

# C-PCLC SYMPTOM ASSESSMENT & MANAGEMENT: IMPROVING QUALITY OF LIFE

Brenda Matti-Orozco, MD, FACP Project Lead, AHS Community PCLC October 25, 2021



## 10 Common Chronic Conditions for Adults 65+

80%
have have at least 1 chronic condition



68% have 2 or more chronic conditions



Hypertension (High Blood Pressure) 58%



High Cholesterol
47%



Arthritis 31%



Ischemic Heart Disease (or Coronary Heart Disease)



Diabetes 27%

## SYMPTOM BURDEN OF CHRONIC ILLNESES



Chronic Kidney Disease 18%



Heart Failure 14%



Depression 14%



Alzheimer's Disease and Dementia

11%



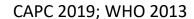
Chronic Obstructive Pulmonary Disease

11%

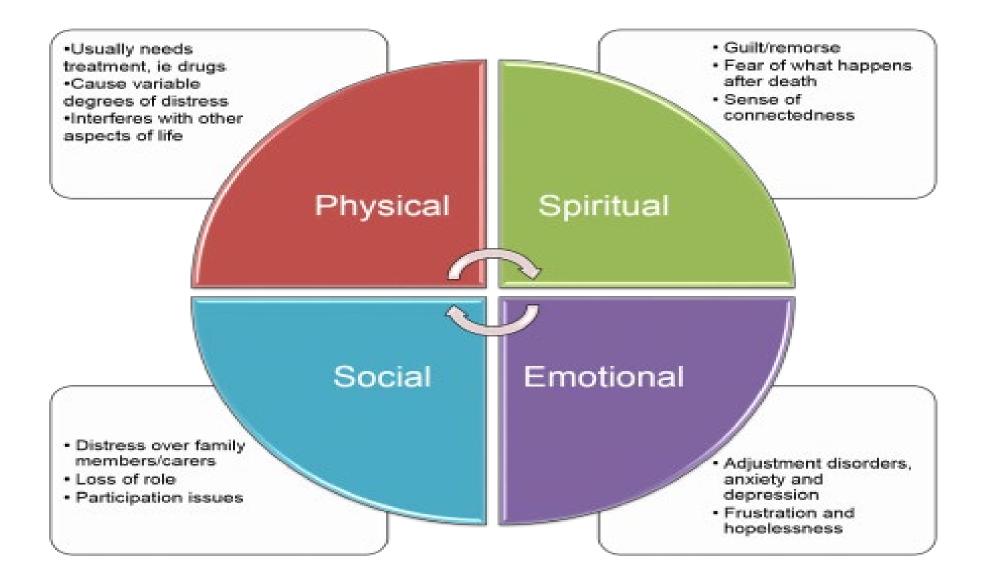


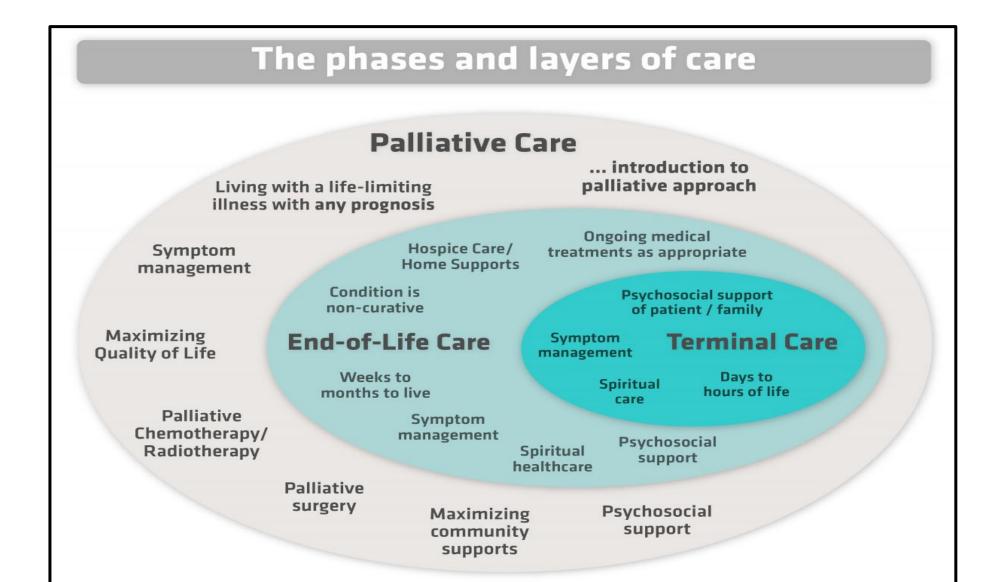
## PALLIATIVE CARE: PRINCIPLES & PHILOSOPHY

- Goals of palliative medicine
  - Prevent and relieve suffering
  - Promote physical and psychosocial health
  - Support for the best quality of life
- Whole-person care for the seriously ill
- A philosophy of care and an organized, structured system of care delivery
- Interdisciplinary team

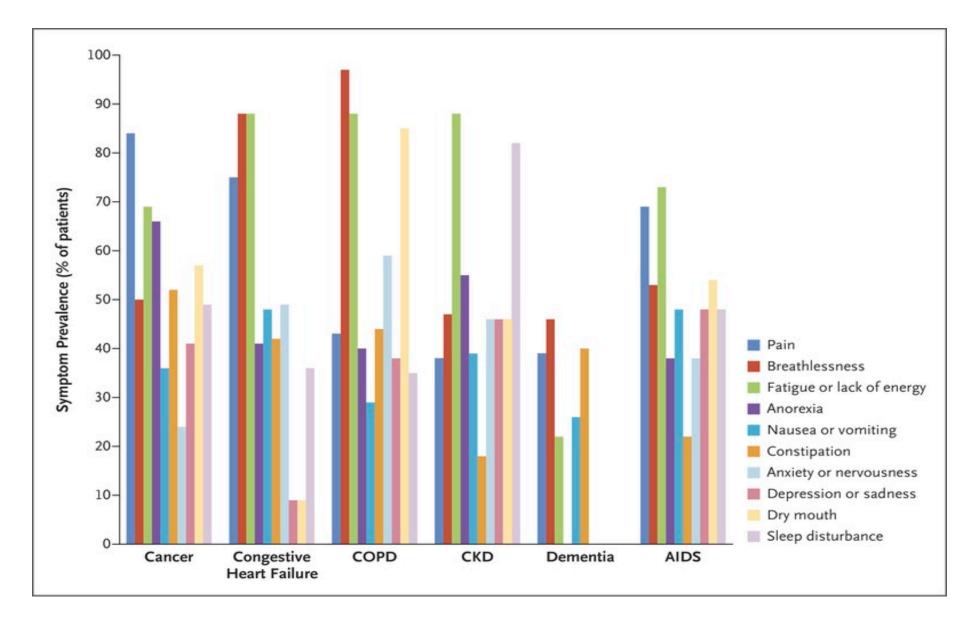






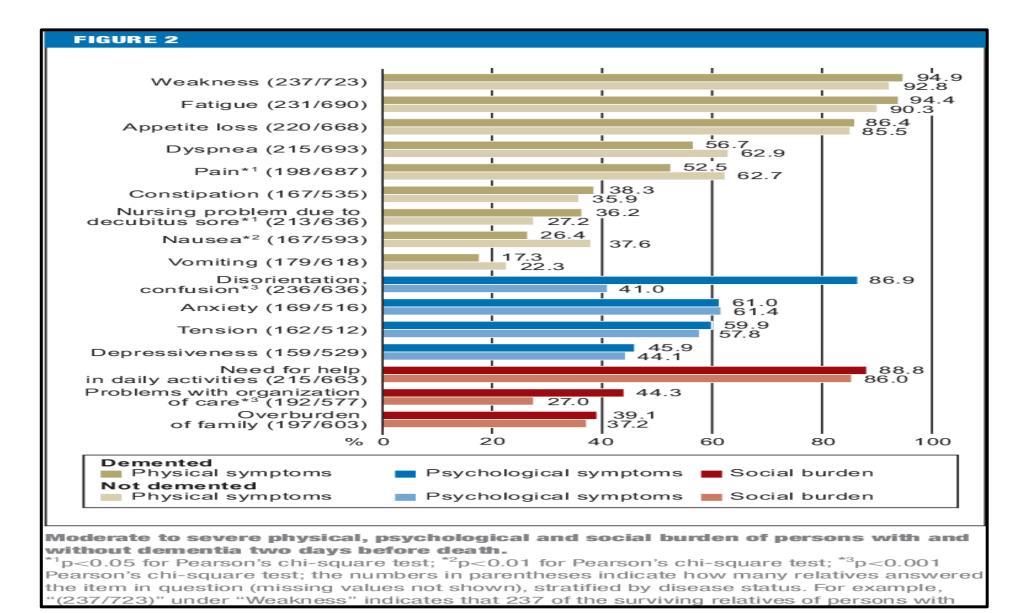








N Engl J Med 2015; 373:747-755





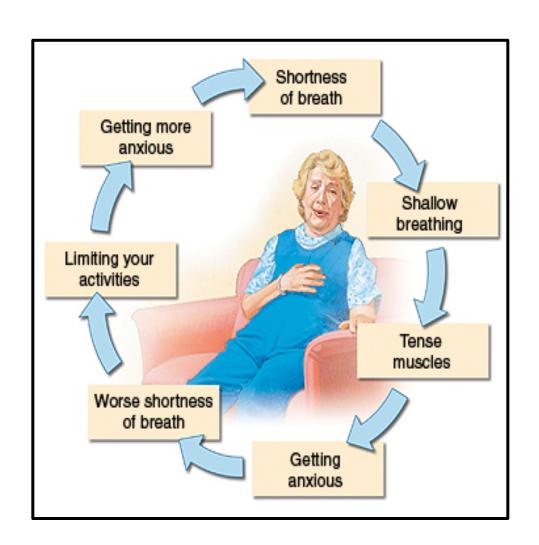
Dtsch Arztebl Int 2013; 110(12): 195-202. DOI: 10.3238/arztebl.2013.0195



**DYSPNEA: ASSESSMENT & MANAGEMENT** 

## **DYSPNEA: MULTIDIMENSIONAL**





Determine and assess cause/s of dyspnea

- Looking for reversible problems is always warranted
- Understanding where patients are at in the dying trajectory, and their identified goals of care, is essential to guide the extent of workup to discover reversible causes

If the patient is clearly dying and the goals of care are comfort, then:

 pulse oximetry, arterial blood gases, EKG, or imaging are not indicated

#### Respiratory Distress Observation Scale (RDOS)

#### Purpose

This tool is to be used for assessing the intensity and distress of patients unable to report dyspnea during monitoring for Palliative Sedation Therapy<sup>1,2,3</sup>.

Variable	0 Points	1 Point	2 Points	Sub-Total
Heart rate per min (beats/min = bpm)	less than 90 bpm	90-109 bpm	greater than or equal to 110 bpm	
Respiratory rate per minute (auscultated) (breaths / min)	less than 19 breaths	19-30 breaths	greater than 30 breaths	
Restlessness: non-purposeful movements	No	Yes - Occasional, slight movements	Yes - Frequent movements	
Paradoxical breathing pattern: abdomen moves in on inspiration	No		Yes	
Accessory muscle use: rise in clavicle during inspiration	No	Yes - Slight rise	Yes - Pronounced rise	
Grunting at end-expiration: guttural sounds	No		Yes	
Nasal flaring: involuntary movement of nares	No		Yes	
Look of fear:   Eyes wide open  Facial muscles tense  Brow furrowed  Mouth open  Teeth together	No		Yes	

#### Total

#### Instructions for Use

- · Count respiratory and heart rates for one full minute;
- · Grunting may be audible with or without auscultation;
- An RDOS score of less than 3 indicates respiratory comfort<sup>2</sup>;
- An RDOS score greater than or equal to 3 signifies respiratory distress and need for palliation<sup>2,3</sup>;
- Higher RDOS scores signify a worsening condition<sup>2,3</sup>.

#### References

- Campbell, M. L. (2008b). Psychometric testing of a respiratory distress observation scale. J Palliative Care Medicine, 11(1), 48.
- 2. Campbell, ML and Templin TN. (2015). Intensity cut-points for the Respiratory Distress Observation Scale. Palliat Med. 29(5): 436-442
- Zhang et al. (2019). Validity, Reliability, and Diagnostic Accuracy of the Respiratory Distress Observation Scale for Assessment of Dyspnea in Adult Palliative Care Patients. J Pain Symptom Manage;57(2):304-310.



#### Atlantic Health System

## **DYSPNEA: GENERAL TREATMENT MEASURES**

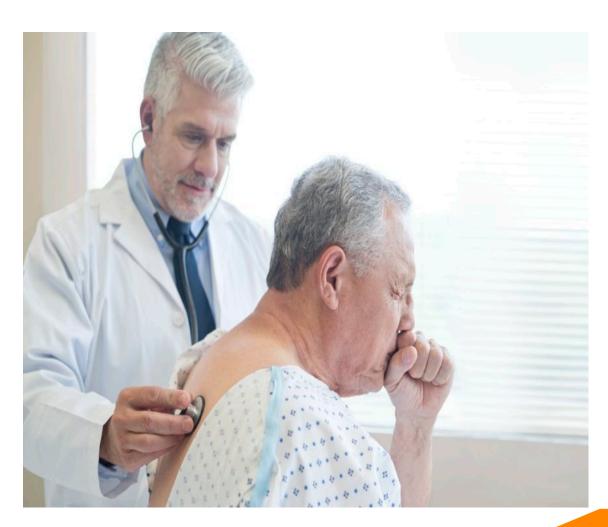
- Avoid strong odors, fumes, & smoke
- Identify & avoid any triggers
- Positioning (sitting up)
- Increasing air movement via a fan or open window
- Use of bedside relaxation techniques
- In the imminently dying patient, discontinuing fluids or feeding is appropriate



Fast Facts, April 2015



## DYSPNEA: NON-PHARMACOLOGIC MANAGEMENT



Multi-disciplinary regimens are most effective for chronic dyspnea

- Disease management
- Anxiety reduction
- Emergency contingent planning
- Self-mastery of breathing mechanics
- Exercise training



## DYSPNEA: NON-PHARMACOLOGIC MANAGEMENT

- Pulmonary rehabilitation
- Patient education including the psych-socialspiritual impact of the dyspnea-anxiety cycle
- Energy conservation techniques: reorganizing living spaces to reduce energy expenditure, prioritizing activities within their ability, and utilizing restorative aids such as walkers or canes
- Cognitive behavioral therapy: delivered by trained therapists
- Relaxation techniques: diaphragmatic and pursed lip breathing training, guided imagery, meditation, and music therapy
- Acupuncture



## DYSPNEA: PHARMACOLOGIC MANAGEMENT



- Opioids: Oral, subcutaneous, and intravenous opioids have long been regarded as the mainstay of pharmacologic treatment for chronic dyspnea
- Opioids appear to be safe and moderately effective at low doses (oral morphine equivalent dose < 30 mg/day) for advanced COPD, interstitial lung disease, and advanced cancer, even when prognosis is anticipated to be several months or years
- When utilizing opioids for chronic dyspnea relief, communication is vital to allay concerns amongst the patient, family, and clinicians

- Extra caution is warranted in patients with sleep apnea and when concomitantly prescribed with benzodiazepines as increased mortality has been noted
- Starting at low doses (e.g. short-acting morphine dose of 0.5-2 mg q4 hours as needed), monitoring for effect, and then titrating up at small intervals until the lowest effective dose is identified, allows for confidence that the treatment is safe and effective
- If tolerated, consider a low dose, once daily, long-acting opioid (e.g. morphine ER 15-30 mg/day)

Fast Facts, April 2019





- <u>Benzodiazepines</u>: A Cochrane systematic review found no convincing evidence for or against the use of benzodiazepines for chronic dyspnea
  - Associated with an increased mortality risk when co-prescribed with opioids
  - Many experts prescribe them for select patients for whom refractory anxiety is a significant component to their symptomatology
- Antidepressants: One case series suggested that mirtazapine could benefit select patients with chronic dyspnea

- For associated cough: Anti-tussives
- For associated secretions: Anti-cholinergics
  - Scopolamine
  - Glycopyrrolate
  - Atropine
- Other agents that may have specific disease modifying effects include diuretics, bronchodilators, and corticosteroids.

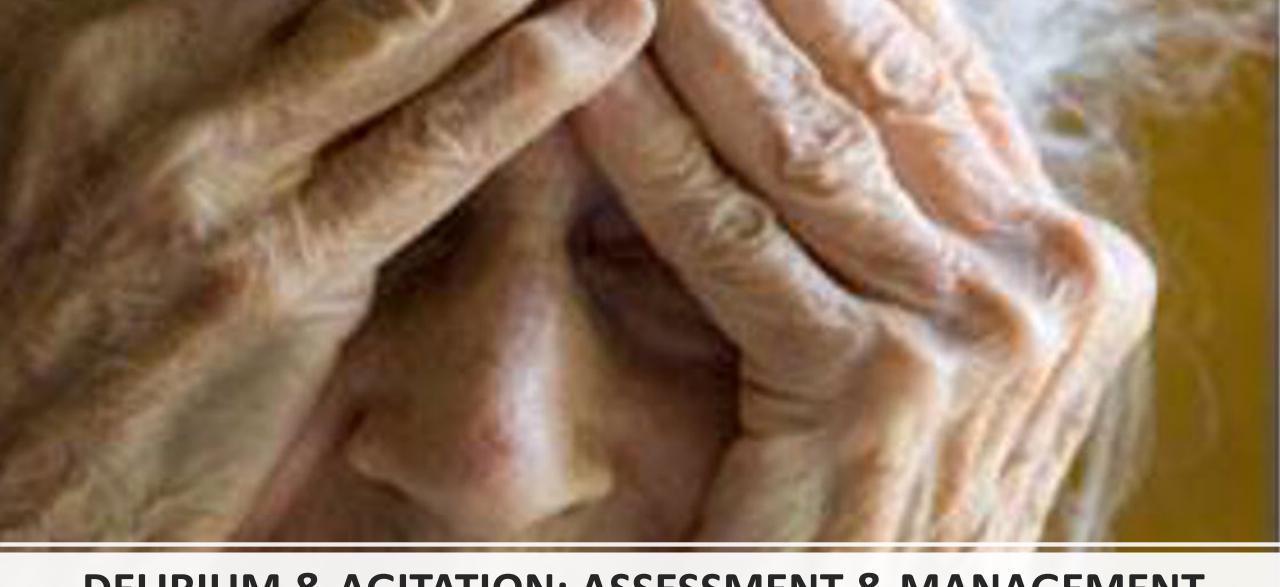
## **DYSPNEA: TREATMENT WITH OXYGEN**





Oxygen is often, but not universally, helpful

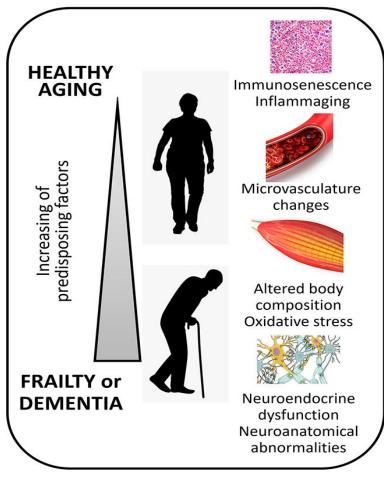
- Supplemental oxygen in those with hypoxemia have been associated with improved symptom control in appropriate patients with COPD and pulmonary fibrosis
- Therapeutic air by means of a fan to the face has shown benefit for cancer and COPD patients
- In dying patients:
  - When in doubt, a therapeutic trial, based on symptom relief, not pulse oximetry, is indicated
  - Patients generally prefer nasal cannula administration than a mask
  - There is little reason to go beyond 4-6 L/min of oxygen via nasal cannula in the actively dying patient



**DELIRIUM & AGITATION: ASSESSMENT & MANAGEMENT** 



## PREDISPOSING FACTORS



## PRECIPITATING FACTORS

#### **DELIRIUM**

Impaired neuro-vascular coupling: hypoxia, hypoglycemia

The lower the burden

of predisposing factors,

the higher the intensity

of the stressor required

to cause Delirium

**Acute stressors** 

The higher the burden

of predisposing factors,

the lower the intensity of the stressor required to cause Delirium Neuroinflammation

Microglia and Astrocytes activation

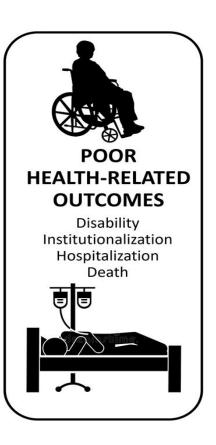
Physical and/or psychological stress

Neurostransmitter alterations

Medications







#### Table 1. Diagnostic Criteria for Delirium.

#### Source of Criteria

DSM-5<sup>\*</sup>

The presence of delirium requires all the criteria to be met:

Disturbance in attention and awareness

Disturbance develops acutely and tends to fluctuate in severity

At least one additional disturbance in cognition

Disturbances are not better explained by a preexisting dementia

Disturbances do not occur in the context of a severely reduced level of arousal or coma

Evidence of an underlying organic cause or causes

#### Confusion Assessment Method (CAM)†

The presence of delirium requires features 1 and 2 and either 3 or 4:

Acute change in mental status with a fluctuating course (feature 1)

Inattention (feature 2)

Disorganized thinking (feature 3)

Altered level of consciousness (feature 4)

\* The criteria are adapted from the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5).5

† The criteria are adapted from Inouye et al.6



Step and Key Issues	Proposed Evaluation and Treatment
Evaluate and treat common modifiable contributors to delirium*	
Drugs	Consider the etiologic role of newly initiated drugs, increased doses, interactions, over-the- counter drugs, and alcohol; consider especially the role of high-risk drugs: lower the dose, discontinue the drug, or substitute a less psychoactive medication
Electrolyte disturbances	Assess for and treat, especially dehydration, sodium imbalance, and thyroid abnormalities
Lack of drugs	Assess possible symptoms of withdrawal from long-term use of sedatives, including alcohol and sleeping pills; assess for and treat poorly controlled pain (lack of analgesia): use local measures and scheduled treatment regimens that minimize the use of opioids (avoid meperidine)
Infection	Evaluate and treat, especially urinary tract, respiratory tract, and soft-tissue infections
Reduced sensory input	Address issues involving vision (e.g., encourage use of eyeglasses) and hearing (e.g., encourage use of hearing aids or a portable amplifier)
Intracranial disorders	Consider such disorders (e.g., infection, hemorrhage, stroke, or tumor) if there are new focal neurologic findings or a suggestive history or if diagnostic evaluation for causes outside the central nervous system is unrevealing
Urinary and fecal disorders	Assess for and treat urinary retention (so-called cystocerebral syndrome) and fecal impaction
Myocardial and pulmonary disorders	Assess for and treat myocardial infarction, arrhythmia, heart failure, hypotension, severe anemi exacerbation of chronic obstructive pulmonary disease, hypoxia, and hypercarbia
Prevent or manage complications	
Urinary incontinence	Implement a scheduled toileting program
Immobility and falls	Avoid physical restraints; mobilize the patient with assistance; use physical therapy
Pressure ulcers	Mobilize the patient; reposition an immobilized patient frequently and monitor pressure points
Sleep disturbance	Implement a nonpharmacologic sleep-hygiene program, including a nighttime sleep protocol; avoid sedatives; minimize unnecessary awakenings (e.g., for measuring vital signs)
Feeding disorders	Monitor dietary intake; provide feeding assistance if needed, aspiration precautions, and supple mentation as necessary
Maintain patient comfort and safety	
Behavioral interventions	Teach hospital staff de-escalation techniques for patients who have hyperactive or agitated delirium encourage family visitation
Pharmacologic interventions	Use low doses of high-potency antipsychotic agents only if necessary
Restore function	
Hospital environment	Reduce clutter and noise; provide adequate lighting; encourage family to bring in familiar object from home
Cognitive reconditioning	Staff should reorient patient to time, place, and person at least three times daily
Ability to perform activities of daily living	Use physical and occupational therapy; as delirium clears, match performance to ability
Family education, support, and participation	Provide education about delirium, its causes and reversibility, the best ways to interact with affected patients, and the role of the family in restoring function
Discharge planning and education	Provide increased support for activities of daily living as needed at discharge; teach family members to follow mental status as a barometer of recovery

\* The first letters of these eight items form the mnemonic DELIRIUM.

N Engl J Med 2017; 377:1456-1466. DOI: 10.1056/NEJMcp1605501

## Table 4. Multicomponent Nonpharmacologic Approaches to Delirium Prevention

Approach	Description
Orientation and therapeutic activities	Provide lighting, signs, calendars, clocks Reorient the patient to time, place, person, your role Introduce cognitively stimulating activities (eg, reminiscing) Facilitate regular visits from family, friends
Fluid repletion	Encourage patients to drink; consider parenteral fluids if necessary Seek advice regarding fluid balance in patients with comorbidities (heart failure, renal disease)
Early mobilization	Encourage early postoperative mobilization, regular ambulation Keep walking aids (canes, walkers) nearby at all times Encourage all patients to engage in active, range-of-motion exercises
Feeding assistance	Follow general nutrition guidelines and seek advice from dietician as needed Ensure proper fit of dentures
Vision and hearing	Resolve reversible cause of the impairment Ensure working hearing and visual aids are available and used by patients who need them
Sleep enhancement	Avoid medical or nursing procedures during sleep if possible Schedule medications to avoid disturbing sleep Reduce noise at night
Infection prevention	Look for and treat infections Avoid unnecessary catheterization Implement infection-control procedures
Pain management	Assess for pain, especially in patients with communication difficulties Begin and monitor pain management in patients with known or suspected pain
Hypoxia protocol	Assess for hypoxia and oxygen saturation
Psychoactive medication protocol	Review medication list for both types and number of medications



JAMA. 2017;318(12):1161-1174.doi:10.1001/jama.2017.12067

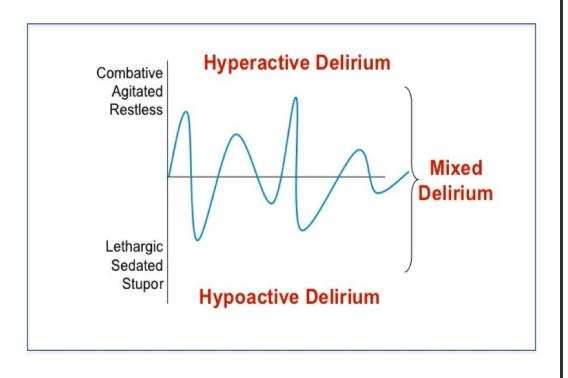
## **TERMINAL DELIRIUM**



Irreversible delirium and agitation at the end-of-life

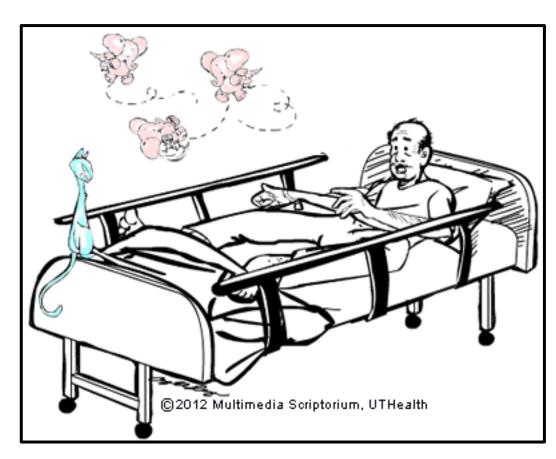
- End-stage organ failure, imminent death
- Accumulation of toxic metabolites
- An adequate therapeutic trial fails to reverse the delirium at end-of-life
- Palliative care emergency
- Common reason for palliative sedation

## Delirium Subtypes



## **APPROACH TO TERMINAL DELIRIUM**





Reidy J. Delirium. AAHPM Intensive Board Review Course, 2016

Educate and support family and caregivers

- To understand its causes
- Finality and irreversibility
- Management approach
   Evaluate and reverse treatable contributing factors
- Pain, urinary retention, constipation
   Irreversible, terminal delirium does not respond to conventional treatments for causes of reversible delirium

### **DELIRIUM: CONSENSUS ON PHARMACOTHERAPY**



- Despite the controversy regarding pharmacotherapy, two areas of consensus seem to remain:
  - a. Hyperactive patients who are a danger to themselves or others (pulling out lines or tubes, striking caregivers, etc) despite behavioral and environmental modification, should be treated pharmacologically.
  - Notably, there is no evidence-based drug approach to this, and reasonable treatment options could include antipsychotics (especially if symptomatology includes hallucinations or delusions), or sedatives such as benzodiazepines or dexmedetomidine if prognosis is felt to be short
  - b. Patients with terminal delirium should be treated pharmacologically if it is the judgment of their caregivers that the delirium is a source of suffering.
  - In these circumstances, it is important to consider the therapeutic goal in the context of the patient's prognosis
  - If sedation is acceptable, or even the goal in a dying patient, a sedating dose of a benzodiazepine or a sedating antipsychotic such as chlorpromazine is probably a prudent approach even though such medications are known to cloud cognitive clarity

Fast Facts, May 2015

## Table 5. Pharmacologic Management of Delirium: Usual Starting Doses\*



Predominantly neuroleptic effects

Haloperidol, 0.5–1 mg every 30 minutes orally (0.5–1 mg every 30 minutes subcutaneously or intravenously, titrate to effect, usual maximal dose not to exceed 3 mg/24 hours)

Olanzapine, 2.5-5 mg orally once daily

Risperidone, 0.5 mg orally twice daily

Predominantly sedative effects

Lorezepam, 0.5-1 mg every 4 hours orally, subcutaneously, or intravenously

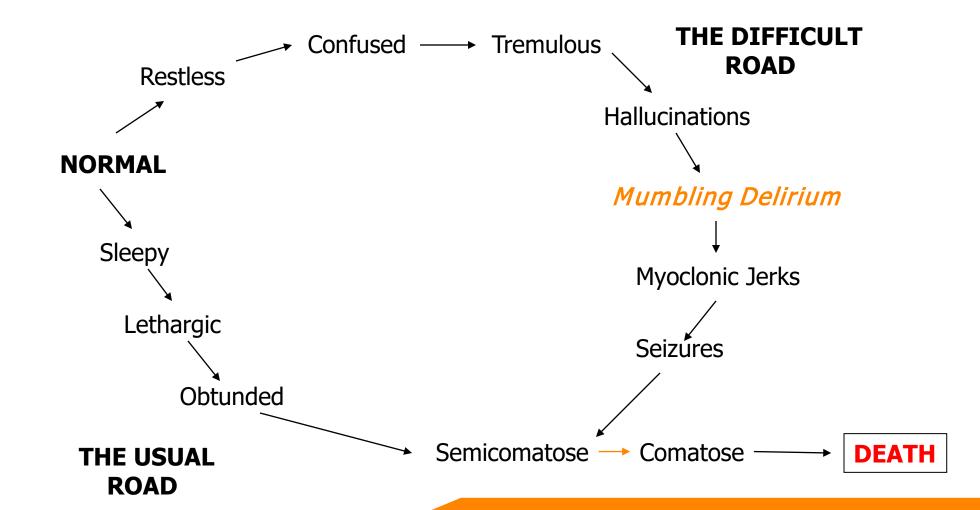
Propofol, 10-mg bolus followed by 10 mg/h intravenously Midazolam, 1–2 mg/h subcutaneously or intravenously

\* Titrate dose to effect in all regimens.



## 2 ROADS TO DEATH





## COMMUNITY PCLC ACTION PERIOD 2: OCTOBER 2021 – JANUARY 2022



### **PCLC BUNDLE ELEMENT 2: PC POWER PLAN**



Provider and staff training via CAPC modules

Case-based learning during Open Office Hours

Interdisciplinary team (IDT) Palliative Care Plan/ Symptom management orders

#### C-PCLC FACILITY - WORKPLAN

Facil	litv	Νa	am	e:

#### SECOND ACTION PERIOD - Palliative Care Power Plan

Date:	Date.

Ensure palliative care education and training of facility providers (MD, NP, PA) and staff members, participate in case-based learning, and implement a set of actionable palliative care and treatment guidelines (care plan/prder sets) for identified patients within the cohort that addresses the symptoms and stressors of their illness. Please complete and submit to your AHS facilitators before the end of your second action period. (By January 2022)

What is your team's strategy to implement this initiative in your facility and achieve your stated goals?						
WHAT	HOW	WHO – person/s responsible	WHEN	Feedback/ Progress Review Process		
Facility Providers &     Staff Training	Activate CAPC account for facility and have providers/ staff members register on CAPC and access at least 1 module     5 facility providers (MD, NP, PA) or staff members per month	Facility champion to identify 5 facility providers/ staff members per month to access CAPC	November 2021     December 2021     January 2022     February 2022	CAPC to track and report monthly on facility engagement  Activation of account  Number of facility providers/ staff members per month  Number of CAPC modules accessed		
<ol> <li>Case-based Learning during Open Office Hours</li> </ol>	Identify and submit 1 case per month for discussion during Open Office Hours     See Case Summary Form attached		<ul> <li>November 2021</li> <li>December 2021</li> <li>January 2022</li> <li>February 2022</li> </ul>	<ul> <li>Complete 1 Case Summary Form per month to Community PCLC coordinator, Lauren Salvatore</li> <li>Any case not discussed during office hours may be scheduled for discussion with Community PCLC Project Director, Dr. Matti-Orozco</li> </ul>		
3. □ IDT Palliative Care Plan, <u>OR</u>	Engage     multidisciplinary team     to develop, create and     implement an IDT		By January 2022	Submit either an IDT Palliative Care Plan or a new Symptom Management Order Set		
PC Order Set – New Symptom Management, specify: Pain Shortness of breath/ dyspnea Delirium/ agitation	Palliative Care Plan or a new Symptom Management Order Set					





#### RECOMMENDED TRAINING ACROSS THE IDT (Recommended refresher courses are denoted with \*)

CAPC Course Title	Drivers	Aides	Administrators	Social Work	Nursing	Providers	Therapists, Dietitians
An In-Depth Look at Palliative Care and Its Services	~	~	~	~	~	~	~
A Palliative Approach to Care for Direct Care Workers*	~	~	~				
Communication Skills							
Delivering Serious News			~	~	~	~	
Discussing Prognosis			~	~	~	~	
Clarifying Goals of Care*	~	~	~	~	~	~	~
Conducting a Family Meeting			~	~	~	~	~
Advance Care Planning Conversations*			~	~	~	~	
Building Skills in Basic Advance Care Planning							
Basic Advance Care Planning: Introduce and Motivate				~	~	~	
Basic Advance Care Planning: Guide and Document				~	~	~	
Beyond Conversation: Integrating Basic Advance Care Planning into Practice				~	~	~	

## **RECOMMENDED CAPC MODULES**



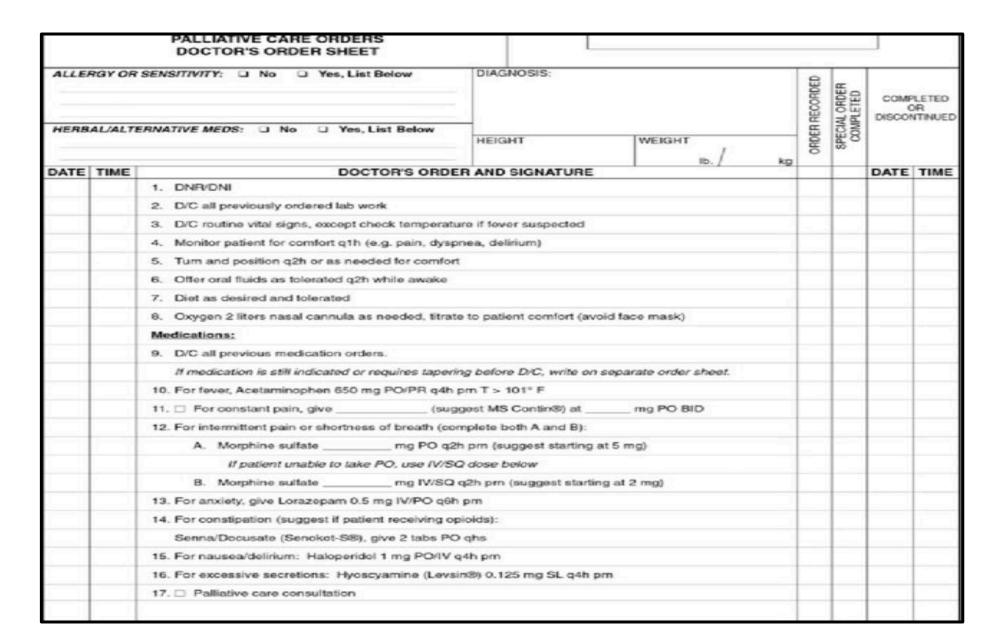
CAPC Course Title	Drivers	Aides	Administrators	Social Work	Nursing	Providers	Therapists, Dietitians
Symptom Management, Preventing Crises, and Relief of Suffering Across the Disease Trajectory							
Comprehensive Pain Assessment*	<b>V</b>	~	~	~	~	~	V
Reducing Risks for Older Adults	V	~	~	~	~	~	~
Relieving Suffering in Patients with Dementia and Their Caregivers	~	<b>~</b>	~	~	~	~	<b>~</b>
Critical Decisions in Advanced Dementia*				~	~	~	
Relieving Suffering in Patients with COPD				~	~	~	
Relieving Suffering in Patients with Heart Failure				<b>V</b>	~	V	

## **SAMPLE: IDT PALLIATIVE CARE PLAN**



Basic Assessment Needs	Review and update Advance Directive and DNR
	Review Hospice Philosophy
	Review 4 levels of care. Ascertain preferred place of death
	Review call system/Triage. How to contact Hospice 24-hours day. Discuss use of 911 versus calls to Hospic
	Continue instructions in funeral planning and what to do when patient dies
	Assess for immediate need for other visits, (i.e., MSW, Chaplain, CHHA, M.D.)
	Review signs and symptoms of death and dying
	Discuss home safety
	Consider increased frequency of visits for each discipline
	Communicate Plan of Care to team members including Triage as needed
Medications	Syringe for sublingual meds
	Anticipate for congestion; consider Atropine/Levsin
	Consider Tylenol supp. For fever
	Instructed on sublingual/rectal administration of meds
	Red sticker on Kaiser card for pharmacy
	Discussed medication side effects
Equipment Needs	Consider hospital bed, commode, over bed table, wheelchair
	Anticipate needs for diapers, chux, syringes, toothettes, urinal, bedpan, etc.
	Educated/evaluated the use of oxygen and safety precautions
Psychosocial Needs	Assessed for coping mechanism
	Addressed for possible unfinished issues with family/patient, financial/legal
	Assessed for increase social worker intervention through visits, telephone calls
	Assessed for cultural beliefs & values, beliefs about death and dying
	Assessed for caregiver status
	Bereavement risk

Pain Management	Assessed disease process and reviewed pain management
	Instructed patient/family route of medication (sub-lingual/rectal) - Syringe provided
	Instructed regarding frequency of meds, adjusting dosage for patients comfort and what meds to use
	Check for adequate supply of pain meds in the home
Constipation	Instructed/reviewed bowel regimen
	Checked patient for fecal impaction if indicated
	Ordered Ducolax supp, fleet enema as needed
Urinary	Assessed when patient last voided – retention
	Anticipated for foley catheter need
Skin Integrity	Instructed re: skin care, bed repositioning, changing diapers, safety, lotion to bony prominence
	Oral hygiene care
Anxiety/Pre-terminal Agitation	Assessed patient for hallucination – educate family / caregiver as needed
	Reviewed medication management, consider Xanax, if Xanax not effective, assess for Thorazine
	Assessed for music therapy
Spiritual Needs	Addressed spiritual status/needs, may need to contact patients clergy or pastor as requested
Educational Needs/Materials	Provided patient education materials
	Reviewed disease pathophysiology
	Instructed patient/family on self management skills
	Instructed patient/family about soft music, massage, aromatherapy, candles, pets, etc.
Signature/Title	Initial/Date





## **THANK YOU! QUESTIONS? COMMENTS?**

