 0 1 2 3 4 5

Locate Problem Areas

Please "X" the site of any pain
Please "O" the site of any skin problems

FRONT BACK

A U.S. Veterans Affairs METRIC(TM) Instrument. Snow, O'Malley, Kunik, Cody, Bruera, Beck, Ashton. Alteration of this instrument is prohibited. This instrument can be copied and distributed free of charge for clinical or scholarly use. Development was supported by VA HSR&D and NIMH. Contact Dr. Snow at asnow@bcm.tmc.edu.

*NOPAIN

Cam Confusion Score:

The diagnosis of delirium by CAM requires the presence of BOTH features A and B

C

A

M

A.
Acute onset
and
Fluctuating course
_____B.
Inattention

Is there evidence of an acute change in mental status from patient baseline?

Does the abnormal behavior:

-come and go?

-fluctuate during the day?

-Increase/decrease in severity?

_____

Does the patient:

-have difficulty focusing attention?

-become easily distracted?

-have difficulty keeping track of what is said?

AND the presence of EITHER feature C or D

C.
Disorganized
Thinking

_____

D.
Altered level of
Consciousness

Is the patient's thinking
-disorganized
-incoherent
For example does the patient have
-rambling speech/irrelevant conversation?
-unpredictable switching of subjects?
-unclear or illogical flow of ideas?

_____

Overall, what is the patient's level of consciousness:
-alert (normal)
-vigilant (hyper-alert)
-lethargic (drowsy but easily roused)
-stupouous (difficult to rouse)
-comatose (unrousable)

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Common Symptoms

- Pain
- Nausea
- Depression/Anxiety
- Dyspnea
- Delirium

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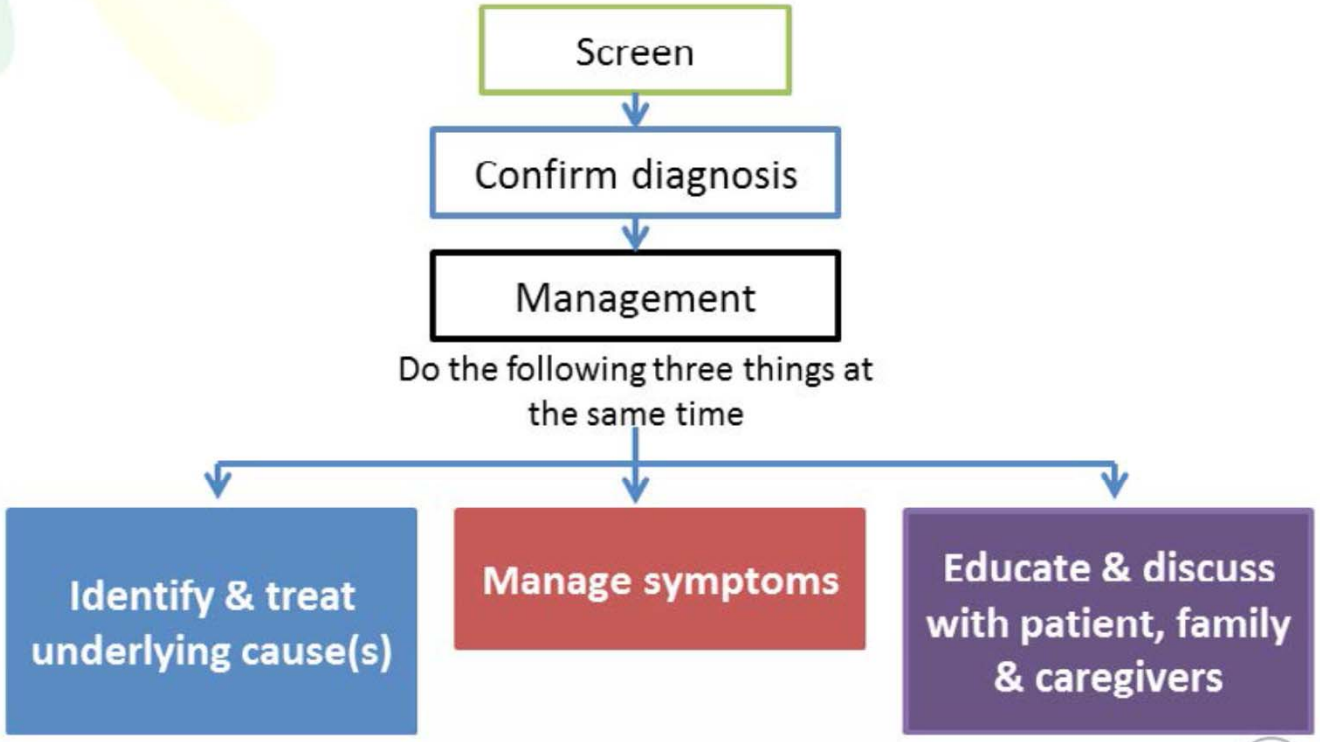
Overall management approach



Pain

- **Treat both baseline pain and break through pain**
  - ❖ Order medications around the clock and hourly prn (start low, go slow in the elderly or frail)*
  - ❖ Use adjuvants: other medications, chemotherapy, radiation therapy, surgery
  - ❖ Use non-pharmacological measures: physiotherapy, equipment, positioning, environmental changes
  - ❖ Use complementary modalities: meditation, reiki, visualization, breathing exercises

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Nausea

- Common causes: constipation, medications, treatments, primary and secondary abdominal disease, metabolic (hypocalcemia, hyponatremia)

- Order medications that target the suspected cause of the nausea (most frequently, the Chemoreceptor Trigger zone or the GI Tract)
  - 1st line Metoclopramide or Domperidone
  - 2nd line Haloperidol, Ondansetron or Methotrimeprazine

- Use non-pharmacological and complementary modalities

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Depression/Anxiety

- Less common than you think
- Hard to diagnose using standard symptoms
  - Helpful to look at more of the psychological symptoms

- Supportive Counseling is the mainstay in treatment
- Persistent symptoms may require pharmacological intervention
- Complementary therapies often helpful, especially in decreasing acute episodes of anxiety

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Dyspnea

- Subjective symptom
- Person's expression of dyspnea may not correlate to what you observe, respiratory rates or oxygen saturations
- Investigations may not always correlate either
- Treatment aimed at managing underlying causes, while decreasing reported shortness of breath
  - 1st line treatment = opioids
  - Oxygen usually only helpful in presence of hypoxia
  - Benzodiazepines should only be used if underlying anxiety or panic disorder is present
  - Intractable dyspnea, at end of life, may be appropriately treated with palliative sedation

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Delirium

- Disturbance in ***attention*** (i.e., reduced ability to direct, focus, sustain, and shift attention) and ***awareness*** (reduced orientation to the environment).
- The disturbance develops over a short period of time (usually hours to a few days), represents an ***acute change*** from baseline attention and awareness, and tends to ***fluctuate*** in severity during the course of a day.
- An additional disturbance in ***cognition*** (e.g. memory deficit, disorientation, language, visuospatial ability, or perception).
- The disturbances in Criteria A and C are *not better explained by a pre-existing, established or evolving neurocognitive disorder* and do not occur in the context of a severely reduced level of arousal such as coma.
- There is *evidence* from the history, physical examination or laboratory findings *that the disturbance is a direct physiological consequence of another medical condition*, substance intoxication or withdrawal (i.e. due to a drug of abuse or to a medication), or exposure to a toxin, or is due to multiple etiologies.

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Delirium

- Three types – Hyperactive, hypoactive, mixed
- “pleasant confusion” is a myth: delirium should be treated promptly
- Common in palliative population
- Very distressing to families; education and communication is key
- Constitutes a “medical emergency” in palliative care
- Not all deliriums are reversible
- Maximize environmental and non-pharmacological interventions
- Use medications in lowest dose possible to control symptoms
- 1st line Methotrimeprazine (dose and frequency will depend on severity)

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Spirituality and Spiritual Assessment

- **F - Faith and Belief**
- **I - Importance**
- **C - Community**
- **A - Address in Care**

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As death nears, the focus, goals and rhythm of care changes. Aim is to prevent and control distressing symptoms and support the family.

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Symptom Management Needs Change

- May need to change method of drug delivery to intermittent SC or continuous infusion.
- May decide to stop certain therapies such as fluids, unnecessary drugs and treatments. Discuss with family.
- May need to treat new symptoms as they appear such as upper airway congestion, anxiety, restlessness, emotional/psychological/spiritual distress.

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Care at Time of Death…

- Rhythm of care changes—focus on family
- Opportunity to support family and care for body—facilitates early process of grieving
- Provide after death care, gently
- Rituals are important— should have been explored in planning stages and recorded on the care plan; ensure they are followed
- Offer family contact - combing of hair, bathing, changing clothes or performing other care, if desired
- Allow to have family spend time with the body, if they wish

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Family and The Team

"From one single second to the next, my life, my mom's life, my dad's life, my brothers' lives, the lives of all of our friends and family, were altered profoundly. My mom had started the journey down the lonely, confusing road called Alzheimer's disease."

"What matters are the moments spent with the people you love. What matters is setting judgement and resentment aside so that tolerance and patience and kindness can move into your soul and live there in their forever home."

- Jann Arden, "Feeding My Mother", 2017

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Resources for Families

- My Health Alberta website
  - https://myhealth.alberta.ca/palliative-care
- Alberta Hospice Palliative Care Association (AHPCA)
  - http://www.ahpca.ca/
- Canadian Hospice Palliative Care Association (CHPCA)
  - http://www.chpca.net/
- Canadian Virtual Hospice
  - http://virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- Alzheimer's Society of Canada
  - http://alzheimer.ca/en/Home
- Caregivers Alberta
  - http://www.caregiversalberta.ca/

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Local Resources for You

- Central Zone Palliative Care Team – contact your local nurse
  - **24/7 on-call for professionals 403-348-2408**
- Community hospice groups
- Hospice suites
- Community grief and bereavement support
- Pastoral Care Association
- My Health Alberta website
  - https://myhealth.alberta.ca/palliative-care

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Other Resources

- Alberta Hospice Palliative Care Association (AHPCA)
  - http://www.ahpca.ca/
- Canadian Hospice Palliative Care Association (CHPCA)
  - http://www.chpca.net/
- Canadian Virtual Hospice
  - http://virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- Alzheimer's Society of Canada
  - http://alzheimer.ca/en/Home
- Canadian Society of Palliative Care Physicians website
  - https://www.cspcp.ca/
- Canadian Nurses Association website
  - https://www.cna-aiic.ca/en

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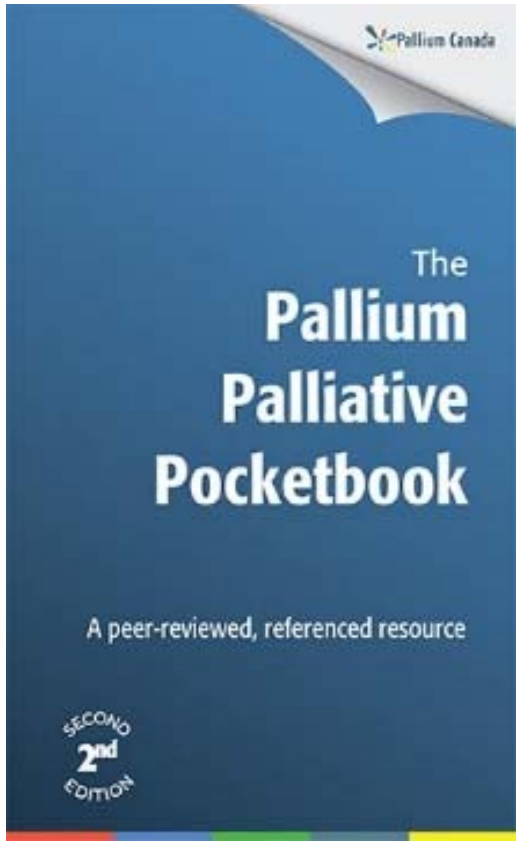
Best Practice Reference



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