Role of the Primary Care Provider in Primary Palliative Care

ANEISHA CROSSBOURNE, MD FHM

USACS STAT

TRAVELLING HOSPITALIST

Financial Disclosure

No relevant financial disclosures

Needs Statement

Many patients in Kentucky are living with one or more serious chronic illness with recurrent admissions to the hospital and high health care utilization.

Appropriate symptom management and psycho-social support would reduce their symptom burden and improve their quality of life.

If more health care providers are aware of these needs and equipped with skills to manage their symptoms this would help to improve the quality of life of these patients and their families.

Expected Outcome

Participants will be able to identify and be willing to provide primary palliative care for appropriate patients

Learning Objectives

Upon completion of this activity, participants will be able to:

Define Palliative Care and Primary Palliative Care

Outline the benefits of palliative care

Identify appropriate patients for primary palliative care

Evaluate the needs of patients who are appropriate for primary palliative care

Outline

Palliative care and benefits of palliative care in general

Focus on Primary Care Practitioners providing primary palliative care

- Select the right patients
- Goals of care discussion
  - Serious illness discussion
  - Advance directives
- Brief intro to symptom management
- Referral to specialist palliative care

65 year old Bunny W diagnosed with COPD x 10 years ago. Treated with LTOT 3L. Hx of HFrEF, EF=25% from ischemic cardiomyopathy. He is awaiting evaluation in advanced heart failure clinic at a tertiary center, but he keeps missing his appointments because he is back in the hospital with shortness of breath. Diuresis and up titration of GDMT is often limited by hypotension and worsening kidney function.

He has developed back pain, from sleeping in his recliner, for which he has been taking NSAIDS without good effect. Back pain has progressed to now prevent him from sleeping

Bunny's wife, Rita worked night shift at the diner but recently quit because she is concerned about leaving Bunny at home alone at nights.

They no longer go to social activities incl to church because they are limited by Bunny's decreased mobility

Is Bunny a candidate for Palliative care?

A No, Bunny will likely live more than 12 months

B No, Bunny wants to be a full code

C Yes, if Bunny chooses to no longer go to Advanced HF care

D Yes, Bunny's recurrent admissions for shortness of breath qualifies

Definition of Palliative Care

Specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family. *(CAPC: Center for Advancement of Palliative Care*)

An approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. *(WHO: World Health Organization)*

Highlights of Definition

Living with serious illness

Aim to relieve symptoms

Identify, assess and treat distress

Improved quality of life for patient

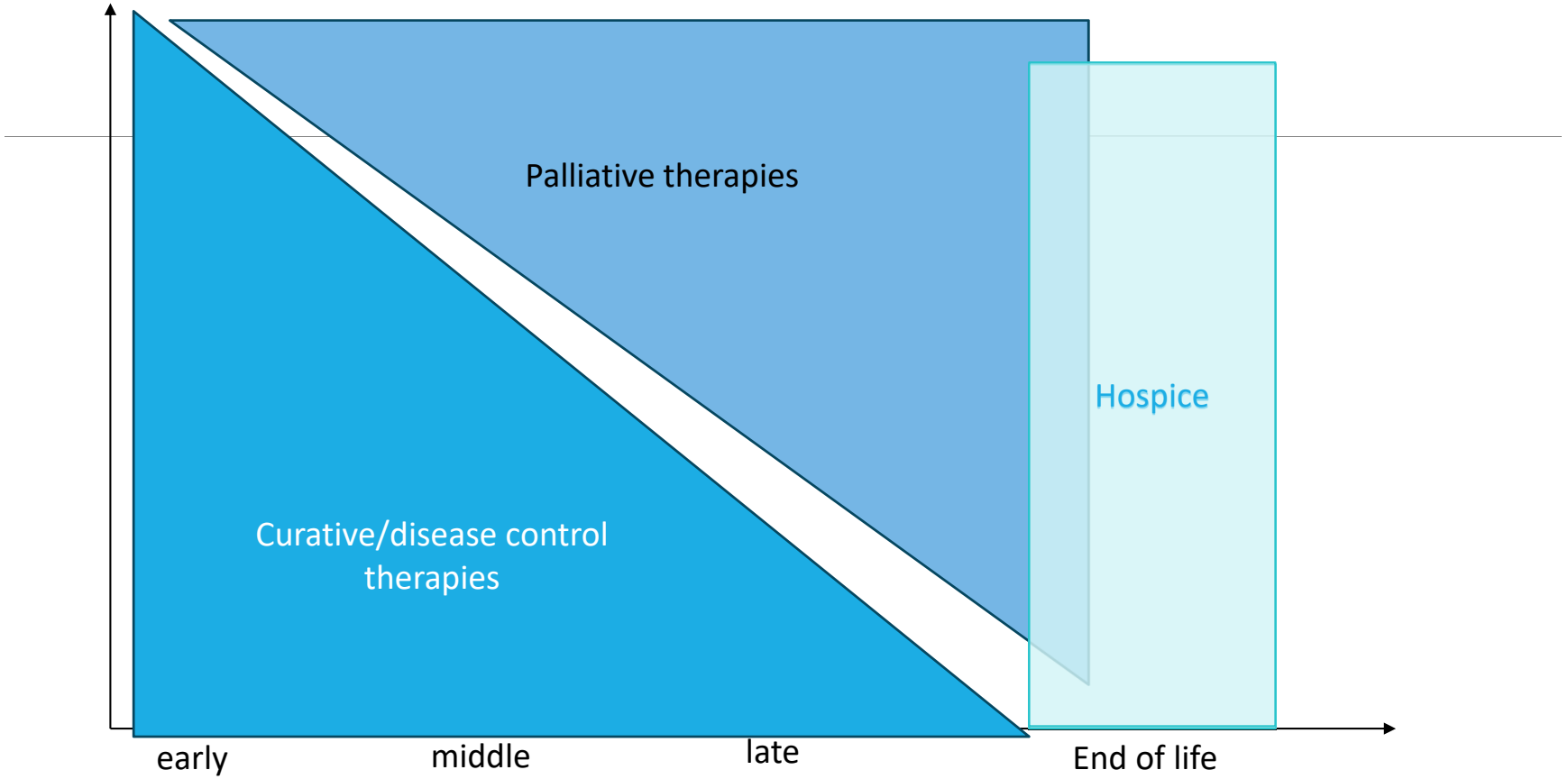
Improved quality of life for family

Address physical, social, spiritual distress

No mention of on-going therapeutic care

No mention of expected length of life

Schematic of Palliative Care



Adapted from Martin Griva et al

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Approximately what percentage of highest need patients (as measured by cost of health care) are in the last year of their life?

A 11%

B 22%

C 55%

D 77%

Benefits of palliative care to patient

Relief of symptoms

Better communication between patient and treating team

Alignment of treatment options with patient's priorities

Improved care coordination

Increased family support

Less 911 calls, ED visits and hospitalizations

Increased life expectancy

Benefits of palliative care to health system

Reduced readmissions

Cost savings

- Fewer and shorter hospital stays
- Fewer and shorter ICU stays
- Decreased in-hospital deaths

Improved satisfaction

TABLE. Palliative Care Quality and Cost Outcomes

Value Equation	Outcome	How Does Palliative Care Help?	Evidence
Higher quality	Patients live longer with higher quality of life	More communication, improved symptom management	Temel, *N Engl J Med*, 2010[5]
	Greater family satisfaction with quality of care	More communication, greater comfort, preferences met	Casarett, *Arch Int Med*, 2011[18]
	Improved pain, symptoms, and satisfaction with care	Symptom management and multidisciplinary team	Bernacki, *JAMA Intern Med*, 2014[19]; Wright, *JAMA*, 2008[20]
Lower cost	Lower costs per day	Goal-concordant care	Morrison, *Arch Int Med*, 2008[15]
	Shorter hospital length of stay	Improved symptom management, goal-concordant care	May, *Palliat Med*, 2017[21]
	Shorter ICU length of stay	Goal-concordant care	Norton, *Crit Care Med*, 2007[22]
	Fewer ICU admissions	Improved symptom management, goal-concordant care	Gade, *J Palliat Med*, 2008[23]
	Reduced readmissions	Symptom management and goal-concordant care with use of standardized triggers for palliative care consult	Adelson, *J Oncol Pract*, 2017[24]
	Fewer hospital admissions and inpatient deaths	Better symptom management and higher hospice utilization with in-home palliative care	Lustbader, *J Palliat Med*, 2016[25]
	Fewer 30-day readmissions	Referral to outpatient support (palliative care or hospice)	Enguidanos, *J Palliat Med*, 2012[12]

NOTE: Abbreviation: ICU, intensive care unit.

Fail MPP, J of Hosp Medicine 12/2017

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Limitations to accessing palliative care

Patient factors

- Belief system

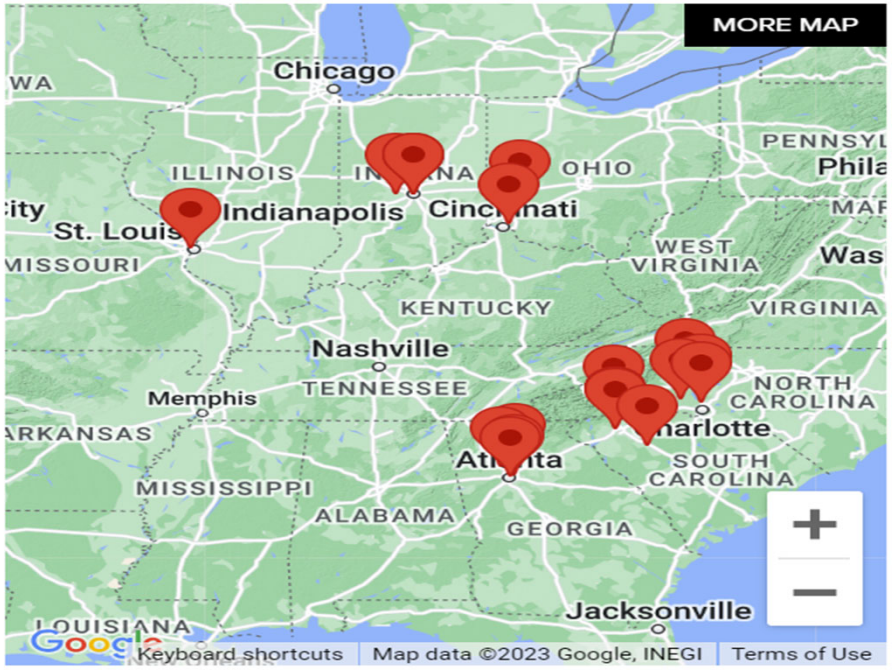
Treating team factors

- Belief system
- Recognizing need

System factors

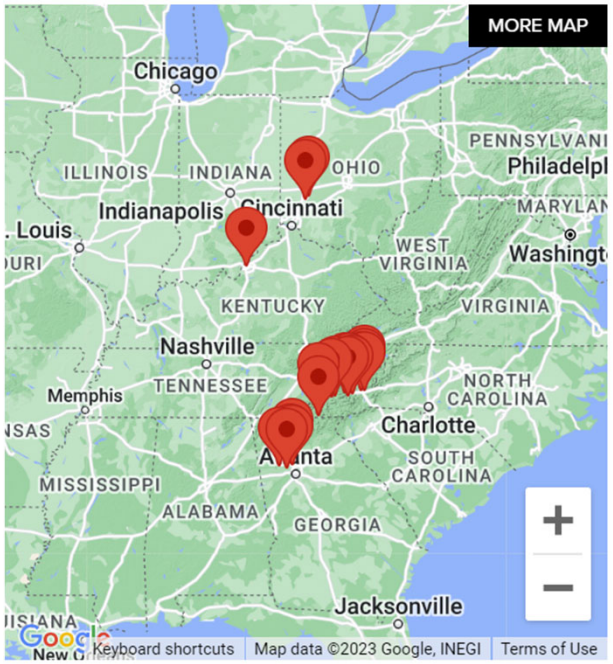
- Recognized shortage of palliative care physicians
- Lack of skills and training for other providers
- Financial considerations

Location of office-based palliative care



https://getpalliativecare.org/provider-directory

Location of NH-based palliative care



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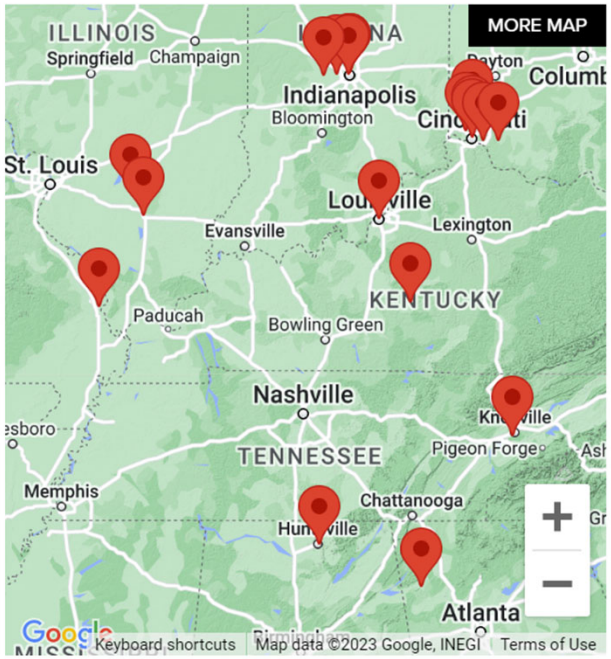
Location of hospital-based palliative care



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Primary Palliative Care

Palliative care provided by non-specialists in palliative care

Skills and competences required of health care professionals to provide ‘basic’ palliative care

Primary palliative care

SHM identifies the responsibilities of hospitalists in 3 key domains

- Leading goals of care discussions, and advanced care planning
- Screening and treating common physical symptoms
- Referring patients to community services to provide post discharge support
- Psychological, social, cultural and spiritual aspects of care

How do primary care providers fit in?

PROS

- Closest to community/easily accessible
- Broad knowledge
- Long standing pt relationships

Barriers

- time
- Keeping up to date with knowledge
- Lack of supporting services

Now that we are convinced

HOW DO WE DO THIS?

Providing primary palliative care

Select the right patients

Goals of care discussion

- Serious illness discussion
- Advance directives

Basic Symptom management

Multidisciplinary approach

Referral to specialist palliative care

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- They no longer go to social activities incl to church because they are limited by Bunny's decreased mobility

Selecting the right patients- primary criteria

Positive answer to the surprise question

- Would you be surprised if the patient died within 12 months (before adulthood if <18 yrs)

Frequent (more than one) admissions for the same diagnosis within several months

Frequent visits for difficult to control physical or psychological symptoms

Decline in function, feeding etc (failure to thrive)

Complex care requirements at home

Selecting the right patients- secondary criteria

Long Term Care patients

Elderly patient, cognitive impairment with hip fracture, frequent falls

Metastatic or locally advanced cancer

No history of completing advanced directives

Chronic home oxygen use, house bound

Out of hospital arrest

Limited social support

Providing primary palliative care

Select the right patients

Goals of care discussions

- Advance directives
- Serious illness discussion

Symptom management

Multidisciplinary approach

Referral to specialist palliative care

Goals of care discussions

Start with identifying the decision maker

Ask about existence of previous advanced directives

Living Will: specifies patient's preferences for artificial feeds, wish for dialysis etc.

Health care power of attorney: designates surrogate to make decisions in the event patient cannot make decisions for themselves

Consider completing MOST form

KY Living Will: 311.625 Form of living will directive

.... Direct that treatment be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical treatment deemed necessary to alleviate pain.

.... DO NOT authorize that life-prolonging treatment be withheld or withdrawn.

.... Authorize the withholding or withdrawal of artificially provided food, water, or other artificially provided nourishment or fluids.

.... DO NOT authorize the withholding or withdrawal of artificially provided food, water, or other artificially provided nourishment or fluids.

.... Authorize my surrogate, designated above, to withhold or withdraw artificially provided nourishment or fluids, or other treatment if the surrogate determines that withholding or withdrawing is in my best interest; but I do not mandate that withholding or withdrawing.

NYS Living Will

I direct that my treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing treatment. While I understand that I am not legally required to be specific about future treatments **if I am in the condition(s) described above I feel especially strongly about the following forms of treatment**:

[2]

- ☐ I do not want cardiac resuscitation.
- ☐ I do not want mechanical respiration.
- ☐ I do not want artificial nutrition and hydration.
- ☐ I do not want antibiotics.

However, I **do want** maximum pain relief, even if it may hasten my death.

KY EMS DNR

Kentucky Emergency Medical Services
Do Not Resuscitate (DNR) Order

Person's Full Legal Name _____

Surrogate's Full Legal Name (if applicable) _____

I, the undersigned person or surrogate who has been designated to make health care decisions in accordance with Kentucky Revised Statutes, hereby direct that in the event of my cardiac or respiratory arrest that this ***DO NOT RESUSCITATE (DNR) ORDER*** be honored. I understand that DNR means that if my heart stops beating or if I stop breathing, no medical procedure to restart breathing or heart function, more specifically the insertion of a tube into the lungs, or electrical shocking of the heart or cardiopulmonary resuscitation (CPR) will be started by emergency medical services (EMS) personnel.

I understand this decision will *not* prevent emergency medical services personnel from providing other medical care.

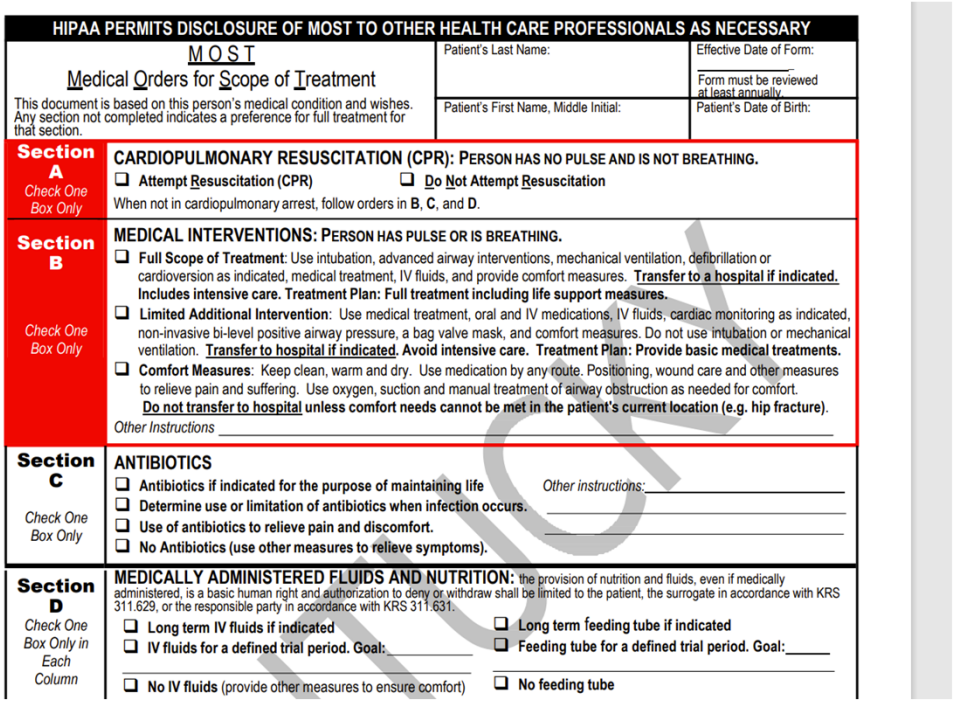
I understand that I may revoke this DNR order at any time by destroying this form, removing the DNR bracelet, or by telling the EMS personnel that I want to be resuscitated. Any attempt to alter or change the content, names, or signatures on the EMS DNR form shall make the DNR form invalid.

I understand that this form, or a standard EMS DNR bracelet must be available and must be shown to EMS personnel as soon as they arrive. If the form or bracelet is not provided, the EMS personnel will follow their normal protocols which could include cardiopulmonary resuscitation (CPR) or other resuscitation procedures. I understand that should I die, EMS personnel will require this form and/or bracelet for their records.

I give permission for information about this EMS DNR Order to be given to the prehospital emergency medical care personnel, physicians, nurses, or other health care personnel as necessary to implement this directive.

I hereby state that this ***'Do Not Resuscitate (DNR) Order'*** is my authentic wish not be resuscitated.

Medical Orders for Scope of Treatment



HIPAA PERMITS DISCLOSURE OF MOST TO OTHER HEALTH CARE PROFESSIONALS AS NECESSARY

MOST
Medical Orders for Scope of Treatment

This document is based on this person's medical condition and wishes. Any section not completed indicates a preference for full treatment for that section.

Patient's Last Name:

Effective Date of Form:
Form must be reviewed at least annually.

Patient's First Name, Middle Initial:

Patient's Date of Birth:

Section A *Check One Box Only*

CARDIOPULMONARY RESUSCITATION (CPR): PERSON HAS NO PULSE AND IS NOT BREATHING.

❑ **Attempt Resuscitation (CPR)** ❑ **Do Not Attempt Resuscitation**

When not in cardiopulmonary arrest, follow orders in **B**, **C**, and **D**.

Section B *Check One Box Only*

MEDICAL INTERVENTIONS: PERSON HAS PULSE OR IS BREATHING.

❑ **Full Scope of Treatment**: Use intubation, advanced airway interventions, mechanical ventilation, defibrillation or cardioversion as indicated, medical treatment, IV fluids, and provide comfort measures. **Transfer to a hospital if indicated. Includes intensive care. Treatment Plan: Full treatment including life support measures.**

❑ **Limited Additional Intervention**: Use medical treatment, oral and IV medications, IV fluids, cardiac monitoring as indicated, non-invasive bi-level positive airway pressure, a bag valve mask, and comfort measures. Do not use intubation or mechanical ventilation. **Transfer to hospital if indicated. Avoid intensive care. Treatment Plan: Provide basic medical treatments.**

❑ **Comfort Measures**: Keep clean, warm and dry. Use medication by any route. Positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. **Do not transfer to hospital unless comfort needs cannot be met in the patient's current location (e.g. hip fracture).**

Other Instructions _____

Section C *Check One Box Only*

ANTIBIOTICS

❑ **Antibiotics if indicated for the purpose of maintaining life**

❑ **Determine use or limitation of antibiotics when infection occurs.**

❑ **Use of antibiotics to relieve pain and discomfort.**

❑ **No Antibiotics (use other measures to relieve symptoms).**

Other instructions: _____

Section D *Check One Box Only in Each Column*

MEDICALLY ADMINISTERED FLUIDS AND NUTRITION: the provision of nutrition and fluids, even if medically administered, is a basic human right and authorization to deny or withdraw shall be limited to the patient, the surrogate in accordance with KRS 311.629, or the responsible party in accordance with KRS 311.631.

❑ **Long term IV fluids if indicated**

❑ **IV fluids for a defined trial period. Goal:** _____

❑ **No IV fluids** (provide other measures to ensure comfort)

❑ **Long term feeding tube if indicated**

❑ **Feeding tube for a defined trial period. Goal:** _____

❑ **No feeding tube**

Medical Orders for Scope of Treatment

Introduced in KY in 2015

Many states have their own

More detailed

Completed with health care professional

Must accompany patient on transfer

Original form must be present

Family meeting about serious illness

Familiarize yourself with patient's care

Set the environment

Make introductions, identify relationships,

Identify final decision maker

- Patient vs health care surrogate vs health care proxy vs POA

Ask about their understanding of their/ family member's condition

Summarize medical facts in language that is jargon free and appropriate for education level

Allow for silence

Family meeting about serious illness

Present options as clearly as possible

- Helps to break decisions down in stages, but try not to present decisions in silos always guide the conversation based on goals of care and the overall picture
- Address code status

Summarize and clarify

Allow for follow up questions

Present opportunities for further follow up

Provide reassurance

Billing for services

Requirements:

- Must be voluntary
- Must be face to face
- Patient or surrogate

May include:

- Goals of care discussion
- Complex medical decisions
- Explanation of documents (but not required to complete)

CPT Codes:

- 99497- first 30 mins, with at least 16 mins performed
- 99498- additional 30 mins

Tools for working on communication

Center to Advance Palliative Care (CAPC)

SHM Palliative Care task force toolkit

The Serious Illness Program at Ariadne Labs

VitalTalk

Providing primary palliative care

Select the right patients

Goals of care discussions

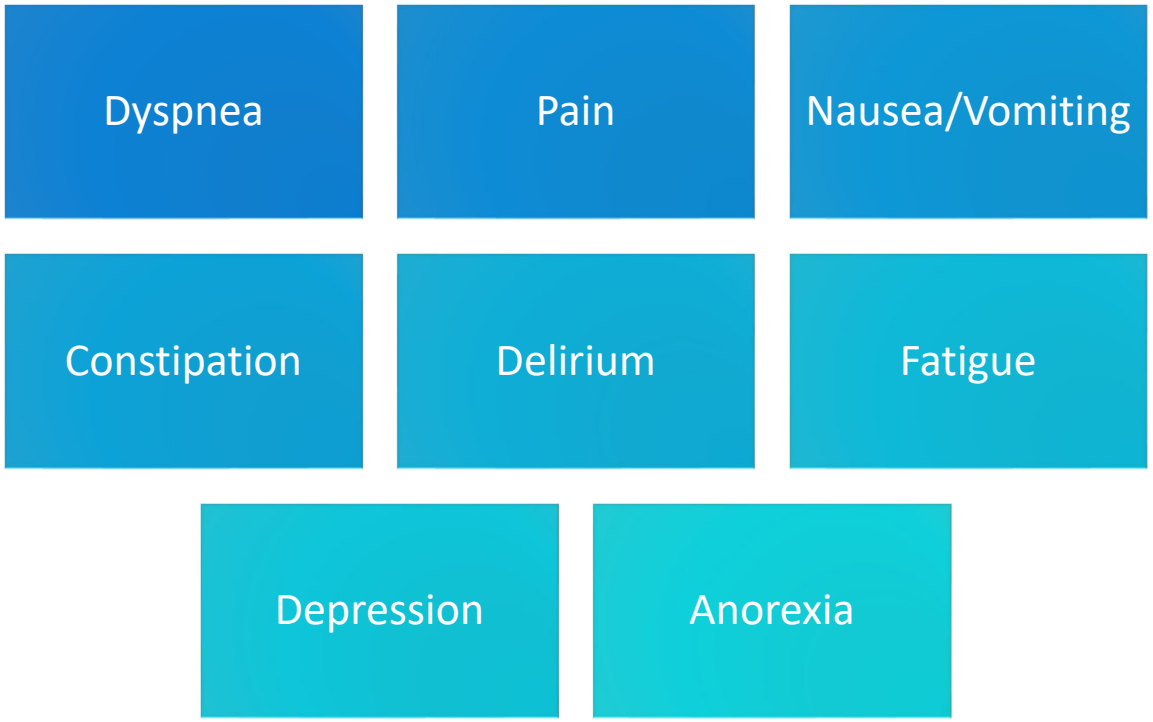
- Advance directives
- Serious illness discussion

Symptom management

Multidisciplinary approach

Referral to specialist palliative care

Common Symptoms



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Bunny's wife, Rita worked night shift at the diner but recently quit because she is concerned about leaving Bunny at home alone at nights.

They no longer go to social activities incl to church because they are limited by Bunny's decreased mobility

Bunny W presents for his 4th visit in 3 weeks for shortness of breath, at first visit he had his diuretic increased and is at goal weight. His COPD treatment is optimized and he has no wheezes on exam. He continues to complain of subjective shortness of breath. O2 sats 92% on his home 3L. He reports some relief with the use of a fan clipped to his bed railing. CXR, ABG V/Q scan all unremarkable. What are the next options for therapy?

A) add low dose benzodiazepine

B) add low dose morphine

C) change his current MDI triple regimen to nebulizer therapy

D) increase his O2 therapy to 5L to achieve a higher O2 sat

Dyspnea

Oxygen

- Hypoxic= treat
- Not Hypoxic= no oxygen
  - (although there is some role for limited trial of O2)

Non-pharmacological:

- Airflow- fan to the face is effective and evidence based
- Positioning- sitting up in bed leaning over on bedside table
- Teaching energy conservation techniques

Pharmacological

- **Opioids first line**
- BDZ to treat the associated panic or anxiety
  - no evidence it improves shortness of breath

Dyspnea

- Can be used on opioid naïve patients
  - Morphine orally: 2.5 mg immediate release every 4 hours.
  - Morphine parenterally: 1 to 1.5 mg SC or IV every 4 hours.
- Any opioid can be used (May 2023; Yamaguchi et al)
- Initiation of treatment with long-acting opioids not effective (May 2022; Ekström et al)

Bunny W is admitted for shortness of breath, he has undergone diuresis and is at goal weight. His COPD treatment is optimized and he has no wheezes on exam. He continues to complain of subjective shortness of breath. O2 sats 92% on his home 3L. He reports some relief with the use of a fan clipped to his bed railing. Repeat CXR, ABG V/Q scan all unremarkable. What are the next options for therapy?

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3 weeks later Bunny W presents to the ER after a fall.

- SOA is improved with initiation of Morphine.
- Last cardiology visit taken off his NSAIDS….”something about my heart failure. But my back pain has not been too bad since last admission.”
- He can walk in his home with his walker.
- Tonight, he was trying to get up from his recliner and it got caught in a new rug and he tripped.
- Work up in the ER →L3 lumbar fracture.
- ER reads your notes about palliative care and calls for your opinion

What is the next management step? What do you recommend?

A) consult surgery for possible intervention

B) switch to long-acting morphine for better pain control, he will need it now

C) resume diclofenac, for additional pain control

D) transfer to hospice, this is a life limiting event

PAIN

Identify cause of pain

Correct underlying cause

Weigh potential discomfort of investigation and management techniques. Eg palliative radiation vs debulking surgery; kyphoplasty

Introduce patients to the concept of ‘function over pain-free’

Involve patients in decision making

PAIN MANAGEMENT

Follow WHO pain management guidelines

Multimodal approach incl non medication tools

- Physiotherapy

Match cause of pain to treatment modality

Familiarize yourself with various opioids

Keep in mind the concept of tolerance

Don’t forget the Narcan and teaching family members how to use

PAIN MANAGEMENT

Consider utilizing expertise of pain management clinic especially with current or previous history of opioid use disorder

PAIN MANAGEMENT

Acetaminophen

NSAIDS

Corticosteroids

- Start high dose and then taper down. If no effect after 7- 10 days then DC

Opioids

- Start low go slow
- Consider route
- start with fixed admin doses
- Breakthrough doses until complete titration
- Anticipate and plan for side effects

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Constipation

Prevention:

- Stool softeners in patients at high risk
- Opioids- give laxative unless bowel obstruction or diarrhea
- R/o overflow incontinence in patients with diarrhea

Consider multiple etiologies:

- Primary: decreased intake, low fiber diet, poor fluid intake
- Secondary: drugs, metabolic eg hypercalcemia, structural

Non pharm tx:

- Hydration, prunes, ? Probiotics
- Manual dis-impaction

Pharm Tx:

- r/o mechanical obstruction
- Avoid if patient is completely obstructed
- Avoid rectal route at the end of life

Constipation

CLASS	MEDICATION	ONSET
Stimulants	Sennosides / Senna: *1 to 2 tablets or 10 mL syrup PO at bedtime*	6 to 12 hrs
	Bisacodyl: *5mg po daily, 1 tab pr*	20mins to 3 hrs
Osmotic	Lactulose: *15 mL PO daily w/food*	1 to 2 days
	Polyethylene glycol: *17G po daily*	1 to 3 days
	Sodium phosphate enema: *130ml pr*	
Suppositories	Glycerin: 1 tab pr *(osmotic+ stool softener)*	15 to 60mins
	Mineral oil ENEMA *(stool softener)*	2 to 15mins
Opioid antagonists	Methylnaltrexone: 450mg po qam or subq weight-based dosing 6-18mg	24mins to 4hrs
	Naloxegol: 12.5mg to 25mg po daily	12 to 24hrs
	Naldemedine: 0.2mg po daily	16-18hrs

Nausea/Vomiting

Identify suspected etiology and treat accordingly

Avoid strong smells

Prevent/treat constipation

Aromatherapy: peppermint, ginger

Oral Hydration: ice chips

Clinically assisted hydration

Nausea/Vomiting

Chemical

- *nausea not relieved by vomiting*
- eg chemotherapy
  - Haloperidol 0.5 to 1.5 q8h prn
  - Ondansetron 4 to 8mg po/sc/IV prn

Cortical

- *anticipatory nausea, distress*
- eg pain, anxiety
- Lorazepam 0.5mg sl qid prn
- Cannabinoids

Cranial

- *AM headache, vomiting w/o nausea, Hx*
- eg raised ICP
- Dimenhydranate 50mg po/sc/pr q 8h prn +/- corticoetroids
- Haloperidol

Nausea/Vomiting

Vestibular

- *associated with movement*
- eg drugs, vestibular tumor
- Dimenhydrinate
- Scopolamine 1-2 patches TD q 72h

Visceral

- *abd pain, vomiting undigested material*
- eg bowel obst/constipation, pharyngeal stimulation (from difficult to handle secretions)
  - Dimenhydrinate
  - Ondansetron

Gastric stasis

- *epigastric pain and fullness, reflux*
- eg drugs, massive ascites
  - Metoclopramide: 5mg tidac po/IV

Nausea/Vomiting

These are starting points

Consider other agents additional

Consider Olanzapine in non-chemo induced vomiting (Oct 2023; Bonar et al)

- 2.5mg qhs uptitrate up to 5mg
- as an adjunct to other antiemetics
- Patients already on at least 2 antiemetics

Identify and treat etiology:

→primary pulm cause

→medications

→other non directly pulm cause

Cough

Dry cough

- Dextromethorphan 15 to 30 mg PO Q4 to 8H
- Simple syrup: (unknown mech of action ? Sugar decreases cough reflex)
- Opioids: morphine 2.5 to 5 mg PO Q4-6H, hydrocodone, hydromorphone

Wet cough

- Guaifenesin 200 to 400mg mg po q4h

Anorexia

Multifactorial

Consider reversible underlying cause: drugs, oral candidiasis, gastric stasis, constipation

Pharmacological therapy

- Corticosteroids eg Dexamethasone 2 to 4mg daily
  - Onset in a few days
- Megestrol Acetate start 160mg po daily
  - off label, effects take up to 2 weeks
- Mirtazipine start 7.5mg daily
  - Off-label, effects full after several weeks (increase every 3-7 days)

Hiccoughs

Identify and treat etiology

→gastric distension

→Reflux

→ medications incl steroids

Pharm Tx first line is PPI

Pharm Tx if persistent> 48hrs

- Baclofen 10mg po once; onset 30mins to 3hrs. May continue tid for 2-5 days
- Gabapentin if suspect central dose
- Chlorpromazine 25mg po tid (mostly replaced by above agents)
- Midazolam: end of life

Symptom Management: resources

CAPC has curriculum on symptom management

SHM Palliative Care Toolkit

BC Centre for Palliative Care (2019). B.C. Inter-professional Palliative Symptom Management Guidelines.

https://bc-cpc.ca/wp-content/uploads/2019/10/SMG-Interactive-Oct-16-2019.pdf

Providing primary palliative care

Select the right patients

Goals of care discussions

- Advance directives
- Serious illness discussion

Symptom management

Multidisciplinary approach

Referral to specialist palliative care

Multidisciplinary approach

PT/OT/ST

Nursing

Pharmacist

Social Workers

Spiritual leaders

Respiratory Therapist

Volunteers

Coordination of care: Multidisciplinary approach

- 65 year old Bunny W diagnosed with COPD x 10 years ago. Treated with LTOT 3L. Hx of HFrEF, EF=25% from ischemic cardiomyopathy. He is awaiting evaluation in advanced heart failure clinic at a tertiary center, but he keeps missing his appointments because he is back in the hospital with shortness of breath. Diuresis and up titration of GDMT is often limited by hypotension and worsening kidney function

Nursing

Resp therapist`

- He has developed back pain, from sleeping in his recliner, for which he has been taking NSAIDS without good effect. Back pain has progressed to now prevent him from sleeping

Pharmacist

Social Services

- Bunny's wife, Rita worked night shift at the diner but recently quit because she is concerned about leaving Bunny at home alone at nights.

Volunteers

- They no longer go to social activities incl to church because they are limited by Bunny's decreased mobility

Spiritual Leader

PT/OT

Providing primary palliative care

Select the right patients

Goals of care discussions

- Advance directives
- Serious illness discussion

Symptom management

Multidisciplinary approach

Referral to specialist palliative care

Indications for referral to Specialty palliative care

Refractory pain or other symptoms
- large doses of opioids, methadone
- Severe delirium

Major conflict within family or treating team

Unrealistic expectations

Resistance to discharge

Complex depression/grief/anxiety

Spiritual suffering

Take Home Points

Palliative care focuses on symptom management to achieve improved quality of life in patients living with serious illnesses.

Basic palliative care can be provided by Primary care providers

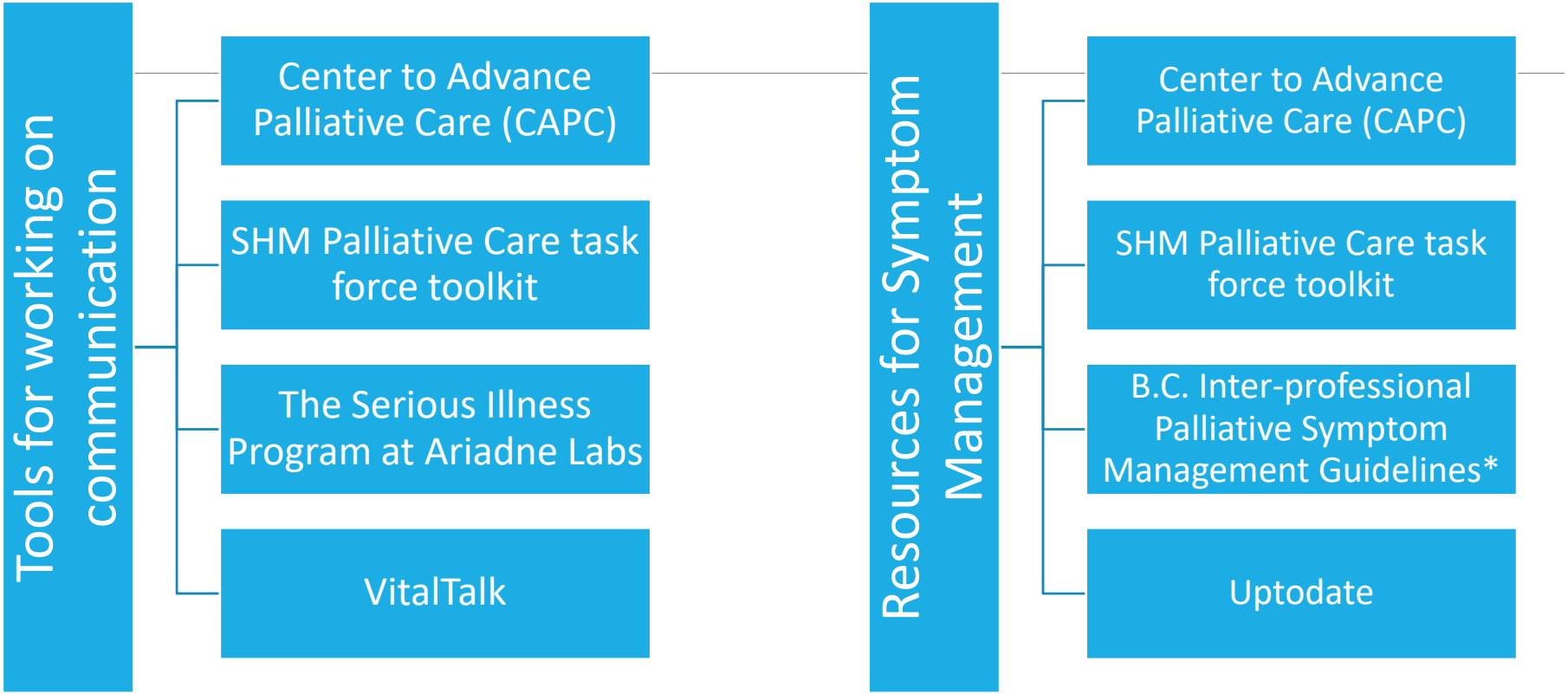
There are benefits to the patient, family and health care system as a whole

There are resources available to help primary care providers be more competent with serious illness conversations and goals of care discussions

Symptom and distress management requires a multimodal and multi-disciplinary approach

Questions?

RESOURCES



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