THE ACTIVELY DYING PERSON

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KAISER PERMANENTE SOUTHERN CALIFORNIA

NO DISCLOSURES

ACTIVE DYING DEFINED

- By definition, actively dying patients are very close to death, and exhibit many signs and symptoms of near-death
  - Typically 3 days within death

IS MY PERSON ACTIVELY DYING?

One to Three Months

- Decreased appetite
- Increased sleep
- Withdrawal from people and environment

One to Two Weeks

- More sleep
- Confusion
- Restlessness
- Vision-like experiences
- Change in temperature, RR, HR, BP
- Congestion
- Not eating

Days or Hours – Active Dying Phase

- Surge of energy
- Decreased blood pressure
- Glassy, teary eyes
- Half-opened eyes
- Irregular breathing
- Increased restlessness
- Cold, purple, blotchy feet and hands
- Weak pulse
- Decreased urine output

Minutes

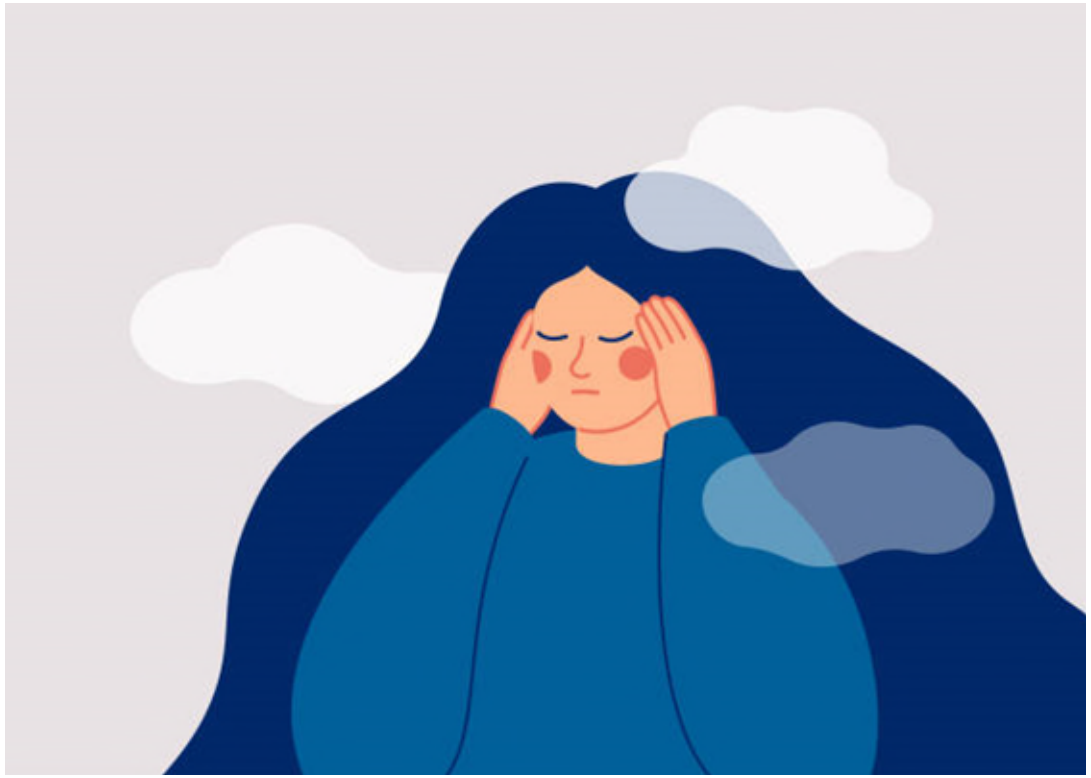
- Gasping breathing
- No awakening

ONE WEEK PRIOR TO DEATH

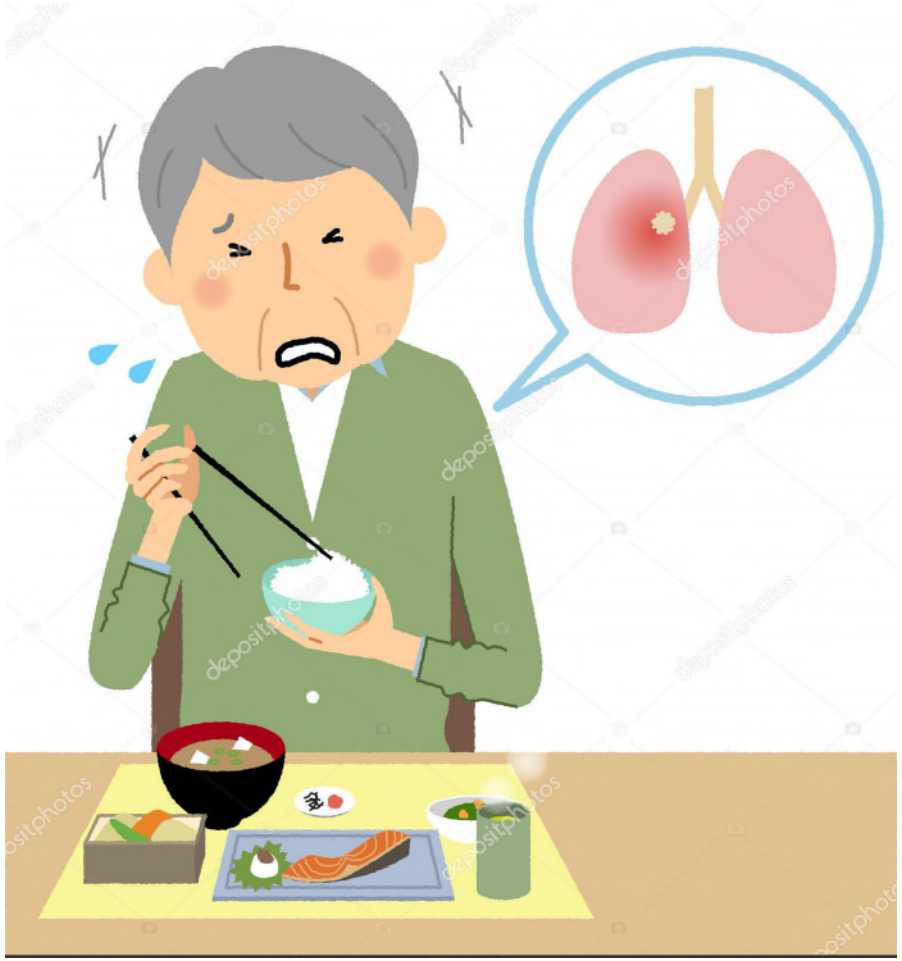
Hui D. et al. Bedside Clinical Signs Associated With Impending Death in Patients With Advanced Cancer: Preliminary Findings of a Prospective, Longitudinal Cohort Study. Cancer 2015;121:960-967.
Hui D, et al. Clinical Signs in Cancer Patients. The Oncologist 2014;19:681–687
Morita T, et al. A prospective study on the dying process in terminally ill cancer patients. Am J Hosp Pall Care. Jul-Aug 1998;15(4):217-22.

PERIPHERAL EDEMA

DELIRIUM / RESTLESSNESS

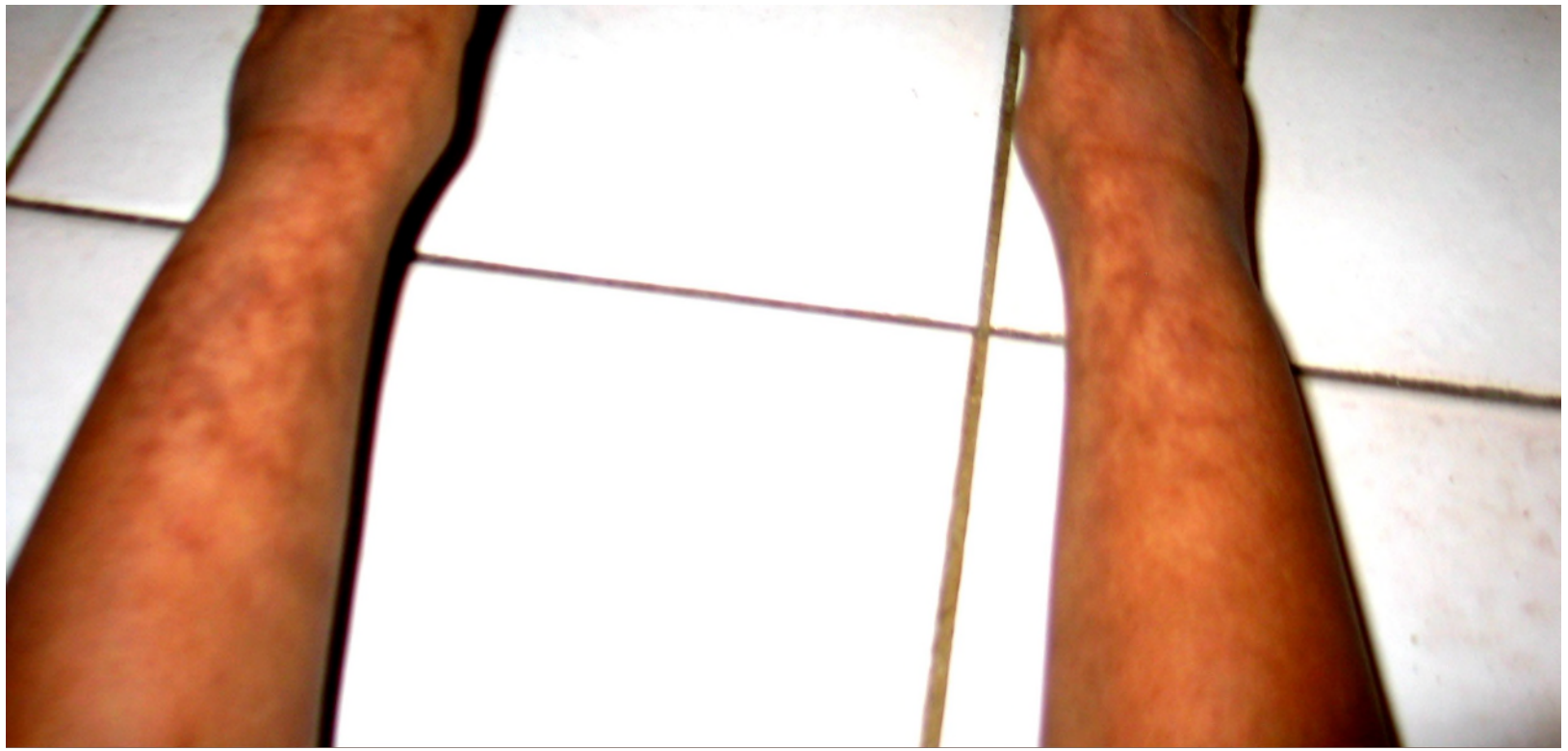


DYSPHAGIA FOR SOLIDS



DECREASED SPEECH

MOTTLED / CYANOTIC SKIN



4-6 DAYS BEFORE DEATH

ABNORMAL VITAL SIGNS

DECREASED LEVEL OF CONSCIOUSNESS

DYSPHAGIA FOR LIQUIDS

2-3 DAYS BEFORE DEATH

ACTIVE DYING PHASE

PPS 20% OR LESS

PALLIATIVE PERFORMANCE SCALE (PPS)

%	Ambulation	Activity Level Evidence of Disease	Self-Care	Intake	Level of Consciousness	Estimated Median Survival in Days (a)	(b)	(c)
100	Full	Normal *No Disease*	Full	Normal	Full	N/A	N/A	108
90	Full	Normal *Some Disease*	Full	Normal	Full			
80	Full	Normal with Effort *Some Disease*	Full	Normal or Reduced	Full			
70	Reduced	Can't do normal job or work *Some Disease*	Full	As above	Full	145		
60	Reduced	Can't do hobbies or housework *Significant Disease*	Occasional Assistance Needed	As above	Full or Confusion	29	4	
50	Mainly sit/lie	Can't do any work *Extensive Disease*	Considerable Assistance Needed	As above	Full or Confusion	30	11	41
40	Mainly in Bed	As above	Mainly Assistance	As above	Full or Drowsy or Confusion	18	8	
30	Bed Bound	As above	Total Care	Reduced	As above	8	5	
20	Bed Bound	As above	As above	Minimal	As above	4	2	6
10	Bed Bound	As above	As above	Mouth Care Only	Drowsy or Coma	1	1	
0	Death	-	-	-	-			

(a) Survival post-admission to an inpatient palliative unit, all diagnoses (Virik 2002).
(b) Days until inpatient death following admission to an acute hospice unit, diagnoses not specified (Anderson 1996).
(c) Survival post admission to an inpatient palliative unit, cancer patients only (Morita 1999).

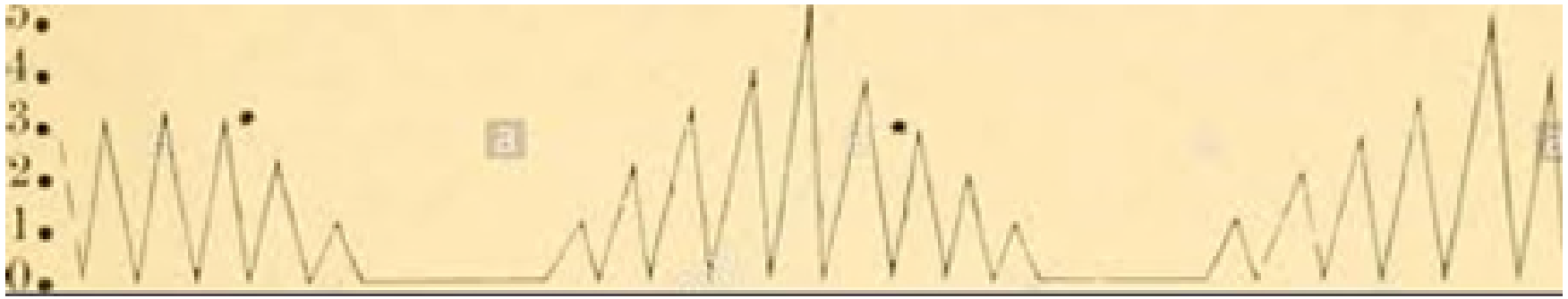
DROOPING OF NASOLABIAL FOLDS

In one study, PPS < 20% + drooping of nasolabial folds = 94% chance of death within 3 days

Hui D, et al. A diagnostic model for impending death in cancer patients: Preliminary report. Cancer. 2015;121(21):3914.

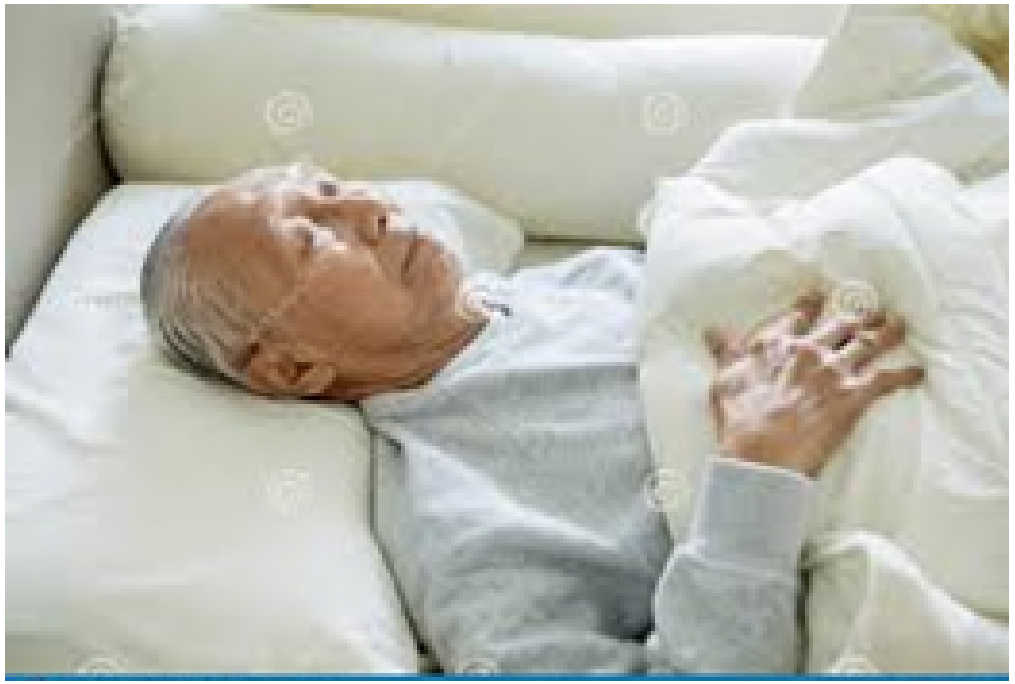
HYPEREXTENSION OF THE NECK

CHEYNE-STOKES BREATHING



NON-REACTIVE PUPILS

DECREASED RESPONSIVENESS



<2 DAYS BEFORE DEATH

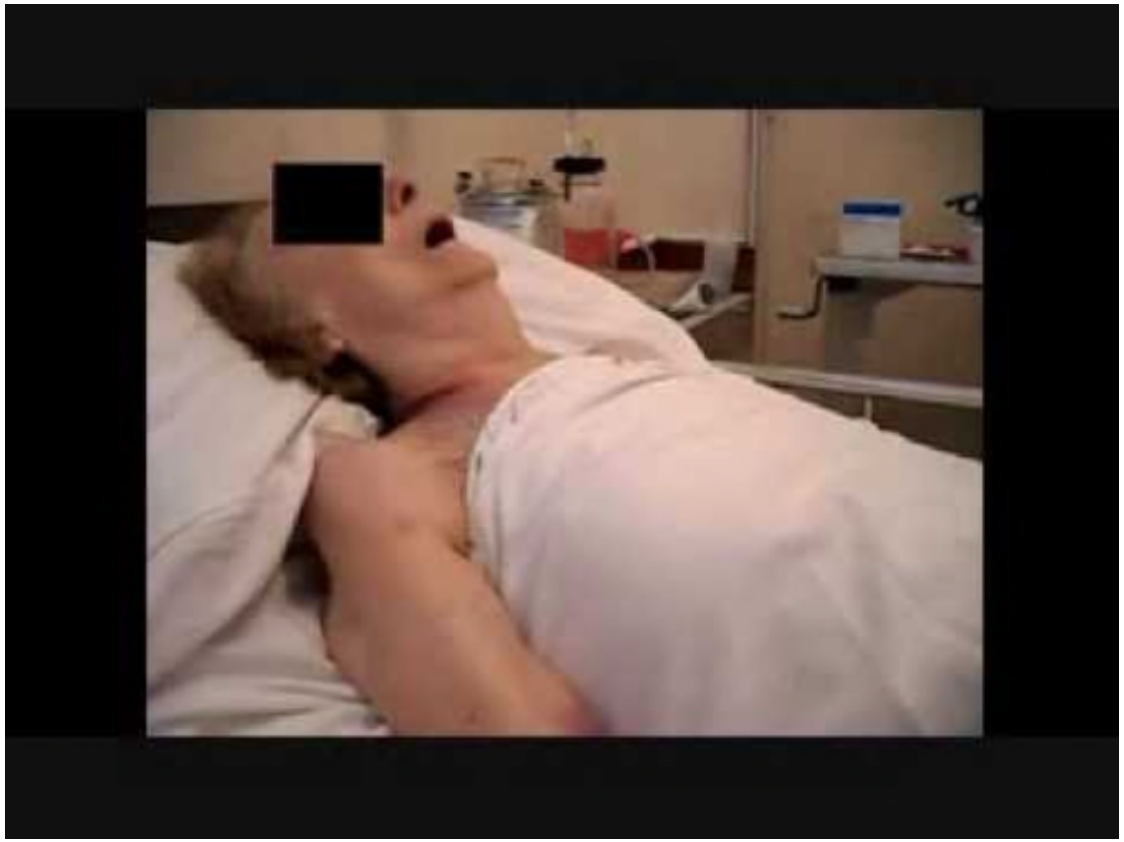
DEATH RATTLE

- Named for Drs John Cheyne and William Stokes - early 1800s
- Average time from symptom to death is 16 hours
- Prevalence: 60%
- Swallowing dysfunction:
  - Tongue loses ability to push saliva backward into the esophagus, so liquid may enter the lung
  - Epiglottis may stop protecting the trachea
- Not correlated with respiratory distress
- Treat: **Repositioning**, Oral swabs, hyoscyamine, atropine, **glycopyrrolate**, scopolamine, octreotide

Manning Peskin, S. The Symptoms of Dying. NYT, June 2017.

APNEA

RESPIRATION WITH MANDIBULAR MOVEMENT



DECREASED URINE OUTPUT

PULSELESS RADIAL ARTERY

INABILITY TO CLOSE EYES

GRUNTING

FEVER

WHAT TO EXPECT

- A direct relationship exists between the number of clinical signs of dying and death:
- Persons with two clinical signs of dying had a 40% chance of dying
- Persons with eight clinical signs of dying had a more than 80% chance of dying

Hui D, et al. A diagnostic model for impending death in cancer patients: Preliminary report. Cancer. 2015;121(21):3914.

THE THREAD OF GRIEF

- Denial – This cannot be happening
- Anger – Why is this happening?
- Bargaining – If I just do better, than this will go away
- Depression – This is devastating and I am hopeless
- Acceptance – I don't like it, but I will do my best
- Meaning – How do I best honor this life?

Kubler-Ross Stages of Grief

Kessler The Sixth Stage of Grief, Nov 2019.

HAS MY PERSON EXPIRED?

- No one can predict the time of death, even if the person is exhibiting typical end-of-life signs and symptoms
- Death pronouncement – ABCs
- Rigor mortis: Occurring two to four hours after death, this is the temporary stiffening of the muscles
- Algor mortis: This is the cooling of the body to room temperature - skin becomes fragile and easily torn
- Liver mortis: This is the decomposition or breakdown of red blood cells - elevating the head of the bed can lessen the color changes in the upper body

DISEASE SPECIFIC FEATURES OF DYING

- Heart disease: 655,381
- Cancer: 599,274
- Accidents (unintentional injuries): 167,127
- Chronic lower respiratory diseases: 159,486
- Stroke (cerebrovascular diseases): 147,810
- Alzheimer's disease: 122,019
- Diabetes: 84,946
- Influenza and pneumonia: 59,120
- Nephritis, nephrotic syndrome, and nephrosis: 51,386
- Intentional self-harm (suicide): 48,344

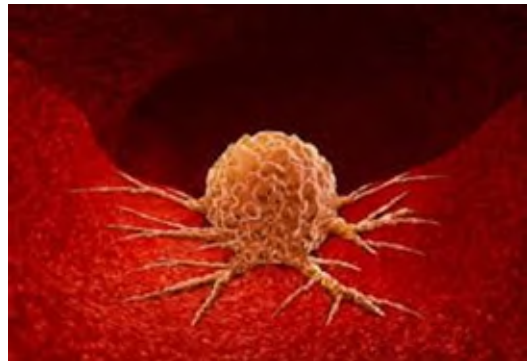
Covid-19 is now 3rd leading cause of death

CDC 2018 data

CONGESTIVE HEART FAILURE

- Dyspnea
- Edema – peripheral, abdominal, sacral
- Cough / wheezing
- Delirium – may be related to hyponatremia
- Tachycardia
- Hypotension
- Cardiac cachexia / anorexia

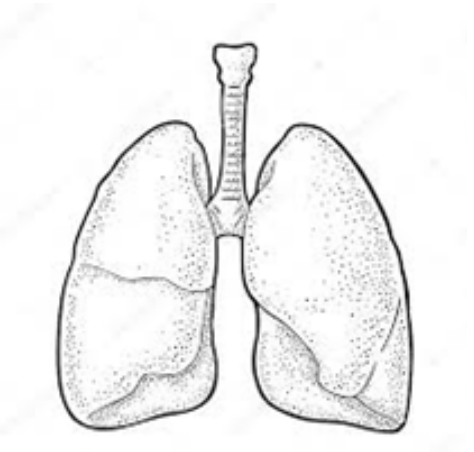
CANCER



- Fatigue
- Anorexia
- Anhedonia
- Organ specific
  - Lung cancer: cough, dyspnea, pulmonary edema
  - Pancreatic / liver cancer: jaundice, abd or back pain, ascites, nausea
  - Colon cancer: bowel obstruction or dysfunction, abd pain

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

- Somnolence – hypercarbia
- Dyspnea – pursed lip breathing
- Anxiety / Depression
- Delirium



DEMENTIA

- Limited speech
- Dysphagia
- Decreased ambulation or truncal control
- Incontinence
- Delirium
- Sleep wake reversal / increased sleep
- Nonverbal behaviors: moan, yell, withdraw, grimace, sweat, restlessness

RENAL FAILURE

- Uremia
  - N/V
  - Fatigue
  - Muscle cramps
  - Delirium
- Pruritis
- Edema
- Decreased urine output

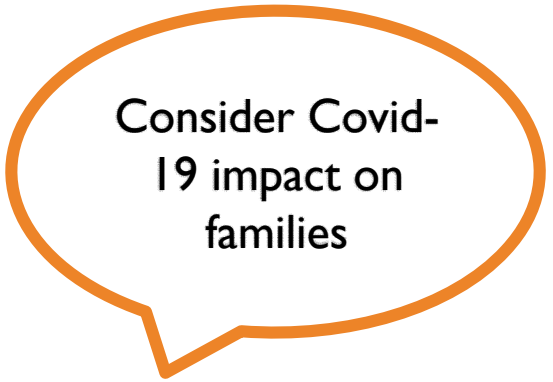
FEATURES OF A HIGH QUALITY DEATH

- Preference for a specific dying process – 94%
- Being pain free – 81%
- Emotional well-being – 64%
- Religious or spiritual element – more important to patients>family
- Treatment preferences
- Dignity - more important to family>patients
- Family
- Quality of life - more important to family>patients
- Relationship with health care provider
- Life completion – more important to family>patients

Meier, E, et al. Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. April 2016, Am J Geri Psych: 24(4): 261.271.

FEATURES OF A HIGH QUALITY CARE TEAM

- Clinical competence
- Willingness to educate
- Calm and empathic reassurance
- Death in an institution requires accommodations to assure privacy, cultural observances, and anticipatory communication
- Care does not end until the family has been supported with their grief reactions



Ferris FD, et al. Competency in End of Life Care. J Palliat Med. 2003;6(4):605.

DIFFERENCES IN ACTIVE DYING BY RACE, GENDER, RELIGION, LANGUAGE, SEXUAL ORIENTATION OR GENDER IDENTITY

- No good evidence to share
- A plea for individual approach – uncover implicit biases, invest in the personal
  - Half of white medical trainees hold false beliefs about black people
  - Black patients are 22% less likely than white patients to receive pain medication

Hoffman k, et al. Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites. Proceedings of the NAS, April 2016, 113 (16) 4296-4301.
Mehani S, et al. Time to take stock: a meta-analysis and systematic review of analgesic treatment disparities for pain in the US. Pain Med. 2012 Feb;13(2):150-74.

ARE WE STARVING MY LOVED ONE?

- Fluid recommendations:
  - Women 91 oz daily
  - Men 125 oz daily
- Around 20% of fluid intake daily comes from food
- Survival without food alone ~ two months
- Survival without water ~ 8-21 days
- Outcome ->
  - Body temperature and blood pressure dysregulation
  - Electrolyte abnormalities
  - Brain edema
  - Joint stiffness

National Academies of Medicine
Kottusch P, et al. Arch Kriminol, Nov-Dec 2009;224(5-6):184-91.

HYDRATION

Pros

- May add hours-days of life if given early enough in disease course (PC vs HO)
- Decreased delirium
- Reduced fatigue

Cons

- Less pain
- Fewer BMs, n/v
- Reduced edema

Bruera E, et al. J Clin Oncol 2013

THIRST

- Oral care – moisten and cleanse oral cavity
- Stop drugs contributing to xerostomia
- Artificial saliva, mouth rinses, popsicles or sour lollipops
- Evaluate dentition / dentures

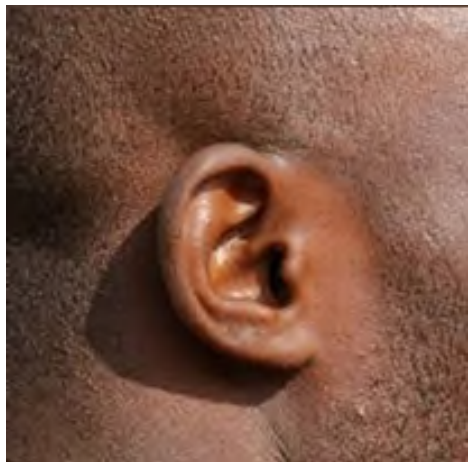
Bruera E Supp Oncology 2004.

IS MY LOVED ONE IN PAIN?

- Pain does not inevitably increase as death advances
- (Dyspnea and dysphagia likely to increase)
- Monitor for nonverbal signs of pain
  - "ouch" "stop" profanity
  - Cries, whines, gasps, combativeness
  - Grimace, furrowed brow, clenched teeth
  - Guarding a limb, restlessness, rubbing
- Limit unnecessary medications and interventions
  - Prioritize family / caregiver communication
  - Symptom control
  - Personalized experience

Booker S, Haedtke C. Controlling pain and discomfort, part 2: assessment in non-verbal older adults. Nursing, 2016 May: 46(5): 66-69.

CAN MY LOVED ONE HEAR ME?



- Evaluate baseline hearing ability
- Assume that that your person can hear you
  - Talk gently
  - Explain direct caregiving
  - Introduce new people
  - Play intermittent music or podcasts or other sounds that may be desired by the person

THERAPEUTIC CONSIDERATIONS

- **"Free from avoidable distress and suffering for patient, family and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural and ethical standards."**

Institute of Medicine