Identifying those who are approaching the End of Life Phase

Practical Skills for Palliative Care

Wednesday Oct 4th 2017

VICTORIA HOSPICE

Faculty/Presenter Disclosure

- **Faculty: Douglas McGregor, Dr. Leah MacDonald and Dr. Christine Jones**
- **Relationships with commercial interests:**
  - **Grants/Research Support: None**
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  None

Mitigating Potential Bias

Not applicable

Original Article

The Clinical Course of Advanced Dementia
CASCADE Study

Susan L. Mitchell, M.D., M.P.H., Joan M. Teno, M.D., Dan K. Kiely, M.P.H., Michele L. Shaffer, Ph.D., Richard N. Jones, Sc.D., Holly G. Prigerson, Ph.D., Ladislav Volicer, M.D., Ph.D., Jane L. Givens, M.D., M.S.C.E., and Mary Beth Hamel, M.D., M.P.H.

N Engl J Med
Volume 361(16):1529-1538
October 15, 2009

The NEW ENGLAND JOURNAL of MEDICINE

Clinical Course of Advanced Dementia

- As Mortality rates from leading causes of death **decrease,** death from dementia **increases**.
- Cohort – **followed 18 months**, Assessed every 3 months
- **N= of 323** people with **Advanced Dementia** with health care proxies (68% children, 10% spouses; 17% other family))
  - Mean Age **85,**
  - MDS Cog Performance scale 5-6 (= **MMSE of 5**)
  - **GDS- Stage 7** (don't recognize family, minimal verbal comm., non-ambulatory, incontinent and 100% dependent in ADL)
  - **ALOS – 3 years** in the nursing home
- 22 nursing homes in greater Boston Area, (55% participation rate and 99% follow up)

Results

- **55% Died**
  - Median Survival **16 months**
  - 25% died within **6 months**
- **Predictors of 6 month Mortality**

  (after adjusting for age, gender and duration in facility):
  - **Pneumonia**- 47%
  - **Febrile illness-** 45%
  - **Eating problem**-39% (dysphagia, reduced intake, chewing, needing to be fed)

Substantially higher mortality than people with advanced dementia without these problems

Other Sentinel Events (10% of residents) did *not* predict death within 3 months:

e.g. Seizures, Stroke, MI, GI Bleed, Hip #

Frailty and Dementia Stage

Frailty Level	Dementia (FAST) stage	
Thriving	No subjective decline	
Normal	Subjective, no objective decline	
Well with treated co-morbid disease	Subjective and objective decline	
Vulnerable	MCI	Help with high level tasks
Mildly Frail: need help with some IADLs	Mild	Help with some IADLs, Forgets current events
Moderately Frail	Moderate	Help with all IADLs, cuing for BADLs Forgets current events
Severely Frail	Severe	Need help with all BADLs, Forgets close relatives
Very Severely Frail	Very Severe	Non verbal, non-ambulatory

isberg B. Functional assessment staging (FAST). Psychopharmacol Bull. 1988;24:653-659.
ckwood K, Song X, MacKnight C et al. A global clinical measure of fitness and frailty in elderly people. CMAJ. 2005;173:489-495.

ICSI

INSTITUTE FOR CLINICAL SYSTEMS IMPROVEMENT

Health Care Guideline:

Palliative Care

Second Edition
May 2008

Imminent Dying

- Inability to swallow any fluids at all. Not taking food by mouth. Vomiting.

- Patient breathing through wide open mouth continuously and no longer can speak even if awake.

- Urinary or bowel incontinence in a patient who was not incontinent before.

- Marked decrease in urinary output and darkening color of urine or very abnormal color of urine, such as red or brown.

- Blood pressure dropping dramatically from patient's normal blood pressure range (more than a 20-30 point drop).

- Systolic blood pressure below 70. Diastolic blood pressure below 50.

- Patient's extremities feel very cold to the touch.

- Fever.

- Patient complains that his or her legs/feet are numb and cannot be felt at all.
- Cyanosis, or a blue or purple coloring to the patient's arms and legs, especially the hands and feet (mottling).
- Patient's body is held in a rigid unchanging position.

• Periods of pausing in breathing (apnea) whether awake or sleeping. Very rapid breathing or cyclic changes in the patterns of breathing (Cheyne-Stokes respirations). Other abnormal breathing patterns.

• Patient reports seeing persons who have already died.

• Patient states that he or she is dying.

• Patient requests family visit to settle unfinished business and tie up loose ends.

• Inability to heal or recover from wounds or infections.

• Increased swelling (edema) of either the extremities or the entire body.

• Inability to arouse patient at all (coma) or ability to arouse patient only with great effort, but patient quickly returns to severely unresponsive state (semicoma).

• Severe agitation in patient, hallucinations, acting "crazy" and not in patient's normal manner or personality.

• Increased respiratory congestion or fluid buildup in the lungs. Shortness of breath.

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Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

The SPICT™ is a guide to identifying people at risk of deteriorating health and dying. Assess these people for unmet supportive and palliative care needs.

Look for two or more general indicators of deteriorating health.

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited.
- Dependent on others for most care needs due to physical and/or mental health problems.
- Two or more unplanned hospital admissions in the past 6 months.
- Significant weight loss (5-10%) over the past 3-6 months, and/ or a low body mass index.
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).
- Patient asks for supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of one or more advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Eating and drinking less; swallowing difficulties.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/ or progressive swallowing difficulties.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Review supportive and palliative care and care planning

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals, and a care plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Record, communicate and coordinate the care plan.

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2015

COHEN IDENTIFICATION TOOL

SQ ☐ not surprised ☐ surprised

Albumin (HR expressed for a 1-U increase)

Age (yr; HR expressed for a 10-yr increase)

PVD ☐ Yes ☐ No

Dementia ☐ Yes ☐ No

Comprehensive Geriatric Assessment

Division of Geriatric Medicine, Dalhousie University

Cognitive Status ☐ WNL ☐ Dementia ☐ CIND/MCI ☐ Delirium MMSE:_____ FAST:_____
Chief lifelong occupation: _____ Education (years): _____

Emotional ☐ WNL ☐ ↓Mood ☐ Depression ☐ Anxiety ☐ Fatigue ☐ Other

Motivation ☐ High ☐ Usual ☐ Low **Health Attitude** ☐ Excellent ☐ Good ☐ Fair ☐ Poor ☐ Couldn't say

Communication **Speech** ☐ WNL ☐ Impaired **Hearing** ☐ WNL ☐ Impaired **Vision** ☐ WNL ☐ Impaired

Strength ☐ WNL ☐ Weak Upper: PROXIMAL DISTAL Lower: PROXIMAL DISTAL

		BASELINE (two weeks ago)	CURRENT (today)	NOTES
Mobility	Transfer	IND ASST DEP	IND ASST DEP	
	Walking	IND ASST DEP	IND ASST DEP	
	AID	_____	_____	
Balance	Balance	IND IMPAIRED	IND IMPAIRED	
	Falls	N Y Number_____	N Y Number_____	
Elimination	Bowel	CONT CONSTIP INCONT	CONT CONSTIP INCONT	
	Bladder	CONT CATHETER INCONT	CONT CATHETER INCONT	
Nutrition	Weight	GOOD UNDER OVER OBESE	STABLE LOSS GAIN	
	Appetite	WNL FAIR POOR	WNL FAIR POOR	
ADLs	Feeding	I A D	I A D	
	Bathing	I A D	I A D	
	Dressing	I A D	I A D	
	Toileting	I A D	I A D	
IADLs	Cooking	I A D	I A D	
	Cleaning	I A D	I A D	
	Shopping	I A D	I A D	
	Medications	I A D	I A D	
	Driving	I A D	I A D	
	Banking	I A D	I A D	

Sleep ☐ Normal ☐ Disrupted ☐ Daytime drowsiness **Socially Engaged** ☐ Freq. ☐ Occ. ☐ Not

Social ☐ Married ☐ Divorced ☐ Widowed ☐ Single
Lives ☐ Alone ☐ Spouse ☐ Other
Home ☐ House (levels____) ☐ Steps (Number____) ☐ Apartment ☐ Assisted living ☐ Nursing home ☐ Other
Supports ☐ Informal ☐ HCNS ☐ Other ☐ None ◯ **Req. more support**
Caregiver Relationship ☐ Spouse ☐ Sibling ☐ Offspring ☐ Other
Caregiver stress ☐ None ☐ Low ☐ Moderate ☐ High
☐ Advance directive in place?
Caregiver occupation: (CG) _____

Patient contact: (Pt.)
☐ Inpatient ☐ Clinic ☐ GDH ☐ NH ☐ Outreach ☐ Home ☐ Assisted living ☐ ER ☐ Other

How many months since last well?

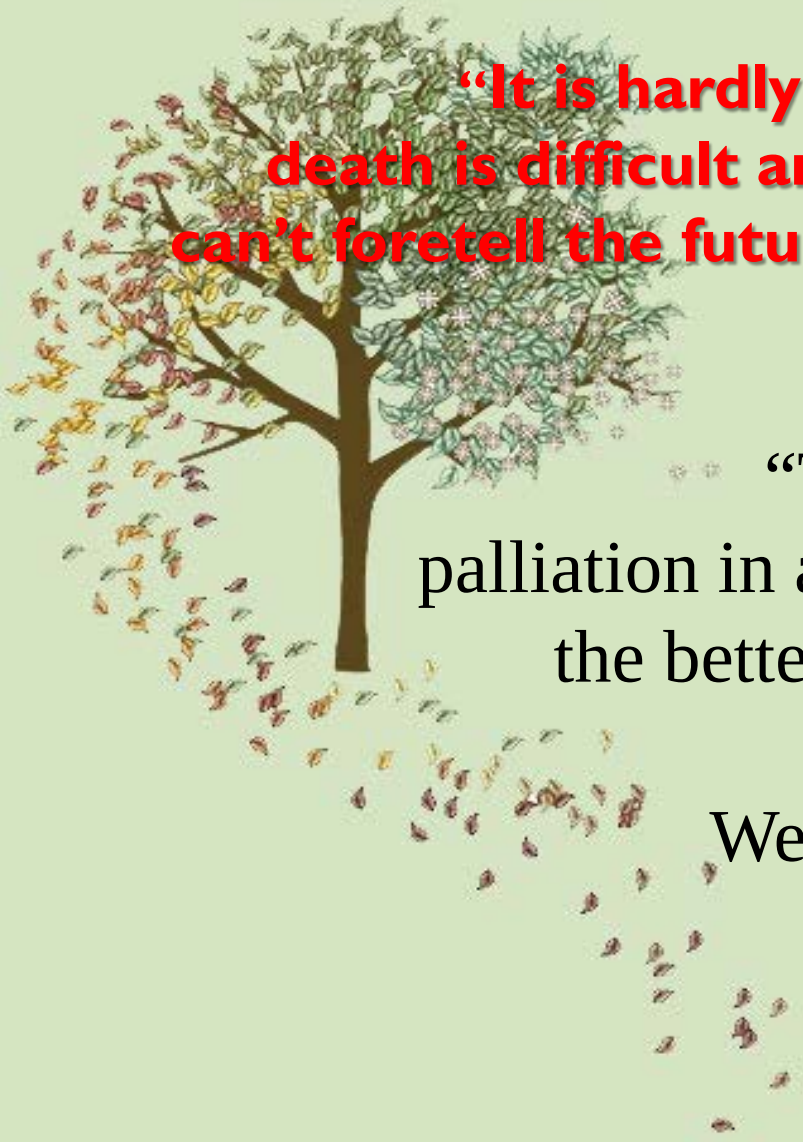
Current Frailty Score:

Scale	Pt.	CG
1. Very fit		
2. Well		
3. Well ∓ Rx'd co-morbid disease		
4. Apparently vulnerable		
5. Mildly frail		
6. Moderately frail		
7. Severely frail		
8. Very severly frail		
9. Terminally ill		

ACTION REQUIRED (check appropriate circles)

Problems:	Med adjust req.	Associated Medications: (*mark meds started in hospital with an asterisk)
1 RFR	◯	
2	◯	
3	◯	
4	◯	
5	◯	
6	◯	
7	◯	
8	◯	
9	◯	
10	◯	

Assessor/Physician: _____ Date: _____
YYYY/MM/DD



"It is hardly news that predicting death is difficult and that doctors can't foretell the future"

"The sooner we start palliation in a patient likely to die soon, the better we can prevent harms of polypharmacy…….

We are much more likely to cause problems by underdiagnosing the end of life than by overdiagnosing it"

Alice Hodkinson, David Spitzer, and Iona Heath:
Overdiagnosis of end of life
BMJ OPINION The BMJ 2 Sept 2017.

College of Physicians and Surgeons of British Columbia

Professional Standards and Guidelines

Safe Prescribing of Drugs with Potential for Misuse/Diversion

Preamble

This document establishes both professional standards as well as guidelines of the Board of the College of Physicians and Surgeons of British Columbia.

85 yo in Residential Care

Advanced vascular dementia
Seizure disorder >50 years
R CVA 2000
CAD
HT
Depression with psychosis 2010

Fall 2015 compression # L4
Fentanyl Patch → good pain control

GP worried about appropriateness, titrated down

Pt became agitated, behaviours emerged, crying , grimacing

GP asks for PCP consult

Fentanyl titrated up to 62 mcg → pt in great form again

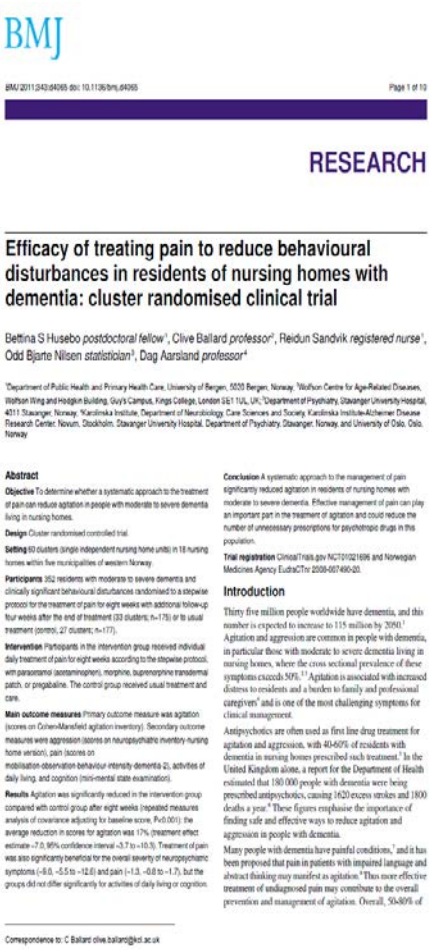
Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving 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 reassured by voice or touch.	Unable to console, distract or reassure.	
			Total**	

*Five-item observational tool (see the description of each item below).

**Total scores 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 pain").

Stepped Approach to Pain Management



BMJ

BMJ 2011;343:d4065 doi: 10.1136/bmj.d4065 Page 1 of 10

RESEARCH

Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial

Bettina S Husebo *postdoctoral fellow*[1], Clive Ballard *professor*[2], Reidun Sandvik *registered nurse*[1], Odd Bjarte Nilsen *statistician*[3], Dag Aarsland *professor*[4]

[1]Department of Public Health and Primary Health Care, University of Bergen, 5020 Bergen, Norway. [2]Wolfson Centre for Age-Related Diseases, Wolfson Wing and Hodgkin Building, Guy's Campus, Kings College, London SE1 1UL, UK. [3]Department of Psychiatry, Stavanger University Hospital, 4011 Stavanger, Norway. [4]Karolinska Institute, Department of Neurobiology, Care Sciences and Society, Karolinska Institute-Alzheimer Disease Research Center, Novum, Stockholm, Stavanger University Hospital, Department of Psychiatry, Stavanger, Norway, and University of Oslo, Oslo, Norway

Abstract

Objective To determine whether a systematic approach to the treatment of pain can reduce agitation in people with moderate to severe dementia living in nursing homes.

Design Cluster randomised controlled trial.

Setting 60 clusters (single independent nursing home units) in 18 nursing homes within five municipalities of western Norway.

Participants 352 residents with moderate to severe dementia and clinically significant behavioural disturbances randomised to a stepwise protocol for the treatment of pain for eight weeks with additional follow-up four weeks after the end of treatment (33 clusters; n=175) or to usual treatment (control, 27 clusters; n=177).

Intervention Participants in the intervention group received individual daily treatment of pain for eight weeks according to the stepwise protocol, with paracetamol (acetaminophen), morphine, buprenorphine transdermal patch, or pregabaline. The control group received usual treatment and care.

Main outcome measures Primary outcome measure was agitation (scores on Cohen-Mansfield agitation inventory). Secondary outcome measures were aggression (scores on neuropsychiatric inventory-nursing home version), pain (scores on mobilisation-observation-behaviour-intensity-dementia-2), activities of daily living, and cognition (mini-mental state examination).

Results Agitation was significantly reduced in the intervention group compared with control group after eight weeks (repeated measures analysis of covariance adjusting for baseline score, P<0.001): the average reduction in scores for agitation was 17% (treatment effect estimate −7.0, 95% confidence interval −3.7 to −10.3). Treatment of pain was also significantly beneficial for the overall severity of neuropsychiatric symptoms (−9.0, −5.5 to −12.6) and pain (−1.3, −0.6 to −1.7), but the groups did not differ significantly for activities of daily living or cognition.

Conclusion A systematic approach to the management of pain significantly reduced agitation in residents of nursing homes with moderate to severe dementia. Effective management of pain can play an important part in the treatment of agitation and could reduce the number of unnecessary prescriptions for psychotropic drugs in this population.

Trial registration ClinicalTrials.gov NCT01021696 and Norwegian Medicines Agency EudraCTnr 2008-007490-20.

Introduction

Thirty five million people worldwide have dementia, and this number is expected to increase to 115 million by 2050.[1] Agitation and aggression are common in people with dementia, in particular those with moderate to severe dementia living in nursing homes, where the cross sectional prevalence of these symptoms exceeds 50%.[2 3] Agitation is associated with increased distress to residents and a burden to family and professional caregivers[4] and is one of the most challenging symptoms for clinical management.

Antipsychotics are often used as first line drug treatment for agitation and aggression, with 40-60% of residents with dementia in nursing homes prescribed such treatment.[5] In the United Kingdom alone, a report for the Department of Health estimated that 180 000 people with dementia were being prescribed antipsychotics, causing 1620 excess strokes and 1800 deaths a year.[6] These figures emphasise the importance of finding safe and effective ways to reduce agitation and aggression in people with dementia.

Many people with dementia have painful conditions,[7] and it has been proposed that pain in patients with impaired language and abstract thinking may manifest as agitation.[8] Thus more effective treatment of undiagnosed pain may contribute to the overall prevention and management of agitation. Overall, 50-80% of

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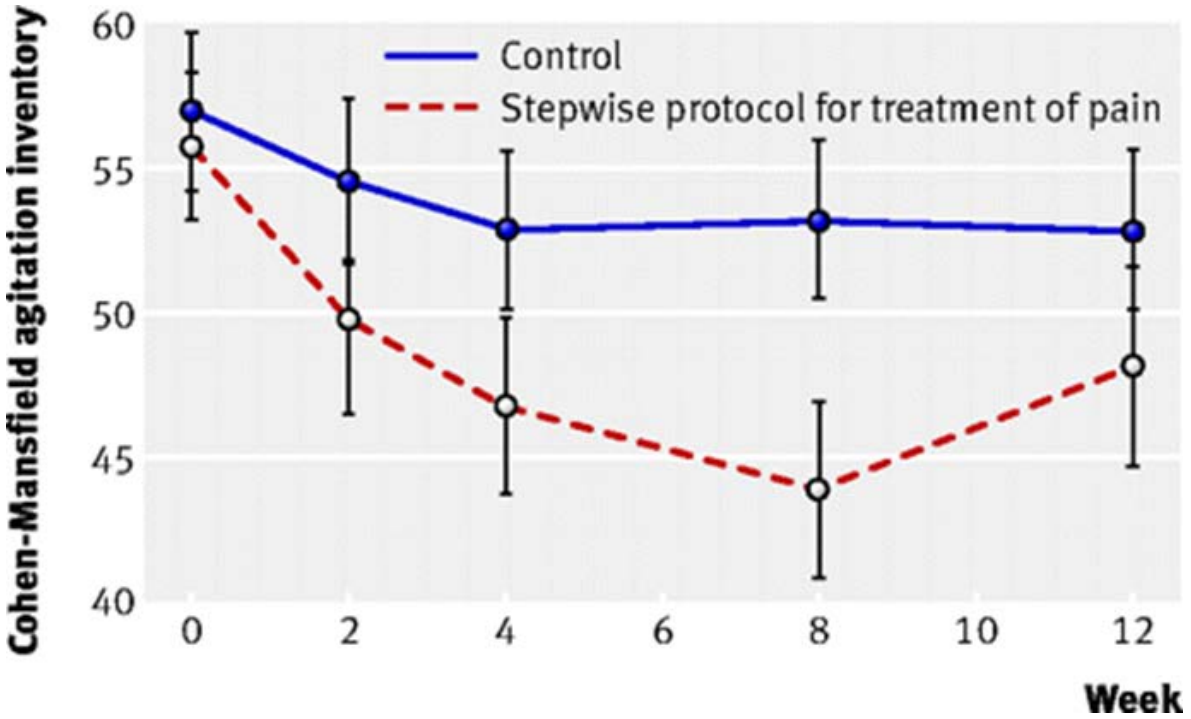
Stepped Analgesia

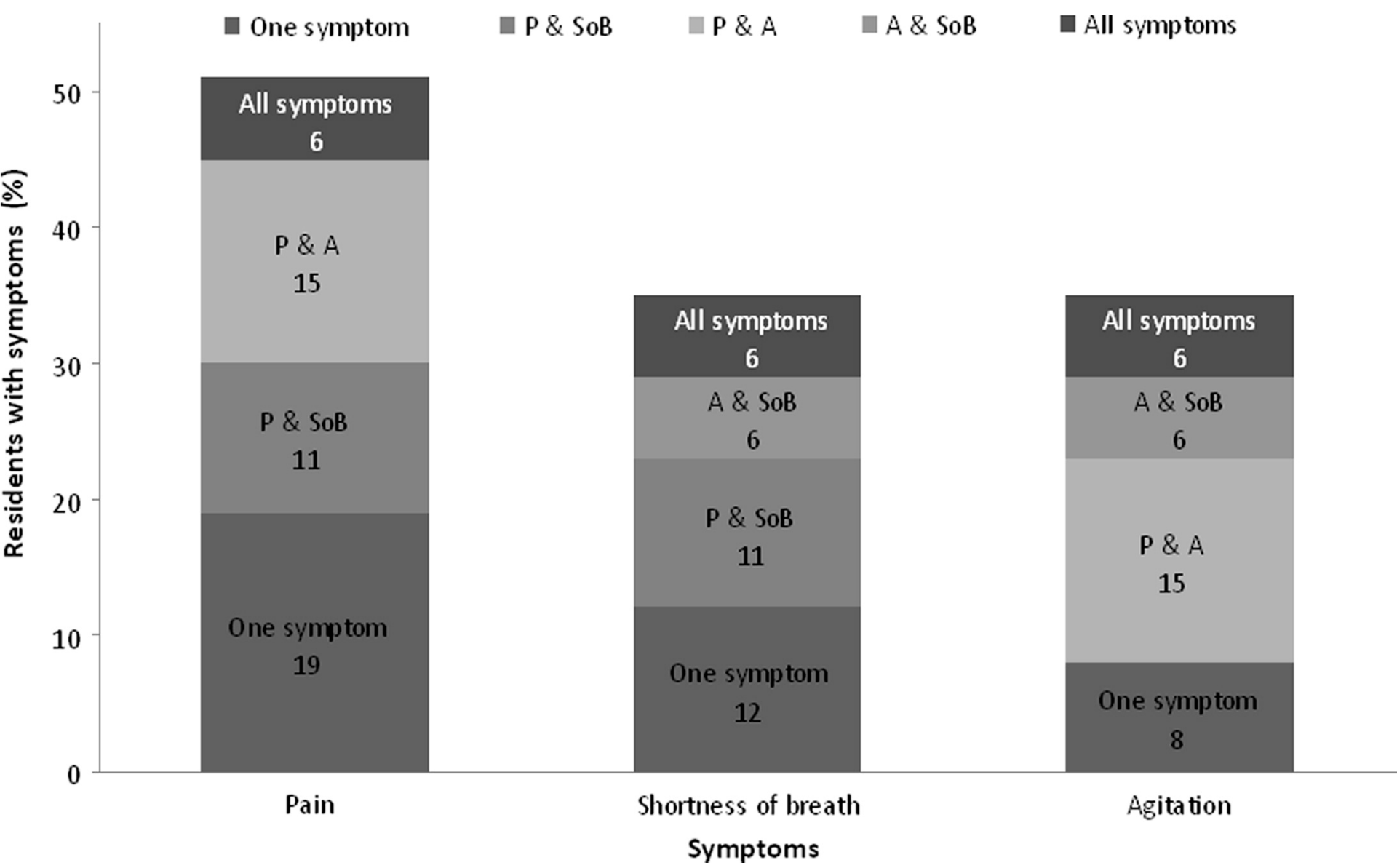
Usual Care

for 8 weeks

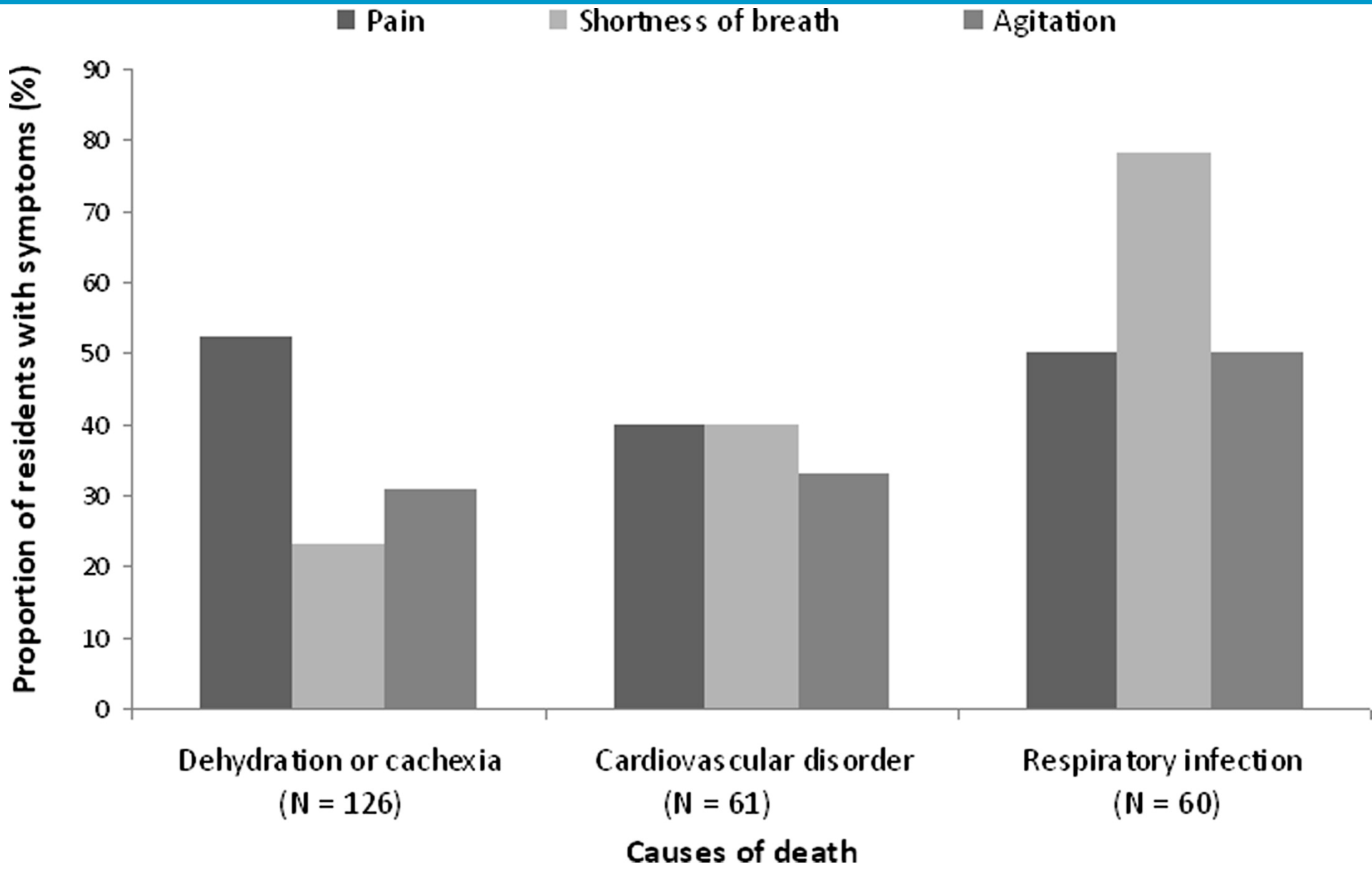
Results- BMJ

- Reduction
  - Agitation (CMAI) – 17% Reduction
  - NPI –BPSD - - 9.0 points
  - No worsening of ADL or Cognition





Dying with Dementia: Symptoms, Treatment and Quality of Life in the Last Week of Life
Journal of Pain and Symptom Management
Volume 47, Issue 4, April 2014, Pages 710-720



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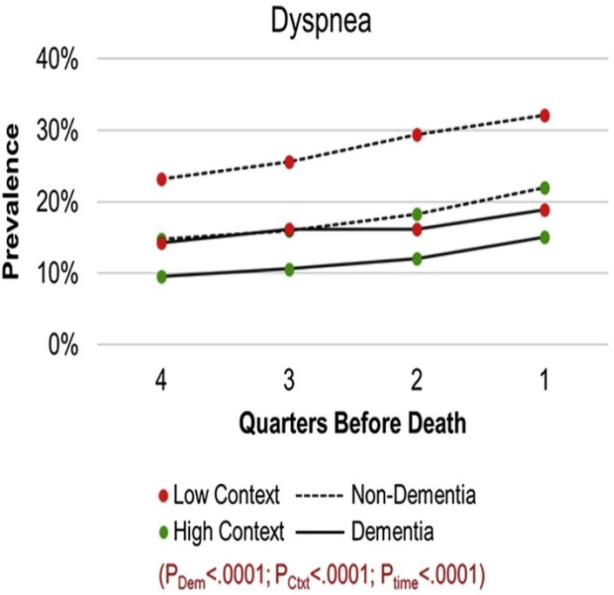
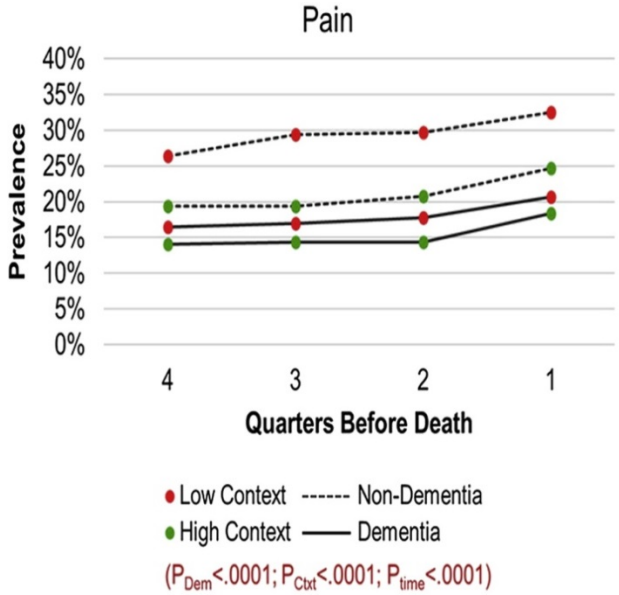
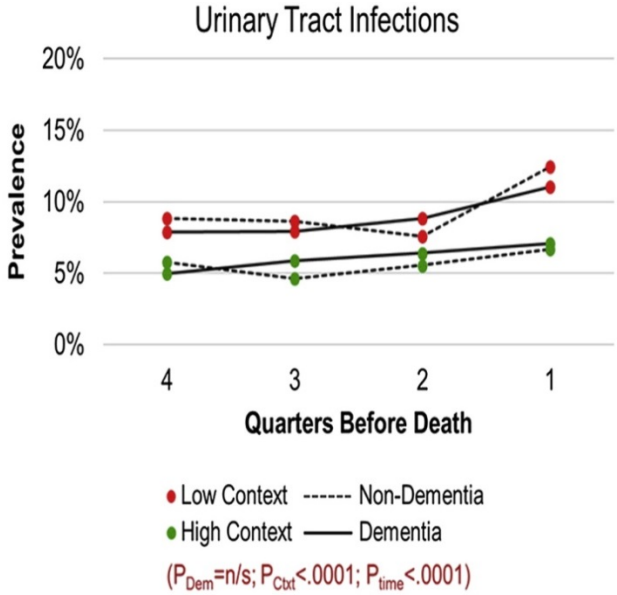
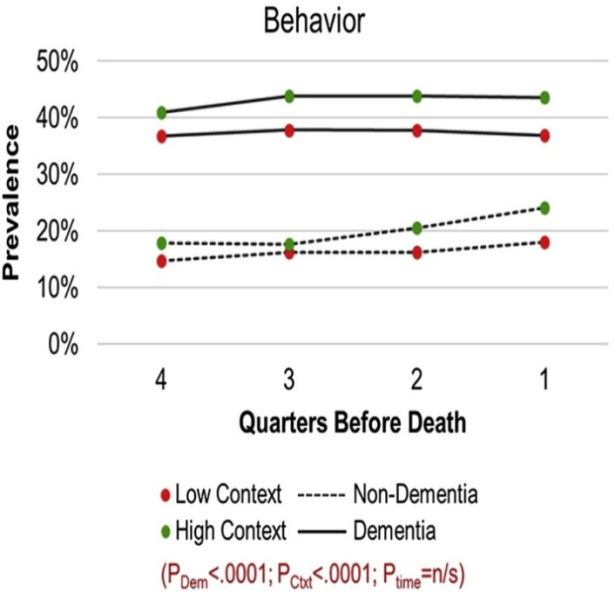
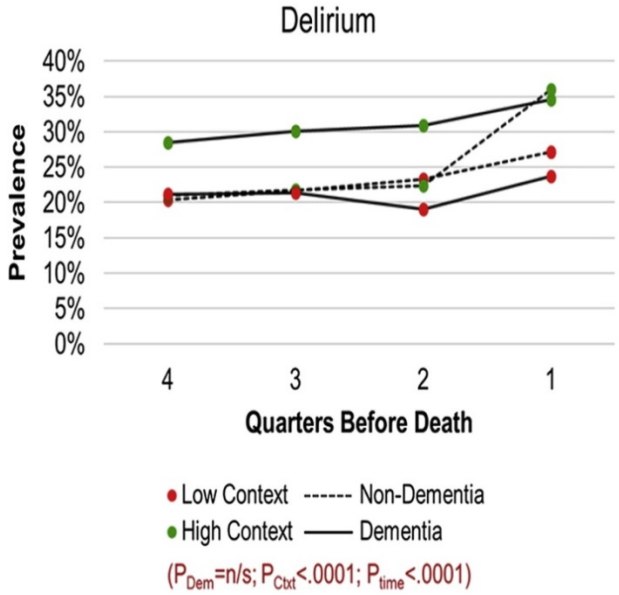
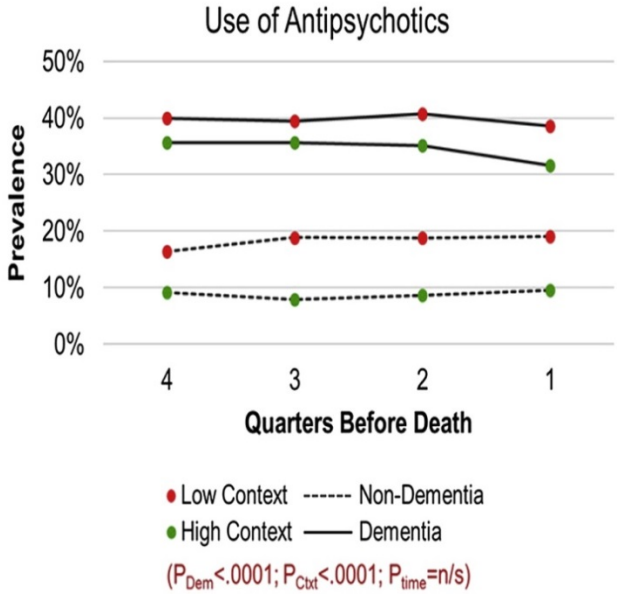












Dying in a Nursing Home: Treatable Symptom Burden and its Link to Modifiable Features of Work Context

Journal of the American Medical Directors Association Volume 16, Issue 6, 1 June 2015, Pages 515-520

Victoria Hospice

Request for Service

For Residential Care Patients

affix patient label here please

VANCOUVER ISLAND health authority

Date: _____/_____/_____

Facility Name: _____ **Telephone #:** _____

Facility Address: _____ **Postal Code:** _____

Ward Name: _____ **Local #:** _____ **Door Code:** _____ **Room #:** _____

Resident Diagnosis: _____ **PPS**:** _____%

Referring Physician/MRP: _____ **Telephone #:** _____

ARO Status: _____

**SEE BACK OF SHEET FOR EXPLANATION OF PPS

☐ ***Patient and/or family member has given consent for service (must be checked).***

Palliative Care Physician (PCP) Referral Process

- PCP consultation is available for patients at end-of-life with terminal diagnosis or evidence of recent global decline
- PCP referral requires MRP approval and must include the EOL symptoms or issues that require review, as well as urgency to be seen (see Reason for Referral section below)
- PCP after hours coverage is physician to physician only

Patient Information

- Resident Admission Date: _____
- Reason for Admission: _____
- Additional diagnosis or health conditions: _____
- Cognitive Status: _____
- Resident Representative or TSDM Name: _____ Telephone #: _____
  Address: _____

Reason for Referral

1. PCP referral for assessment and/or medical consultation for complex unresolved symptoms

Please indicate symptoms: ☐ **Pain** ☐ **Nausea/Vomiting/Bowels** ☐ **Dyspnea** ☐ **Delerium/Agitation** ☐ **Other**

and/or

2. PCP consultative support for complex unresolved EOL issues including:

☐ **Prognosis** ☐ **Goals of Care** ☐ **Medical DecisionMaking** ☐ **Other**

Urgency to be seen: ☐ **less than 24 HRS** ☐ **1-3 DAYS** ☐ **4-7 DAYS**

If urgent consult required (less than 24 hrs) then physician to physician phone referral required. Call Victoria Hospice (250) 370-8715.

Fax to 250-370-8625

For further info call the VHS Community Response Coordinator, 250-370-8714

For VHS Use Only

Service first provided: Date _____/_____/_____ Time _____ hrs
dd mm yr

By Whom: _____

Please sign and return to Community Intake Clerk after initial service is provided.

EOL order sets

Pearls and Pitfalls

Dr. Douglas McGregor

Leah MacDonald, MD

Christine Jones MD

VICTORIA HOSPICE

EOL ORDER SETS Objectives

- Recognize when a resident is actively dying
- Develop skills and knowledge in treating the distressing symptoms of dying (beyond the palliative order set)
- Integrating others into the resident's end of life goals

Brenda

- 87 year old with Advanced Dementia, retired piano teacher
- Progressive functional decline over 18 months
- 6 months previously, GI bleed, hospitalized; treated symptomatically with transfusion, PPI
- Mild contractures of knees
- Sacral ulcer
- CFS 8: dependent on others for all personal care; feeds self inconsistently; chokes on food occasionally
- FAST 7:
  - Incontinent of bladder and bowels
  - Up in the chair via lift most days, verbalizes very short sentences
- Moans when moved, but smiles on occasion
- Known to love animals and jazz standards

Brenda

- **Identified** by care staff
  - General indicators: deteriorating performance status; significant irreversible weight loss
  - Disease specific (frailty): Eating and drinking less, unable to dress self, swallowing difficulties
- **Palliative Approach** instituted:
  - **Palliative Care Conference with family**
    - **In GP office or at Care Home**
  - MOST reassessed (M1)
  - Pain and other symptoms routinely assessed and managed,-regular Tylenol instituted
  - ACP tracking record instituted to track multidisciplinary staff conversations about shifting goals of care-reviewed weekly by CNS
  - Medication Rationalization
    - Matching medications to Goals
    - Deprescription of medications (ASA, Statin, Vitamins, anti-hypertensives, oral hypoglycemics)
  - Staff informed of shifting care goals through Palliative Specific Care Plan and in staff huddles
  - Animal visits arranged

Brenda-Anticipate, Communicate and Prepare

- Brenda's favorite food is Kentucky Fried Chicken coleslaw which she was given four days ago by a family member and she choked, with possible aspiration.
- Declining level of consciousness, trouble swallowing medications, increased RR.
- Coffee ground emesis X 1
- **Anticipate**: what symptoms are likely?
- **Communicate:** what do you tell the family?
- **Prepare**: how do you support the staff to give the best care possible?

John

59 yo man in Residential Care since his MVA 18 months earlier. Had a traumatic brain injury with some cognitive damage and has a L hemi - paresis. He has very basic verbal responses, but can generally say what he needs. He developed painless jaundice 2 months ago and was found to have a pancreatic mass and liver metastases present at the time of diagnosis. This was confirmed by biopsy at the time his biliary stent was put in.

His wife has had an MI and is unable to care for him, but visits regularly and is his Health Care Representative. He has 2 grown children who live in town. When the biopsy results came back his wife felt that he would not have chosen chemotherapy and so no referral was made to the Cancer Agency.

VICTORIA HOSPICE

John-Palliative Approach

- **Identified:**
  - General indicators:, declining intake, weight loss, representative asks for supportive care
  - Disease specific (cancer): declining performance status, too frail for treatment,
- **Palliative Approach instituted**
  - Family teleconference
  - MOST M1
  - Medication Rationalization
  - Goals: Pain management primary goal, peaceful death at facility, sedation preferable to pain
  - Staff informed at monthly supportive care rounds
  - MAR is marked with a "Palliative Approach" sticker

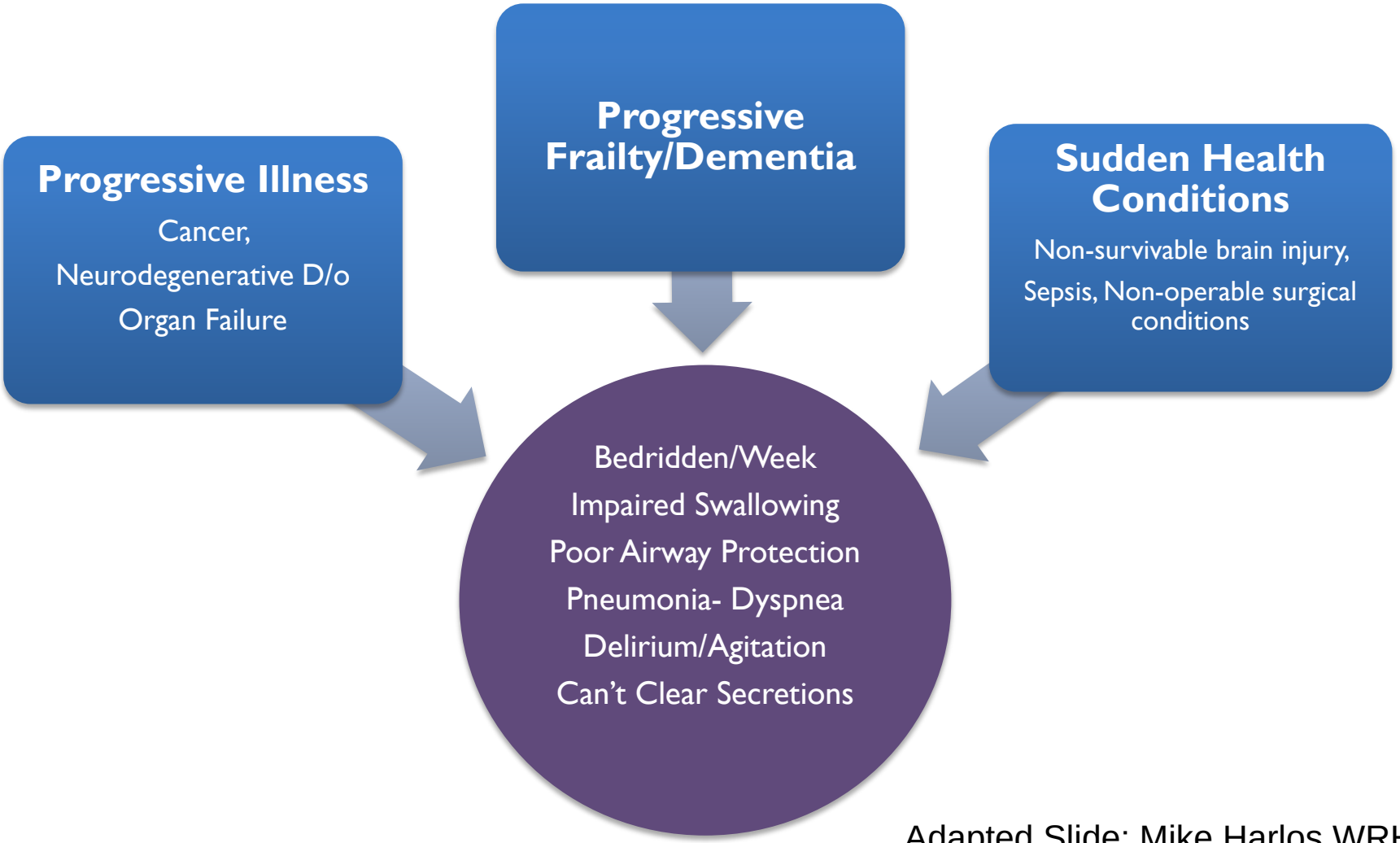
John

- John is now a PPS of 30% and declining (CFS 9)
- Pain is stable (for now) on Hydromorphone 8 mg po bid with only occasional need for breakthroughs.

- **Anticipate**: What symptoms might lie ahead?
- **Communicate:** How will you communicate the family?
- **Prepare:** How will you assist the staff to best care for this patient?

- How might the care look different for John and Brenda? How are they the same?

Dying: Final Common Pathway



Adapted Slide: Mike Harlos WRHA

Role of the Health Care Team

- Anticipate
  - What symptoms might worsen or newly arise?
  - Impaired swallowing…..requiring medication route changes
  - Are there pre-existing medical conditions needing attention in final days (seizure d/o, Parkinson's)?
- Communicate with Family
  - What can we expect?
  - Reassess comfort with plan
  - How do we know they are comfortable?
  - Role of food and fluids
- Prepare Plan
  - Personalize EOL order set

Care Plan: includes the **family**

- Encourage family involvement in care to their desired level
  - mouth care/skin care (virtualhospice.ca)
  - positioning
  - familiar objects/music/pets

- Ask the family for direction:
  - emotional,
  - spiritual,
  - cultural needs

- Anticipate declining function
  - equipment/skin care, transfers, turns
  - family support during and after the dying process
  - prepare for changes, provide information interpret the process

Be prepared to manage uncomplicated End of Life Care

Anticipate difficult symptoms and have a plan.

Residential Services - EOL Order Set

Key: **Req** – Requisition **MAR** – Medication Administration Record **K** – Kardex **Dis** – Discontinued **P** – Drug Profile

Anticipatory prescribing will ensure that in the last days and hours of life there is no delay in responding to a symptom if it occurs. The following criteria should guide the appropriateness of initiating the End of Life Clinical Order Set:

- Resident has declined and has been assessed at a PPS of 20% or less (see page 2) and
- Appears to be in the last hours/days of life

- Discontinue oral medications, except: _____ (does not apply to sublingual medications)
- Discontinue all blood work, vital signs and weight monitoring
- No CPR
- Foley Catheter PRN for comfort
- To avoid repeated subcut injections, insert subcut device with the initial dose of each subcut medication

☐ RN/RPN/LPN to Pronounce

Distressing Restlessness/Agitation

If increasingly confused, agitated or hallucinating

- haloperidol 1 mg subcut STAT continue with 1 mg subcut BID and 1 mg subcut q4h PRN
- If resident is not settling in 30 minutes, give additional haloperidol 1 mg subcut STAT continue with 1 mg subcut BID and 1 mg subcut q4h PRN

If still confused or agitated add

- LORazepam 1 to 2 mg SL/subcut TID and q2h PRN

If still agitated or distressed

- methotrimeprazine 12.5 mg subcut STAT and discontinue haloperidol. Continue with methotrimeprazine 12.5 mg subcut BID and q2h PRN

If lucid but anxious or frightened

- Explore fears
- LORazepam 0.5 mg SL/subcut q2h PRN

If still lucid but has continuous or worsening anxiety

- Increase LORazepam 1 to 2 mg SL/subcut q4h and q1h PRN

If still agitated or distressed

- methotrimeprazine 12.5 mg subcut STAT continue with 12.5 mg subcut BID and q2h PRN

Dry Eye Therapy: • hypromellose 0.5% eye drops, 1 drop to each eye q2h PRN

Dyspnoea and Pain Management

- **If fentaNYL Patch in-situ continue and give** _____subcut q1h PRN
- **If currently taking an oral opioid - calculate the equivalent oral q4h dose - give half of this dose subcut q4h and one quarter this dose subcut q1h PRN**

- If not currently taking an oral opioid ie opioid naive

☐ HYDROmorphone 0.5 to 1 mg subcut q1h PRN. If more than 3 doses required in 24 hours, contact GP for regularly scheduled order

If Nausea and Vomiting occur

☐ haloperidol 0.5 mg subcut BID and q4h PRN. If more than 3 PRN doses in 24 hours contact GP for a dose increase

If Upper Airway Secretion Management required

☐ glycopyrrolate 0.4 mg subcut initially, then 0.2 mg subcut q6h

Pain Management

Leah

John

- John is able to swallow LA hydromorphone with applesauce.
- He is beginning to moan and staff worry regarding increased pain
- The RN reports: O 3 days ago; P epigastruim; Q dull ache; R to mid back; S "terrible" T hydromorphone btd now only lasts about 2.5 hours; U-cancer; V "make it go away"

Brenda

- Brenda is no longer swallowing her medication, including tylenol 1 gm qid
- RN reports to physician: Abbey Pain Scale 13 and PAINAD scale 8/10
- Afebrile; HR 100; RR20; BP 100/70 Her abdomen is tender in RLQ, but soft, BS are present

Pain Assessment

Assess: OPQRSTUV

Onset	When did it start?
Provoking/palliating factors	What makes it better ? What makes it worse?
Quality	What does it feel like?
Region/Radiation	Where is it? Spread?
Severity	Scale 0-10 (worst possible)
Treatment	Current meds? Effective?
Understanding/ Impact	What do you think the cause is? What is the impact?
Values /Goals of Care	What is important to Know? Comfort Goal?

Pain Assessment in the Cognitively Impaired

Pain recall and integration of pain experience over time may be less reliable BUT often able to report pain reliably *at the moment* or when prompted

- Try simple yes/no questions and non-verbal communication, try words like "ache" and "hurt"
- Need input from the entire care team and family
- Observations are crucial: behavioral indicators are more evident with activity
  - vocalization, breathing patterns, facial patterns, and consolability.

Pain Assessment in Advanced Dementia (Pain AD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Low-level speech with a negative or disapproving 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 reassured by voice or touch.	Unable to console, distract or reassure.	
			Total**	

Common Signs of Pain in Late-Stage Dementia

- Increased agitation, fidgeting & repetitive movements
- Tense muscles, body bracing
- Increased calling out, repetitive verbalizations
- Decreased functional ability, withdrawal
- Change in sleep pattern
- Increase in pulse, blood pressure & sweating

Parke 1992; Parmalee et al 1993; Hurley et al 1992

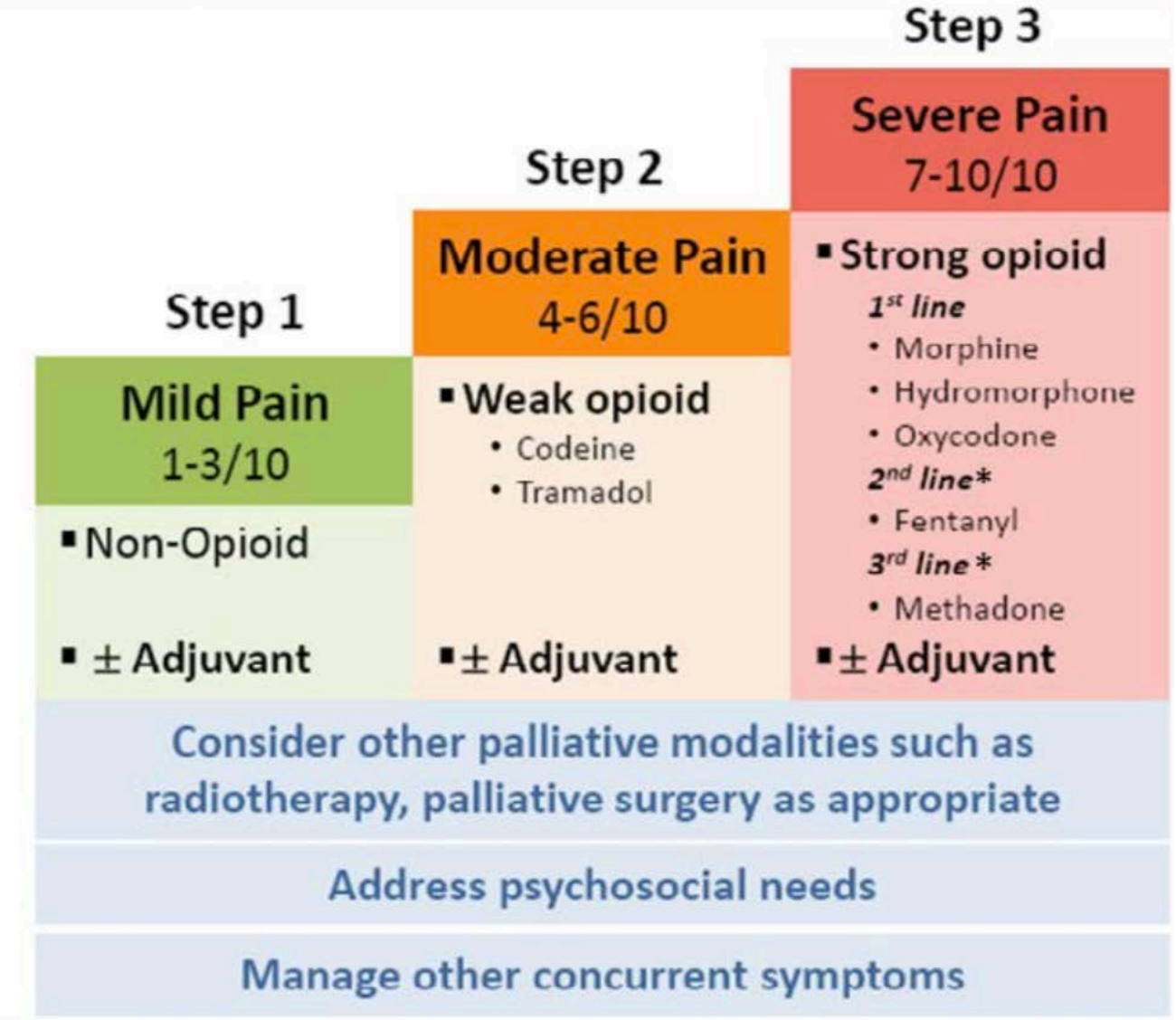
Assess for Reversible Causes

- Urinary Retention
- Positioning
- Fecal Impaction

WHO Principles of Cancer Pain Management

- By the Ladder
- By the Clock
- With prn (10% of TTD)
- By Mouth
- For the Individual
- Attention to detail

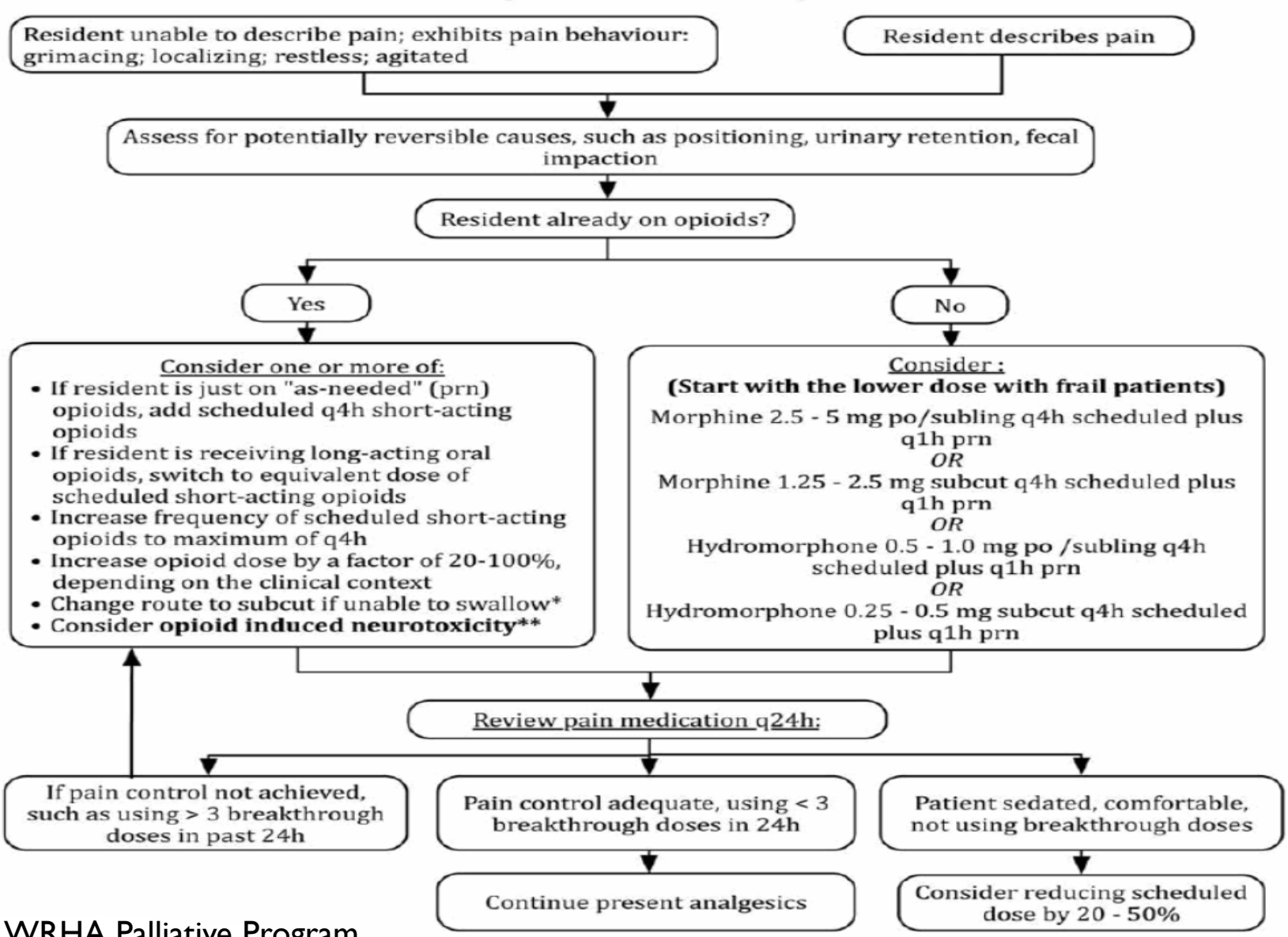
WHO Pain Ladder



WHO Principles of Cancer Pain Management

- By the Ladder
- By the Clock
- With prn (10% of TTD, appropriate interval)
- By Mouth
- For the Individual
- Attention to detail

Pain Management at EOL



From WRHA Palliative Program

Opioid Adverse Effects

Common

- Constipation*
- Sedation
- Nausea
- Dry Mouth

Less Common

- Pruritis
- Urinary Retention
- Myoclonus
- Delirium

Rare

- Respiratory Depression
- Allergy

Tolerance to adverse effects usually develops after 3 to 5 days

EOL Order Set
Dyspnea and Pain Management

Dyspnoea and Pain Management

- **If fentaNYL Patch in-situ continue and give _____** subcut q1h PRN
- **If currently taking an oral opioid - calculate the equivalent oral q4h dose - give half of this dose subcut q4h and one quarter this dose subcut q1h PRN**

_____

- If not currently taking an oral opioid ie opioid naive

☐ HYDROmorphone 0.5 to 1 mg subcut q1h PRN. If more than 3 doses required in 24 hours, contact GP for regularly scheduled order

Back to John & Brenda

- John
  - Hydromorphone 2mg subcut q4h and 1mg q1h prn
  - Consider subcut dex as adjuvant
- Brenda
  - Rec'd 3 prn doses of hydromorphone subcut first day on order set
  - Regular order for Hydromorphone 0.5-1mg q4h and q1h prn

Undertreatment Prevalent at EOL

Quote

"Given the risk of undertreatment, clinicians should assess pain frequently and maintain a low threshold for the conclusion that pain exists. Noting the physical condition of the patient, the clinician should ask "would I be in pain?". If the answer is "yes," it is best to assume that pain exists and that intervention is appropriate."

– Kathleen Broglio, & Russell K Portenoy, Pain assessment and management in the last weeks of life, UpToDate

Beyond the Basics – Pain Crisis

- Causes
  - Ruptured viscus
  - Pathological fracture
  - Internal hemorrhage
- "Opioid Stacking"
  - 2x regular po prn q20-30 min until relief
- Adjuvants for accompanying agitation/anxiety
  - Lorazepam/midazolam
  - Methotripmirazine (nozinan)

Beyond the Basics

- Methadone
  - Excellent choice in renal failure
  - Long-acting liquid formulation
  - Beneficial for neuropathic pain

- www.methadone4pain.ca

Breathlessness

Christine

VICTORIA HOSPICE

John is breathless

- RN calls physician
  - John has acute onset breathlessness, for about 12 hours
  - RR>30, HR 100; he seems restless, nares are flaring and there is occasional grunting. He look frightened, with a furrowed brow.
  - O2 saturations are 86% on room air
  - He keeps pulling of the nebulizer

Respiratory Distress Observation Scale © Margaret L Campbell PhD RN, 19/2/2009

Variable	0 points	1 point	2 points	Total
Heart rate per minute	< 90	90 – 109	>110	
Respiratory rate / minute	<18	19 – 30	> 30	
Restlessness	None	Occassional	Frequent	
Paradoxical abdominal movt	None		Present	
Grunting	None		Present	
Nasal flaring	None		Presenet	
Look of fear	None		Eyes wide open, facial muscles tense, brow furrowed, mouth open, teeth together	
Total				

EOL Order Set
Dyspnea and Pain Management

Dyspnoea and Pain Management

- **If fentaNYL Patch in-situ continue and give _____** subcut q1h PRN
- **If currently taking an oral opioid - calculate the equivalent oral q4h dose - give half of this dose subcut q4h and one quarter this dose subcut q1h PRN**

_____

- If not currently taking an oral opioid ie opioid naive

☐ HYDROmorphone 0.5 to 1 mg subcut q1h PRN. If more than 3 doses required in 24 hours, contact GP for regularly scheduled order

Symptom Management Approach

- Reverse the Reversible
- Medication Management
- Non-pharmacologic Management
- Educate and Support

Symptom Management Approach

Baseline Breathlessness (or with minimal activity)

- Regular opioids, round the clock
- Breakthrough q1 h as needed
- Call MD if > 3 BTD required

Incident breathlessness (transfers or turning)

- Consider ultra short acting opioids (fentanyl or sufentanyl)
- Subling, buccal or intranasal

Breathlessness with Anxiety

- Add in anxiolytic:
- Ativan, Midazolam (intermittent or continuous)
- Methotrimiprazine (Nozinan)

Symptom Management Approach

Non pharmacologic-UNDERVALUED

- Loose clothing/sheets
- Fan
- Music/quiet room/ open window/space
- Massage, peaceful, calm presence

Oxygen-OVERUSED

- Rarely needed
- Sometimes helpful if patient hypoxic, or if "path of least regret" for family

Excellent mouth care-UNDERVALUED

- Artificial saliva (I like Moistir)
- Vaseline for lips
- Mouth swabs

Symptom Management Approach

Prepare for acute crisis

- Orders prepared in advance
- Hydromorphone 2X usual dose subcut q30 minutes until settled
- Ativan 2 mg subcut q30 min until settled
- Call MD
- Sometimes sedation required, continuous midazolam

Educate Family

- Cause of breathlessness
- How we/they monitor for distress and how we respond
- That symptoms can be managed in facility

Symptom Management Approach

CHF

- Consider subcut furosemide for pulmonary edema

COPD

- Consider subcut dexamethasone
- Generally avoid nebulizers (but individualized)

Pneumonia

- Antibiotics are NOT required for comfort
- Control fever, breathlessness and cough (opioids also excellent for this)

Nausea and Vomiting

Christine

VICTORIA HOSPICE

Nausea and vomiting

- Brenda continues to vomit; sometimes coffee grounds, sometimes bile, sometimes flecked with bright red blood.
- Haldol .5 mg subcut instituted, but requiring three breakthroughs daily

Nausea and Vomiting-beyond Haldol

- For delayed gastric emptying/dysmotility/opioid induced:
  - Metoclopromide 10 mg subcut qid (watch for agitation as reflection of akathasia; watch for parkinsonian side effects)
- For refractory
  - Methotrimiprazine 2.5-5 mg qid, but can be titrated up to 10 mg used for refractory nausea
  - Olanzapine wafer 2.5-5 mg
  - Ondansetron can usually be stopped
- Avoid Gravol
  - Unless worked well before-consider supp or subcut
- Off label Pearl
  - Ranitidine 50 mg subcut

Agitation

Leah

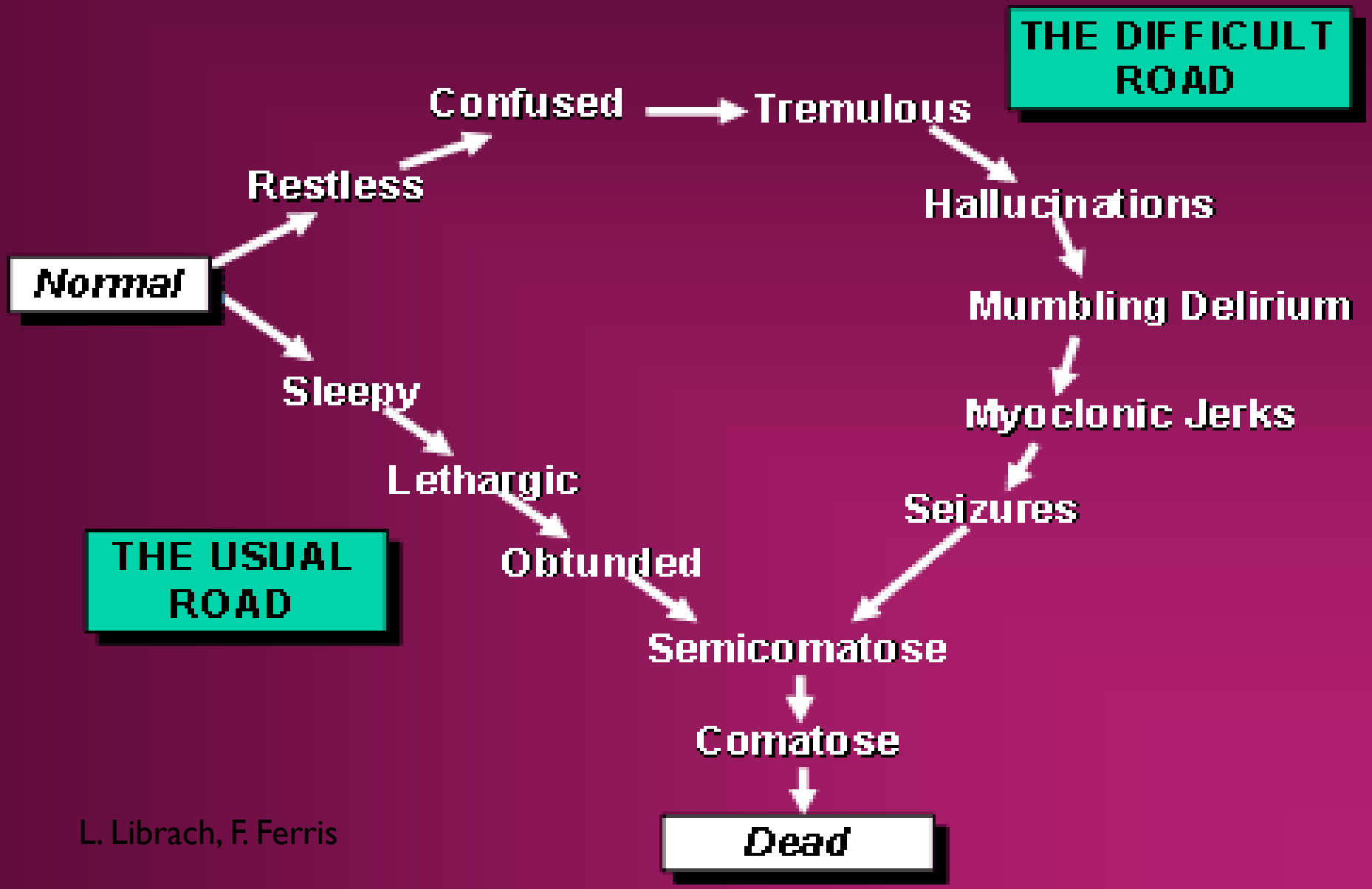
VICTORIA HOSPICE

Brenda

Despite settling with prn dilaudid initially, Brenda becomes restless and agitated. She is pulling at her foley catheter and picking at the bedsheets. She is calling out and resistant to care?

How will we assess and management this situation?

Two roads to death



L. Librach, F. Ferris

Common Causes of Delirium in EOL Care

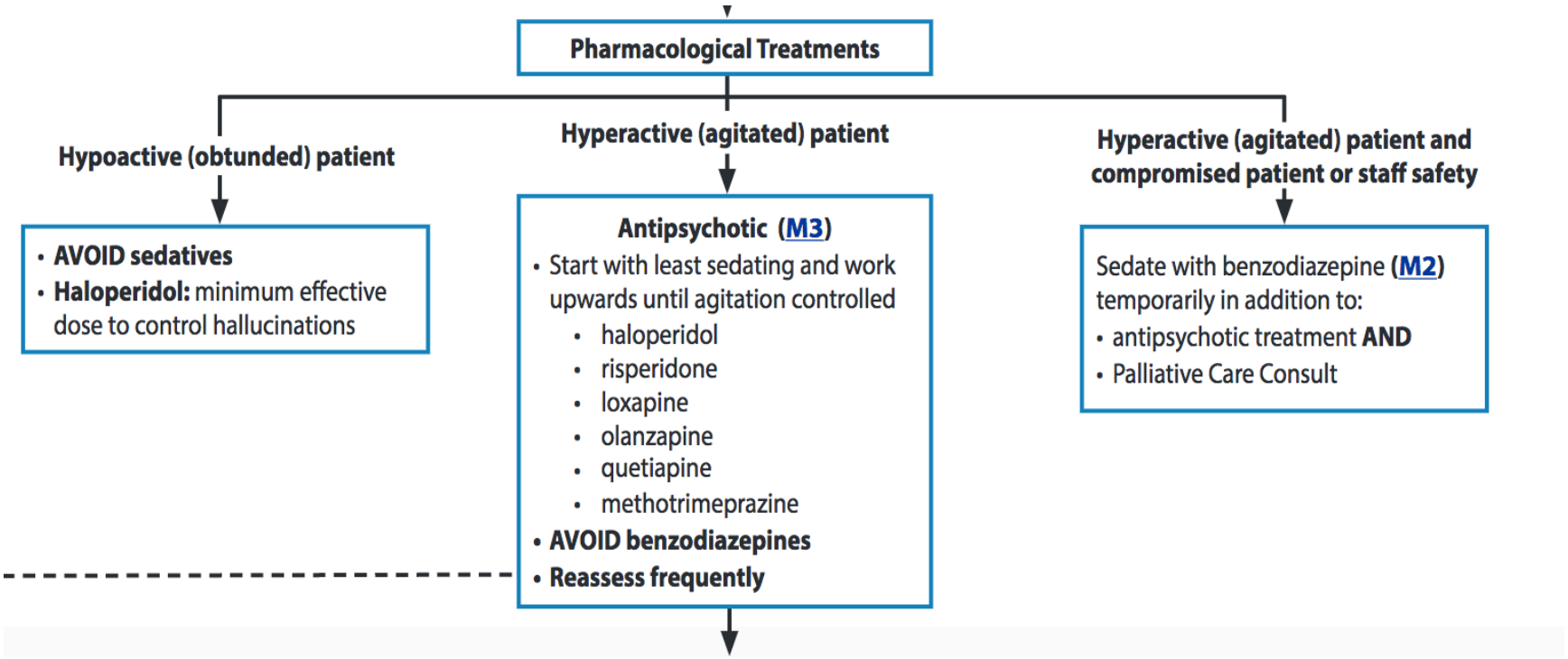
Drugs	• Anticholingerics (TCAs), antihistamines (gravol), benzos, opioids, Withdrawal
Infections	• UTI, pneumonia
Metabolic	• Renal or liver failure, hyponatremia, hypercalcemia
Hypoxemia	
Brain Disease	• Brain mets • Leptomeningeal spread
Dehydration	

Causes Contributing to Restlessness

Physical	Drug Effect	Pyschosocial
• Pain • Constipation • Bladder Retention • Hypoxia • Organ Failure	• Extrapyradmidal effects • Akathisia • Opioid-induced neurotoxicity	• Personal suffering • Anxiety • Existential anguish

BCGuidelines.ca

Palliative Care For Patient with Incurable Cancer Or Advanced Disease (2017)



2016 Agar Study

JAMA Internal Medicine | Original Investigation

Efficacy of Oral Risperidone, Haloperidol, or Placebo for Symptoms of Delirium Among Patients in Palliative Care
A Randomized Clinical Trial

Meera R. Agar, PhD; Peter G. Lawlor, MB; Stephen Quinn, PhD; Brian Draper, MD; Gideon A. Caplan, MBBS; Debra Rowett, BPharm; Christine Sanderson, MPH; Janet Hardy, MD; Brian Le, MBBS; Simon Eckermann, PhD; Nicola McCaffrey, PhD; Linda Devilee, MBus; Belinda Fazekas, BN; Mark Hill, PhD; David C Currow, PhD

IMPORTANCE Antipsychotics are widely used for distressing symptoms of delirium, but efficacy has not been established in placebo-controlled trials in palliative care.

OBJECTIVE To determine efficacy of risperidone or haloperidol relative to placebo in relieving target symptoms of delirium associated with distress among patients receiving palliative care.

DESIGN, SETTING, AND PARTICIPANTS A double-blind, parallel-arm, dose-titrated randomized clinical trial was conducted at 11 Australian inpatient hospice or hospital palliative care services between August 13, 2008, and April 2, 2014, among participants with life-limiting illness, delirium, and a delirium symptoms score (sum of Nursing Delirium Screening Scale behavioral, communication, and perceptual items) of 1 or more.

Invited Commentary

Supplemental content

Published Online Dec 5, 2016

If Delirium Worsens…

- Review potential causes again
- Escalate doses of methotrimeprazine and benzodiazpine
- Consider adding Phenobarb (120mg SC loading dose, then 60mg q4h prn)

EOL Order Set
Delirium, Restlessness/Agitation

Distressing Restlessness/Agitation

If increasingly confused, agitated or hallucinating

- haloperidol 1 mg subcut STAT continue with 1 mg subcut BID and 1 mg subcut q4h PRN
- If resident is not settling in 30 minutes, give additional haloperidol 1 mg subcut STAT continue with 1 mg subcut BID and 1 mg subcut q4h PRN

If still confused or agitated add

- LORazepam 1 to 2 mg SL/subcut TID and q2h PRN

If still agitated or distressed

- methotrimeprazine 12.5 mg subcut STAT and discontinue haloperidol. Continue with methotrimeprazine 12.5 mg subcut BID and q2h PRN

If lucid but anxious or frightened

- Explore fears
- LORazepam 0.5 mg SL/subcut q2h PRN

If still lucid but has continuous or worsening anxiety

- Increase LORazepam 1 to 2 mg SL/subcut q4h and q1h PRN

If still agitated or distressed

- methotrimeprazine 12.5 mg subcut STAT continue with 12.5 mg subcut BID and q2h PRN

Back to Brenda

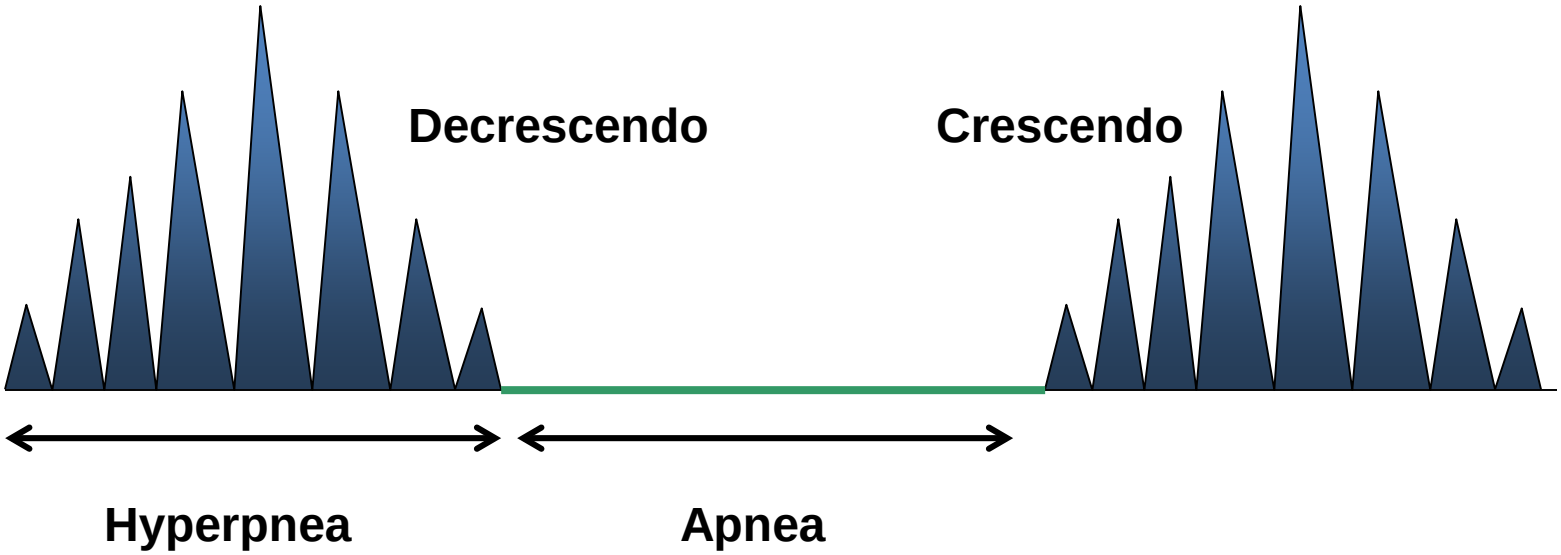
- Nurses started EOL order set and were using
  - Haldol 1mg BID subcut plus prn
  - Ativan 1mg TID subcut plus prns
- Physician reviewed after 24 hours and ordered:
  - Methotrimeprazine 12.5-25 mg q8h and continued ativan order

Respiratory Changes in the Final Hours

Christine

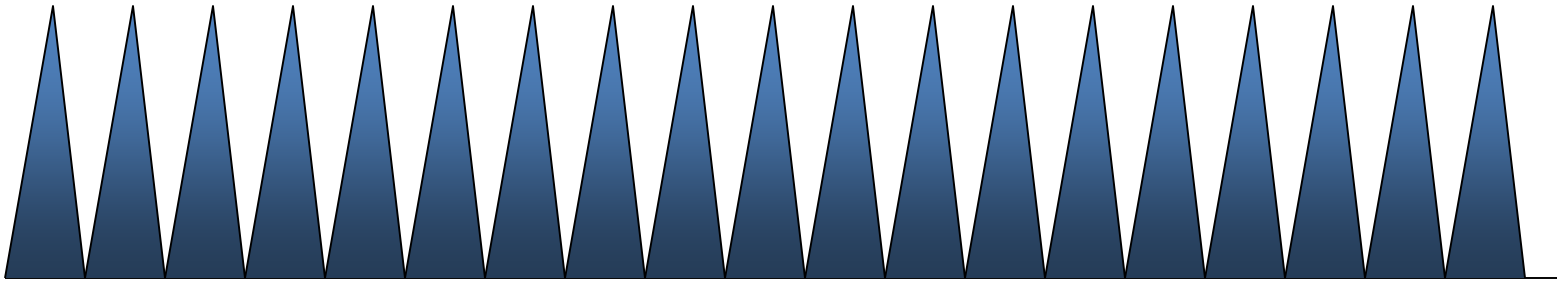
VICTORIA HOSPICE

Cheyne-Stokes Respiration (CSR)



CSR controlled at Diencephalon level

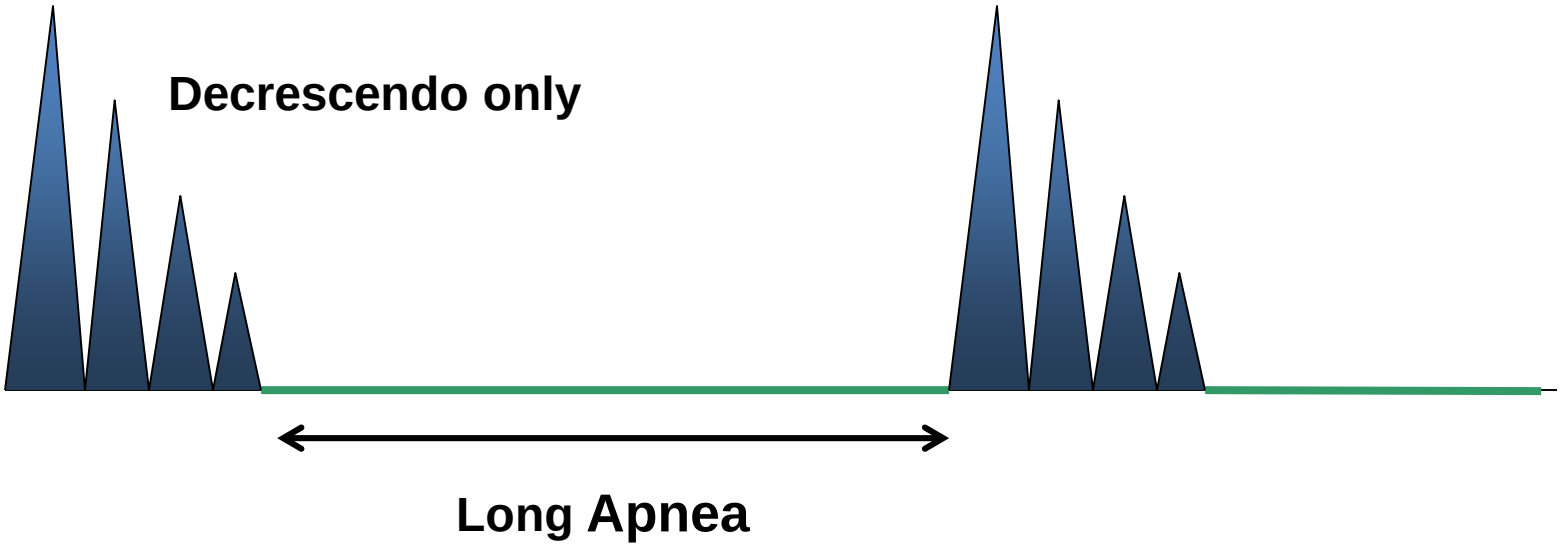
Central Neurogenic Hyperventilation (CNH)



Constant Tachypnea & Hyperpnea

CNH controlled in low Midbrain or Pons

Cluster Breathing



Cluster breathing controlled in Medulla Oblongata

Respiratory Congestion

- Research in the non-residential care setting
  - 44-56% of patients
  - In last 24-48 hours of life
  - Risk factors: prolonged dying, lung involvement (pneumonia, lung metastatic disease) brain injury, dysphagia
  - Incidence in frail pts, dementia, CHF, COPD not really known
- Two types
  - Salivary (Type 1)
  - Bronchial (type 2)
- No excellent research to guide us in treatment

Treatment Respiratory Congestion

- Why do we treat?
  - For the patient?
  - For the professional staff?
  - For the family?
- RCT of sL atropine vs placebo showed no real benefit –though we usually use subcut
- Natural history unknown; distress caused to patient unknown distress caused to family is really unknown

Respiratory Congestion Treatment

- My suggestion
  - Prepare family for the possibility
  - Explain what is happening
  - Primary Rx is NOT anticholinergic~!
    - Educate family, positioning, use suction, only if profuse and easily accessed secretions
    - Distress of the family is often deeper than just the sound of secretions, but can be channeled to this symptom
    - If you use anti-cholinergic, use early and regularly-works only on preventing secretions.
    - I prefer glycopyrrolate as it doesn't cross BBB

Crises

Leah

VICTORIA HOSPICE

End of Life Urgent Care in LTC

- Severe Breathlessness
- Severe Pain
- Severe Agitation
- Seizures
- Hemorrhage
- Family Distress
- Staff Distress

Seizure Management at End of Life

- Patients with hx of seizure should continue antiseizure drug as long as able to take oral meds
- Decision to be made when patient no longer able to swallow
  - D/C versus Phenobarb subcut versus benzo sl/subcut
- Benzodiazepines should always be available as abortive medication.

Seizure Management at EOL

Lorazepam usually drug of choice

- Simple Partial Seizure:
  - Lorazepam 1 to 2 mg SL or SQ STAT then 1 to 2 mgq4h to q6h

- Generalized Tonic/Clonic
  - Lorazepam 4-8 mg IV/SQ/SL STAT then 2-4mg prn
  - Phenobarb 80-120 mg SQ q15min until settled then start 80-240mg SQ q12h with 120mg 1h prn
  - Midzolam 5mg SQ STAT and then infusion 1-5mg/hr to control seizures

www.fraserhealth.ca/health-professionals/professional-resources/hospice-palliative-care

Exsanguination at EOL

- Crisis Orders*
  - Midazolam 5-10mg subcut/IM prn
  - Double dose of usual opioid prn
- Preparation: dark towels, etc.
- "This is a traumatic experience for health care providers. Time should be taken to support one another and provide reassurance for actions and feelings."

www.fraserhealth.ca/health-professionals/professional-resources/hospice-palliative-care

Key Points

- Benefit of planning ahead (case conference, family meeting)
- Anticipate
- Communicate
- Prepare and customize EOL orders

Questions/Discussion