# Basics of Primary Palliative Care

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### **Objectives**

- Discuss the definition and importance of primary palliative care
- Review useful prognostication and communication tools
- Review indications for referral to specialist palliative care
- Discuss the management of commonly encountered symptoms
- Briefly review New Mexico law and regulations for medical aid in dying

# **Primary Palliative Care**

### What is Palliative Care?

**Palliative care** – supportive medical care for people with serious illness that focuses on providing relief from the pain, symptoms and distress of serious illness

Other supportive care

- Family meetings and patient/family counseling
- Resolves conflicts between families/patients and physicians on achievable goals of care
- Spiritual support

#### **Palliative** Care

Use a palliative approach for life limiting illness

Optimizing Quality of Life

Maximizing community supports

#### End-of-Life Care

- · Weeks to months
- · Palliative and medical treatments
- Ongoing supports
- Hospice Care
- · Respite and caregiver relief

#### Last Days/Hours Care

Pain & Symptom Mgt

Psychosocial & Spiritual supports

Early symptom management

Advanced care planning

## The Institute of Medicine (IOM)

Primary palliative care: "Palliative care that is delivered by health care professionals who are not palliative care specialists, such as primary care clinicians; physicians who are disease oriented specialists, and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care."

## **Basic Steps in** *Primary* **Palliative Care**

- Have the conversation about advance directives and goals of care
- Talk about the prognosis and disease progression
- Assist with symptom management
- Address family and social needs

## **Communication Pearls**

## Why Do We Need to Do It?

- In patients with stage IV cancer, oncologists documented discussions about goals of care only 27% of the time.
- The majority of patients dying of cancer spend time in the hospital in the last month of life.
- 6% of patients dying of cancer receive chemotherapy within 2 weeks of death.

## **Communication About Code Status**

- Normalize & contextualize the discussion.
- Provide basic definitions.
- Hand the conversation to them.
- Empathize, normalize, partner, and reassure.
- For patients who have adequate context and voice a code status choice, thank them for the discussion.
- Educate patients who need more context.
- Wait for their response.
- Discuss respiratory arrest if appropriate.
- Let the patient know the discussion may be revisited.

https://www.mypcnow.org/fast-fact/language-for-routine-code-status-discussions/

### **Cardiac Arrest Survival**

- Survival to hospital discharge after EMS-treated OHCA is estimated at 10.8% to 11.4%
- Survival to hospital discharge after in-hospital cardiac arrest IHCA is 25.8%
  - o 11% long term survival



American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics update

## **Goals of Care Communication**

- Ask-Tell-Ask
  - Assess understanding of current condition
  - Request permission to give information
  - Elicit patient goals and values
  - Respond to emotion

https://www.vitaltalk.org/topics/reset-goals-of-care/

#### New Mexico Uniform Health Care Decisions Act

- "advance health-care directive" individual instructions, and/or designation of a healthcare decision maker, for end of life made while the individual has capacity
- Provides a sample form entitled "Optional Advance Health-Care Directive"
- Provide direction and hierarchy for medical decision makers if no decision maker is named

N	New Mexico Medical Orders	Last Name/First/Middle Initial			
	r Scope of Treatment (MOST)	Address			
These n	Ilow these orders, then contact the healthcare provider. nedical orders are based on the person's current medi- dition and preferences. Any section not completed does	City/State/Zip			
	alidate the form.	Date of Birth (mm/dd/yyyy)			
Α	EMERGENCY RESPONSE SECTIO	N: Person has no pulse or is not breathing.			
Check	Attempt Resuscitation/CPR Do Not Atten	npt Resuscitation/DNR			
	When not in Cardiopulmonary arrest, follow orders in I	3, C and D.			
B	MEDICAL INTERVENTIONS: Patie	ent has a pulse			
Check One	Comfort Measures: Do not transfer to hospital unless comfort needs cannot be met in current location. 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.				
	Limited Additional Interventions: May include care as described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. Transfer to hospital if indicated. Avoid Intensive Care.				
		as described above. Use intubation, advanced airway ioversion as indicated. Transfer to hospital if indicated.			
С	ARTIFICIALLY ADMINISTERED I	HYDRATION / NUTRITION:			
Check	(Always offer food and liquids by mouth if feas				
One		o artificial hydration.			
	Time-limited trial of artificial nutrition. Ti Goal of the trial:	me-limited trial of artificial hydration.			
	Long-term artificial nutrition/hydration.				
D	Discussed with:  Patient  Healthcare Decision Make	er DParent of Minor Court Appointed Guardian Other			

#### DESIGNATION OF HEALTHCARE DECISION MAKER

(This designation can be completed only by a patient with decisional capacity)

The Designation of Healthcare Decision Maker is an advance healthcare directive and must be honored in accordance with state law (NMSA 1978§24-7A-1 et seq.) If there is a conflict between this directive and an earlier directive, the most current choice(s) made by the patient shall control.

If the time comes when I lack capacity and there are individual instructions as set forth in this MOST, I do decisions for me:		
Name:		
Address:		
Telephone Number:		
Signature of Patient:		Date:
If my agent listed above is not willing, able or availab individual as my alternate agent for the purposes of m		ne, I designate the following
Name:		
Address:		
Telephone Number:		
Signature of Patient:		Date:
SEND FORM WITH PATIENT WH	IENEVER TRANSFERRED OR DISCH	ARGED
Directions fo	or Healthcare Professional	

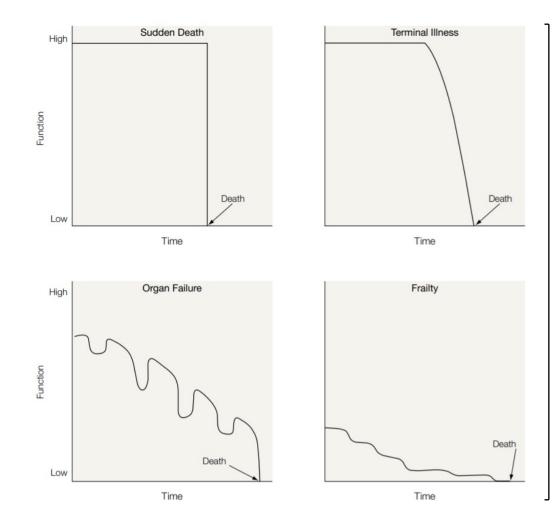
- · Must be completed by healthcare professional based on patient preferences and medical indications.
- · Choice of Medical Intervention and Cardiopulmonary Resuscitation status must be clinically aligned:
- Example: "Comfort Care" and "Attempt Resuscitation" are contradictory choices.
- MOST must be signed by an authorized healthcare provider and the patient/decision maker to be valid. Verbal orders are acceptable with follow-up signature by the authorized healthcare provider in accordance with facility/community policy.
- · Use of the original form is strongly encouraged. Photocopies and faxes of signed MOST forms are legal and valid.
- Authorized Provider is defined and updated in the Department of Health, Emergency Medical Services Regulation—Chapter 27.

# Prognosis and Disease Progression

#### Prognostication

- It allows for better decision making.
- It helps determine risk and benefits for treatment decisions.
- Patients and families want to know.
- It is necessary for the Medicare Hospice Benefit.





#### **Advanced Cancer**

- 30% of all deaths
- Single biggest predictive factor in cancer is functional status
- Patients with solid tumors typically lose ~ 70% of their functional ability in the last 3 months of life
- Karnofsky Scale, ECOG, and Palliative Performance Scale commonly used

#### KARNOFSKY PERFORMANCE STATUS SCALE DEFINITIONS RATING (%) CRITERIA

20

Moribund; fatal processes progressing rapidly.

GRADE	ECOG PERFORMANCE STATUS		100	Normal no complaints; no evidence of disease.
0	Fully active, able to carry on all pre-disease performance without restriction	Able to carry on normal activity and to work; no special care needed.	90	Able to carry on normal activity; minor signs or symptoms of disease.
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or		80	Normal activity with effort; some signs or symptoms of disease.
	sedentary nature, e.g., light house work, office work	Unable to work; able to live at home and care for most personal needs; varying amount of	70	Cares for self; unable to carry on normal activity or to do active work.
	Ambulatory and capable of all selfcare but unable to carry out any work activities; up and about			
2	more than 50% of waking hours		60	Requires occasional assistance, but is able to care for most of his personal needs.
3	assistan Capable of only limited selfcare; confined to bed or chair more than 50% of waking hours		50	Requires considerable assistance and frequent medical care.
4	Completely disabled; cannot carry on any selfcare; totally confined to bed or chair		40	Disable; requires special care and assistance.
5	Dead	Unable to care for self; requires equivalent of	30	Severely disabled; hospital admission is indicated although death not imminent.
	ech RH, Tormey DC, Horton J, Davis TE, McFadden ET, Carbone PP. Toxicity and response criteria of the Eastern Cooperative Oncology	institutional or hospital care; disease may be	20	Very sick; hospital admission necessary; active supportive treatment necessary.

progressing rapidly.

10

0

Dead

Group. Am J Clin Oncol. 1982 Dec;5(6):649-655. PMID: 7165009.

#### Karnofsky < 40 or ECOG 3 → median survival 3 months

#### **Advanced cancer**

- Malignant hypercalcemia: 8 weeks, except newly diagnosed breast cancer or myeloma.
- Multiple brain metastases: 1-2 months without radiation; 3-6 months with radiation.
- Malignant ascites, malignant pleural effusion, or malignant bowel obstruction: < 6 months.</li>

## **Organ Failure**

- Account for 40% of all deaths
- Multiple exacerbations, often frequent hospitalizations
- Patients usually die during exacerbations
- Renal, liver, cardiac, pulmonary

## **Heart Failure**

- NYHA classification remains the major gauge of disease severity
- 1-year mortality estimates are:
  - Class II (mild symptoms): 5-10%.
  - Class III (moderate symptoms): 10-15%.
  - Class IV (severe symptoms): 30-40%.

ACC/AHA Stage	NYHA Classification	Exercise Tolerance	Symptoms
A	-	Normal	None
В	-	Normal	None
C/D	Т	No limitations	No symptoms during physical activity
C/D	н	Mild limitation	Symptoms with moderate exertion
C/D	ш	Moderate limitation	Comfortable at rest only. Symptoms with mild exertion
C/D	IV	Severe limitation	Refractory symptoms at rest. Any physical activity causes discomfort

## **Heart Failure-prediction models**

- Seattle Heart Failure Model
  - Predicts 1, 2, 3 year survival with and w/o meds
  - Currently the most widely used scoring system
  - <u>http://depts.washington.edu/shfm/press.php</u>
- CCORT-CHF Rick Model
  - For patients presenting with heart failure in hospital-based setting
  - Predicts death at 30 days and one year
  - <u>http://www.ccort.ca/Research/CHFRiskModel.aspx</u>

Circulation 2006:113:1424-33. JAMA 2003; 290(19):2581-2587.

### **Liver Failure**

- Compensated chronic liver failure (without ascites, variceal bleeding, encephalopathy, or jaundice) → median survival of 12 years.
- After decompensation, median survival drops to ~ 2 years.
- Hepatorenal syndrome (HRS) renal failure from renal arterial under-filling due to decompensated liver failure
  - type-1 HRS (rapid and severe renal failure) most die within 8-10 weeks
  - type-2 HRS (chronic, less severe renal failure with serum creatinine usually 1.5-2 mg/dL) median survival around 6 months.
- Older age
- Hepatocellular carcinoma

#### **Liver Failure-prediction tools**

The Child's-Turcotte-Pugh (CTP) score includes 5 variables, each scored 1-3:

		Numerical Value	
Variable	1	2	3
Ascites	None	Slight	Moderate/Severe
Encephalopathy	None	Grade 1-2	Grade 3-4
Bilirubin (mg/dL)	< 2.0	2.0-3.0	>3.0
Albumin (mg/L)	> 3.5	2.8-3.5	<2.8
Increase in seconds from normal Prothrombin time	1-3	4-6	>6.0

- 5-6 points 'Class A' failure = 1 and 2 year median survivals are 95% and 90%
- 7-9 Class B with median survivals of 80% at 1 year and 70% at two years.
- 10-15 Class C 1-year median survival is 45% and 2-year is 38%.

#### **Liver Failure-prediction tools**

★ \$ MELD Score fo	or Liv	er Disease	Ċ
Serum Bilirubin:	0.4	mg/dL	
INR:	1.5	]	
Serum Creatinine:	0.8	mg/dL	
Patient has had dialysis at least twice in the past week:			
MELD Score: 21			Add to Chart
			Calculate

MELD Score	Predicted 6 month survival	Predicted 12 month survival	Predicted 24 month survival
0-9	98%	93%	90%
10-19	92%	86%	80%
20-29	78%	71%	66%
30-39	40%	37%	33%

#### **Renal Failure**

- Age is a strong predictor, five year survivals decrease with age
  - Age 45 to 54 years 60.5%
  - Age 55 to 64 years 46.3%
  - Age 64 to 74 years 31.7%
  - $\circ$  75 years and older 19.6%
- For patients > 80 years old dialysis offers **NO** mortality benefit

#### **Renal Failure**

- Overall 1 and 5 year mortality rates on dialysis are 25% and 60%, respectively.
- Albumin < 3.5  $\rightarrow$  50% one year survival and 17% 2 year survival!
- Functional status: increased relative risk of dying within 3 years of starting dialysis with Karnofsky Performance Status scores of <70</li>
- Long-term HD patients with no residual kidney function if stopping dialysis → 5-12 days

## **Renal Failure-MCCI**

#### Modified Charlson Comorbidity Index: Total score is the sum of the comorbidity points

#### **Comorbidity Points**

1 point each for coronary artery disease, congestive heart failure, peripheral vascular disease, cerebrovascular disease, dementia, chronic pulmonary disease, connective tissue disorder, peptic ulcer disease, mild liver disease, diabetes

1 point for every decade over 40 (e.g. a 65 year old would receive 3 points).

2 points each for hemiplegia, moderate-to-severe renal disease (including being on dialysis), diabetes with end-organ damage, cancer (including leukemia or lymphoma)

3 points for moderate-to-severe liver disease

6 points each for metastatic solid tumor or AIDS

Modified CCI Score Totals	Low score (≤3)	Moderate (4-5)	High (6-7)	Very High (≥8)
Annual mortality rate	0.03	0.13	0.27	0.49

- Stratifies patients based on medical comorbidities and age
- Successfully used to predict mortality in dialysis-dependent patients

#### **COPD-outpatient**

- A FEV1 of less than 35% of the predicted value  $\rightarrow$  severe disease
  - 25% of these patients will die within two years and 55% by four years
- Functional status
- Age
- Low body mass index (BMI)
- Serum inflammatory biomarkers (CRP, IL-6, and fibrinogen)

### **COPD-BODE** index

Variable	Points on BODE Index				
	0	1	2	3	
FEV1 (% predicted)	≥65	50-64	36-49	≤35	
Distance walked in 6 min (meters)	>350	250-349	150-249	≤149	
MMRC dyspnea scale*	0-1	2	3	4	
Body-mass index (BMI)	>21	≤21			

\*MMRC dyspnea scale range from 0 (none) to 4 (4 dyspnea when dressing or undressing).

BODE Index Score	One year mortality	Two year mortality	52 month mortality
0-2	2%	6%	19%
3-4	2%	8%	32%
4-6	2%	14%	40%
7-10	5%	31%	80%

Note: these variables do not appear to help predict prognosis within six months of death.

Figure 6. The Modified Medical Research Council Dyspnea Scale

#### mMRC Breathlessness Scale

Grade	Description of Breathlessness
0	I only get breathless with strenuous exercise
1	I get short of breath when hurrying on level ground or walking up a slight hill
2	On level ground, I walk slower than people of the same age because of breathlessness, or have to stop for breath when walking at my own pace
3	I stop for breath after walking about 100 yards or after a few minutes on level ground
4	I am too breathless to leave the house or I am breathless when dressing

Chris Stenton. The MRC breathlessness scale. Occup Med (Lond)(2008)58(3): 226-227 doi:10.1093/occmed/kqm162, Table 1. By permission of Coderd University Press on behalf of the Society of Occupational Medicine. A mMRC score of 1 or more suggest significant symptoms.

#### **COPD-inpatient**

- 10% of patients admitted with a PaCO2 >50 mmHg will die during the index hospitalization, 33% within 6 months, 43% within 1 year
- COPD patients requiring mechanical ventilation have in-hospital mortality of ~25%
- Previous mechanical ventilation, failed extubation, or intubation for greater than 72 hours all increase mortality
- Patients ventilated more than 48 hours had a 50% one year survival

# **Specialty Palliative Care**

#### **Domains of Palliative Care**



#### Primary Palliative

#### <u>Care</u>

-Basic symptom management -Shared decision-making - Discussions re: prognosis

#### -Discussions re: preferences for and goals of treatment -Advance care planning

#### Secondary Palliative Care

-Refractory or complex symptoms -Psychosocial or spiritual distress -Conflict resolution -Complex decision-making -Transition to hospice is desired Provided by:

- General cardiologist
- Advanced HF
- Internist

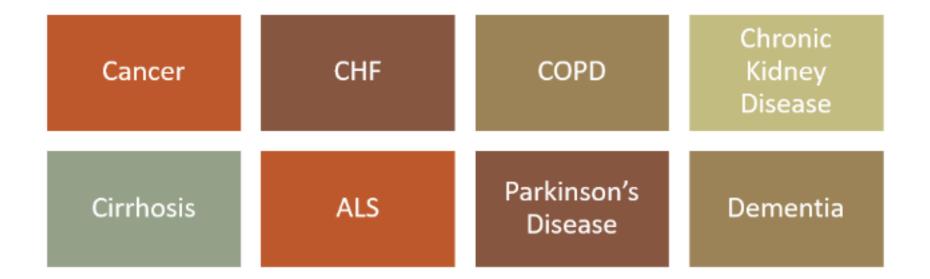
 Provided by:
 Board certified palliative care clinician

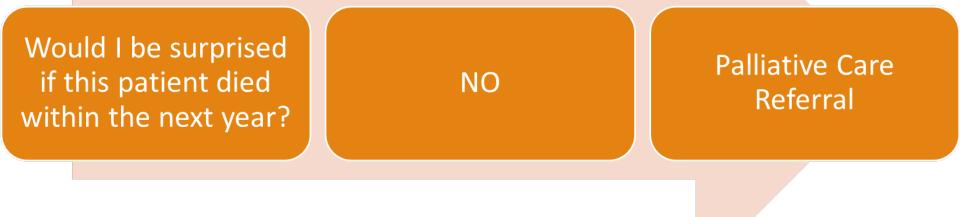
Rate of Pallative Care in the Outpatient Management of the Chronic Heart Failure Patient - Scientific Figure on ResearchGate. Available from: https://www.researchgate.ret/figure/Primary-en-specialty-secondary-pallative-care\_sig1\_137712386 [accessed 7 Apr, 2022]

# Who is an Appropriate Referral?

- Anyone with a serious illness experiencing uncontrolled symptoms, such as
  - Pain
  - Dyspnea
  - Anxiety
  - Nausea/vomiting
  - GI symptoms
- Anyone with a serious or chronic illness needing
  - Spiritual support
  - Emotional support
  - Goals of care clarification
  - Care coordination

### **Common Disease States**

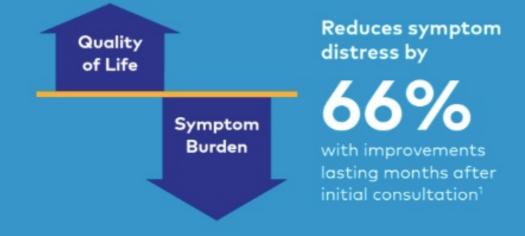




BMC Med. 2017; 15(1):139.

### **Benefits of Specialty Palliative Care**

#### IMPROVES QUALITY OF LIFE AND SYMPTOM BURDEN



DRIVES HIGH SATISFACTION AND POSITIVE PATIENT EXPERIENCES

93%

of people who received palliative care are likely to recommend it to others<sup>2</sup>

www.capc.org

Kavalieratos, D, J Corbelli, and D Zhang. JAMA, (2016): 316(20) Boehler, A. NICHM Foundation Webinar, "Prioritizing Super-Spenders: Coverage and Care for High-Need Patients." (May 19, 2017)

### **Benefits of Specialty Palliative Care**

#### PALLIATIVE CARE REDUCES AVOIDABLE SPENDING AND UTILIZATION IN ALL SETTINGS 48% 50% 43% 36% readmissions total costs ED transfers 28% 35% ED visits cost/day INPATIENT OUTPATIENT SKILLED NURSING HOME-BASED

www.capc.org

# Pearls of Symptom Management

# **Principles of Symptom Management**

- Use frequent, standard assessment
- Oral medications when possible, altering the route as needed
- Assess for medication side effects; anticipate and treat as necessary
- Discontinue medications no longer contributing to symptom control
- Address possible reversible contributing causes

# **Medication Reconciliation**

- Verify indication
- Assess for potential vs. actual burdens
  - Side effects  $\bigcirc$
  - Frequency of administration 0
  - Financial toxicity Polypharmacy Ο
  - Ο
  - How has the patient's overall health changed since 0 initially prescribed
- - Patient preference goals of care 0
  - Prognosis 0

# Deprescribing

- The practice of discontinuing potentially inappropriate prescription and nonprescription medications in patients when the possible risks outweigh the benefits
- Management of polypharmacy
- Decrease drug-drug interactions
- Decrease drug-disease interaction
- Identify inappropriate dosing
- Decrease pill burden for patients and in turn improve adherence to medications
- Encourage and improve patient engagement in medication management
- Resolution of adverse drug reactions

#### Edmonton Symptom Assessment System

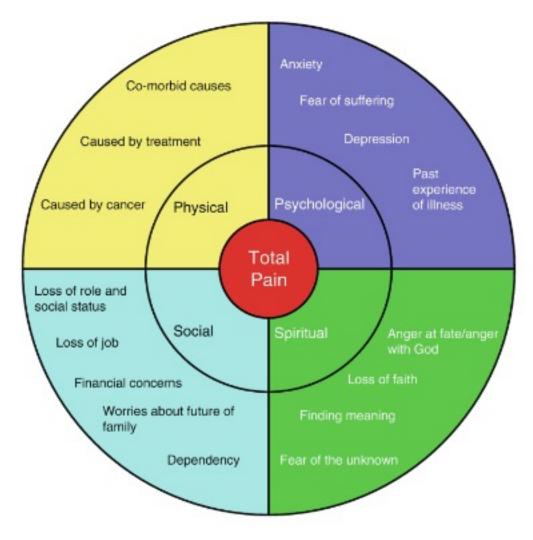
Print/stamp	nam	e:											
Asessed by (	(sign	atur	e/cre	eden	tials	/ID#	/dat	e/tin	ne):				
Completed by:							Patient				E Family		
Please circle the number that best describes your average symptom over the past 24 hours:													
No pain	0	1	2	3	4	5	6	7	8	9	10	Worst pain	
No fatigue	0	1	2	3	4	5	6	7	8	9	10	Worst fatigue	
No nausea	0	1	2	3	4	5	6	7	8	9	10	Worst nausea	
No depression	0	1	2	3	4	5	6	7	8	9	10	Worst depression	
No anxiety	0	1	2	3	4	5	6	7	8	9	10	Worst anxiety	
No drowsiness	0	1	2	3	4	5	6	7	8	9	10	Worst drowsiness	
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst shortness of breath	
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite	
Best feeling or wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst feeling of wellbeing	
Best sleep	0	1	2	3	4	5	6	7	8	9	10	Worst sleep	

Originally published in: Bruera E, Kuehn N, Miller MJ, et al. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991; 7:6.

Copyrights apply

### **Pain Assessment**

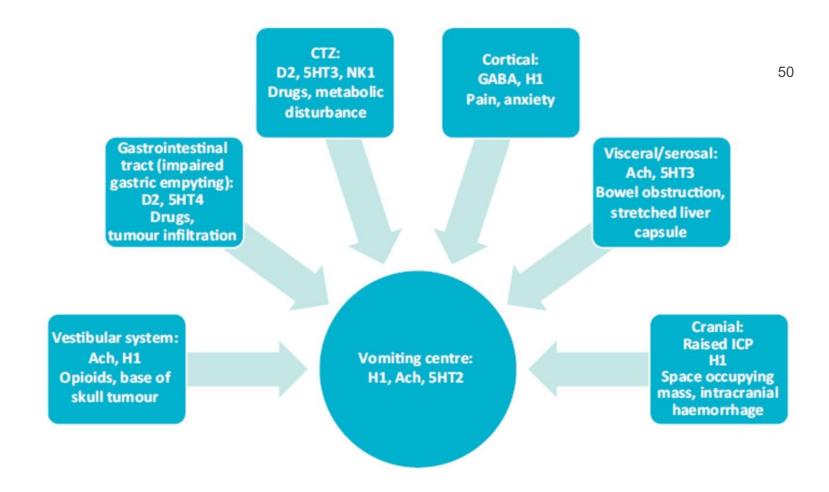
- P = palliating/provoking
- Q = quality
- R = region/radiation
- S = severity
- T = timing (onset, duration, frequency)
- U = YOU (goals, activity level, QOL)



# **Nausea and Vomiting**

Gastric + non-gastric trigger areas are involved in N/V Five principal receptors mediate vomiting: •Muscarinic M1 •Dopamine D2 •Histamine H1 •5 hydroxytryptamine 5HT-3 •Neurokinin NK1

•N/V are common at end of life: 40% of patients report N/V during the last 6 weeks of life



## **Fatigue in Advanced Cancer**

Potential contributors

Anemia

•Autonomic dysfunction

Cancer-related symptoms

Pain, anxiety, depression, dyspnea, anorexia/cachexia, insomnia

Treatment related

Comorbidities

Deconditioning

Dehydration

Hypoxia

Infection

•Neuroendocrine alterations

Polypharmacy

Tumor byproducts - inflammatory cytokines

# **Fatigue Management**

Non-pharmacologic

Education, exercise, acupuncture

•Pharmacologic

Psychostimulants

Methylphenidate – initial dose of 2.5-5 mg PO daily, increase to 15-30 mg PO daily Modafanil – initial dose of 50 mg PO daily, increase to 200-400 mg PO daily

Corticosteroids

Dexamethasone 1-4 mg PO daily – BID

•Megestrol acetate 160 mg PO TID

•Antidepressants

Bupropion 150 mg PO daily

Paroxetine 20 mg PO daily

# Dyspnea

·Defined as a discomfort in breathing

Common symptom in advanced cancers and other advanced illnesses (e.g. CHF, COPD, AIDS)

 Subjective sensation influenced by physical, psychological, social, and spiritual factors

### Pathophysiology

•Physical respiratory impedance – pleural effusions, PE, increased secretions, pneumonia, COPD, weakness in respiratory muscles

•Chemical causes – hypercapnia, hypoxia

•Neuromechanical dissociation – mismatch between what the brain expects as respiration and signals it receives

# **Dyspnea Treatment**

- Non-pharmacologic
  - Re-positioning (avoid lying flat), maintain cool room temps, relaxation exercises, acupuncture, minimal exertion
- Pharmacologic
  - Oxygen therapy for documented hypoxia esp. COPD
  - Opioids first-line treatment
    - MOA: Decrease chemoreceptor response to hypercapnia, increase peripheral vasodilatation with decrease in cardiac preload, decrease anxiety and subjective feeling of dyspnea
    - No optimal agent or dose although nebulized route not shown to be superior; consider opioid naïve vs. opioid-tolerant patient
      - Morphine most commonly used (typical starting dose 2.5-5mg PO/SL q4h PRN)
      - Rescue doses at 30-50% of scheduled dose typically effective
  - Anxiolytics
    - Benzodiazepines reserved for breakthrough or refractory dyspnea compounded by anxiety or when ADRs limit titration of opioids to efficacy

## **Top Ten Tips from PC Pharmacists**

1.Fentanyl is tricky due to variable PKs

2.Drug-induced QT prolongation is dose and route related; uncommon at doses typically used in PC

3.Corticosteroids are amazing (my favorite drug is dexamethasone J)

4.Opioid selection should depend on PK with particular caution using methadone

5.Remember the "odd ball" side effects with PC medications

6.Management of refractory constipation

7.Immunotherapy targeted oral oncolytics – adverse effects and management

8.Uses and adverse effects of olanzapine

9.Consider the good, bad, and ugly of NSAID use

10.Benzodiazepines may be useful for anxiety, dyspnea, and insomnia

# Medical Aid in Dying

### **Definitions**

# Medical Aid in Dying (MAID)/Physician-assisted dying/Death with Dignity

"A practice in which the physician provides a terminally ill patient with a prescription for a life-ending dose of medication, upon the patient's voluntary, informed request."

### **Reasons patients seek MAID**

• Data from Oregon

loss of autonomy (87%)

 decreasing ability to participate in activities that made life enjoyable (90%)

loss of dignity (72%)

 "Poor pain control is an indication for better palliation, not death."

> https://deathwithdignity.org/news/2020/03/2019-report-onoregon-death-with-dignity-act/

## **Current legal and ethical status**

- 9 states plus the District of Columbia now with death with dignity/medical aid in dying statue
  - o Oregon 1997
  - Montana 2008 By supreme court ruling
  - o Vermont 2013
  - o California 2015
  - o Colorado 2016
  - Washington D.C. 2017
  - o Hawaii 2018
  - Maine and New Jersey 2019
  - New Mexico 2021

https://deathwithdignity.org/news/2021/09/2021-annual-report/

# Elizabeth Whitefield End-of-Life Options Act (HB 47)

- New Mexico's End-of-Life Options Act provides for "medical aid in dying"
- The law went into effect June 18, 2021
- Updates during the 2023 Legislative Session
  - Use of Medicaid funds to cover the medication cost for Medicaid eligible patients
  - Added that providers will not be disciplined or sanctioned for declining to provide information on or referral for MAID

# **Qualified Individual**

The individual must be an **ADULT** at least 18 years old and a **RESIDENT** of NM.

The prescribing provider must determine that the individual has:

- **1. CAPACITY**
- 2. TERMINAL ILLNESS
- **3. VOLUNTARILY**
- 4. ABILITY TO SELF-ADMINISTER

## **Healthcare Provider**

Any of the following individuals licensed in New Mexico and authorized under NM law to prescribe a medication to be used in MAID:

- 1. Medical Physician
- 2. Osteopathic Physician
- 3. Advanced Practice Nurse
- 4. Physician Assistant

If the individual is not enrolled in hospice, two providers, at least one physician (MD/DO), must determine that the individual is qualified.

Only one provider is needed if the individual is already enrolled in Hospice.

# Capacity

- Should be determined according to professional standards of care and the NM
   Uniform Health Care Decisions Act
- If concern exists about capacity, or if current or recent mental illness or disability that could impair capacity for end-of-life decision-making, must be referred to a mental health professional
- Mental Health Professional a NM-licensed psychiatrist, psychologist, master social worker, psychiatric nurse practitioner or professional clinical mental health counselor
- MAID cannot proceed until the individual has been determined to have capacity to make end-of-life decisions.

## **Prescribing MAID**

- A form required by law must be completed and signed by the individual requesting MAID and witnessed by two persons.
  - One of which must be a disinterested party.
  - Prescriber must include it in the health record.
- 48-hour hold before it can be filled UNLESS the prescriber affirms the individual will not survive the waiting period.
- The prescribing provider is responsible for reporting required information to State.

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## **Other Provisions**

- "Right to Know" Providers must inform terminally ill patients of all reasonable and legally available options for end-of-life care.
- "Medical Aid in Dying" NOT considered "suicide" for any purpose (including death certificate); and, if the law is followed in good faith, it is also not considered "assisted suicide". ("Assisting Suicide" remains 4<sup>th</sup> degree felony)
- A <u>person</u> shall not be subject to criminal liability, licensing sanctions or any type of professional or employment disciplinary actions for participating or refusing to participate in MAID; or for being present when a qualified patient self-administers the medication.
- A health care entity, provider, professional organization, health insurer or managed care organization shall not subject a person to censure, discipline, suspension, loss/denial of license, credential, privileges, membership or other penalty for participating in MAID or not.

### **Other Provisions**

• If a "health care provider" is unable or unwilling to participate, he/she must inform the individual, refer to another willing provider OR to an individual or entity who will assist the individual seeking MAID. No health care provider shall be required to participate.

2023 update specifies a provider is not required to refer

- "Health Care Entity" is an entity (not individual) licensed to provide any form of healthcare in NM, including a hospital, clinic, hospice agency, home health agency, pharmacy, group medical practice, medical home or similar entity.
  - A health care entity that prohibits MAID on premises or by employees shall provide appropriate public notice on their website and in relevant materials given to patients.
  - A health care entity shall not forbid or otherwise sanction a provider who participates off premises, off hours or outside scope of employment

# **Medication Ingestion**

- Powder form, specifically compounded for MAID
   Medications to control nausea are administered beforehand
- Medication is mixed in liquid and put in a glass...straw may be used
  - May be ingested through feeding tube or rectal/Macy tube but patient must still be able to physically initiate ingestion in order to still meet Self-Administration requirement
- Ingestion should be completed within 2 minutes
- Sleep occurs within 2-10 minutes, then coma; death usually within 2-5 hours
- Cost of medications approx. \$700

# Aid in Dying Pharmacologic Regimen

DDMAPh

• Digoxin 100 mg (from powder, not crushed tablets)

- Diazepam 1 gm (1,000 mg)
- Morphine 15 gm (15,000 mg)
- o Amitriptyline 8 gm (8,000 mg)

• Phenobarbital 5 gm (5,000 mg)

- Pre-medicate for nausea/vomiting: Ondansetron 8mg, Metoclopramide 20mg (10mg tabs, #2)
- Sleep in 2-10 minutes, death usually in usually < 2 hours</li>

# Hospice and Medical Aid in Dying

- Experience in other states More than 90% of MAID patients are on Hospice
- Level of participation can differ from hospice to hospice, including:
  - Provides emotional support in decision-making
  - Participates in logistical planning coordination with prescriber, pick-up medications, assist patient/family to plan timing, etc.
  - Medical Director serves as consulting provider
  - Present for ingestion
  - Mix medications
  - Hospice Medical Director prescribes MAID

### Conclusions

- Primary palliative care is the provision of basic supportive care by primary care physician for patients with serious illness
- Easy to use and readily available tools exist for communication with patients and families abut prognosis and goals-of care
- Specialist palliative care may be appropriate for those with complex supportive needs
- Commonly encountered symptoms of serious illness can be managed effectively by primary care physicians
- New Mexico law allows for medical aid in dying as an end of life option for qualifying individuals