THE ACTIVELY DYING PATIENT

PURVI PATEL, MD MBA

HOSPICE & PALLIATIVE MEDICINE

KAISER PERMANENTE SOUTHERN CALIFORNIA

DISCLOSURES

I have nothing to disclose.

“ACTIVELY DYING”

Very close to death

2 phases

- Pre-active
- Active

Signs/symptoms

- Within 3 days of death

1 – 3 MONTHS
↓ appetite
↑ sleep
Withdrawal from people & environment
Less need to socially engage

1 – 2 WEEKS
↑ sleep
Disorientation
Restlessness
Non-pathologic vision-like experience
△ VS (temperature, RR, HR BP)
Congestion
Little PO/taste △es

DAYS – HOURS
Surge of energy (false sense of recovery)
↓ BP
Glassy/teary eyes, eyes ½ open
Irregular breathing/apneic periods
Delirium/agitation
Mottling (cold, purple, blotchy feet & hands)
Weak pulse
↓ U.O.
Fever

MINUTES
Gasping
No awakening

1 – 3 MONTHS
↓ appetite
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Gasping
No awakening

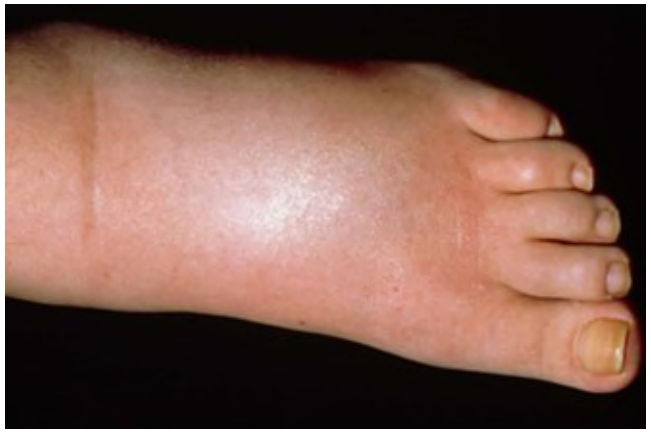
1 WEEK PRIOR TO DEATH

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

Confusion Assessment Method (CAM)

Short form

island health

The diagnosis of delirium by CAM requires the presence of **BOTH** features ***A*** and ***B***		
C A M Confusion Assessment Method	**A.** **Acute onset** and **Fluctuating course**	Is there evidence of an acute change in mental status from patient baseline? Does the abnormal behavior: ➢ come and go? ➢ fluctuate during the day? ➢ increase/decrease in severity?
	B. **Inattention**	Does the patient: ➢ have difficulty focusing attention? ➢ become easily distracted? ➢ have difficulty keeping track of what is said?
	AND the presence of EITHER feature *C or D*	
	C. **Disorganized thinking**	Is the patient's thinking ➢ disorganized ➢ incoherent For example does the patient have ➢ rambling speech/irrelevant conversation? ➢ unpredictable switching of subjects? ➢ unclear or illogical flow of ideas?
	D. **Altered level of consciousness**	Overall, what is the patient's level of consciousness: ➢ alert (normal) ➢ vigilant (hyper-alert) ➢ lethargic (drowsy but easily roused) ➢ stuporous (difficult to rouse) ➢ comatose (unrousable)

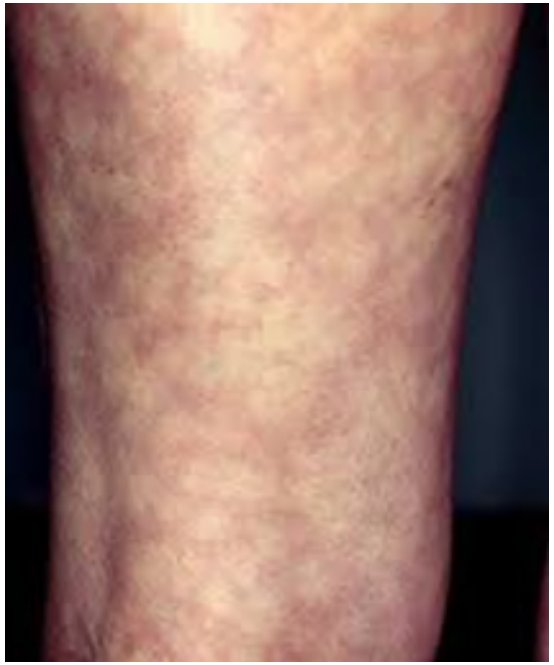
Adapted with permission from: Inouye SK, vanDyck CH, Alessi CA, Balkin S, Siegal AP, Horwitz RI. Clarifying confusion: The Confusion Assessment Method. A new method for detection of delirium. Ann Intern Med. 1990; 113: 941-948. Confusion Assessment Method: Training Manual and Coding Guide, Copyright © 2003, Hospital Elder Life Program, LLC.

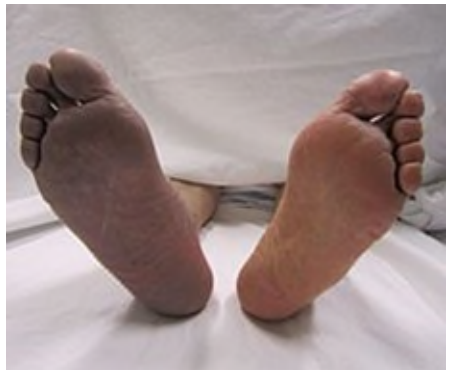
Please see the **CAM Training Manual**, available at
http://www.hospitalelderlifeprogram.org/private/cam-disclaimer.php?pageid=01.08.00

DYSPHAGIA FOR SOLIDS

DECREASED SPEECH

MOTTLED/CYANOTIC SKIN





4-6 DAYS BEFORE DEATH

ABNORMAL VITAL SIGNS

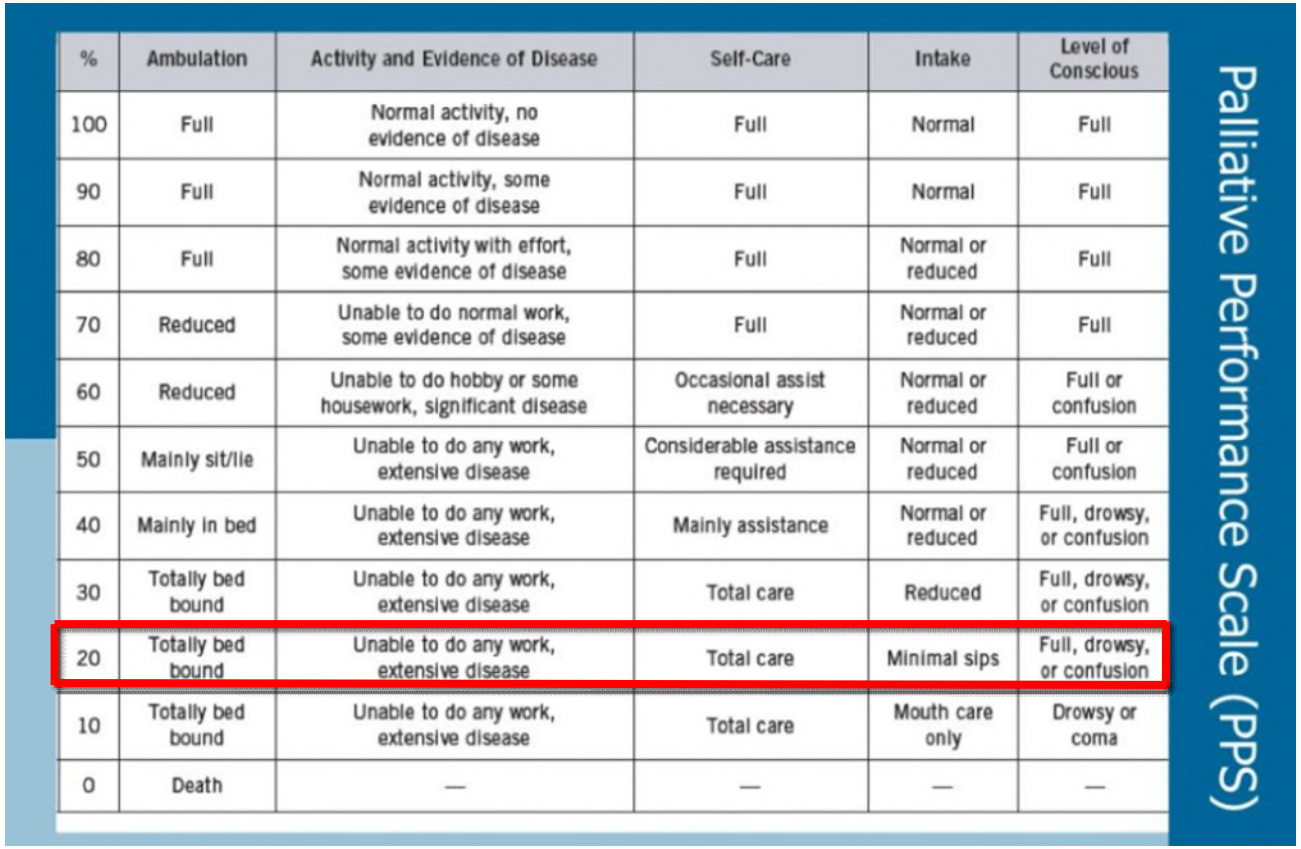
DECREASED LEVEL OF CONSCIOUSNESS

DYSPHAGIA FOR LIQUIDS

2-3 DAYS BEFORE DEATH

ACTIVE DYING PHASE

PPS 20% OR LESS

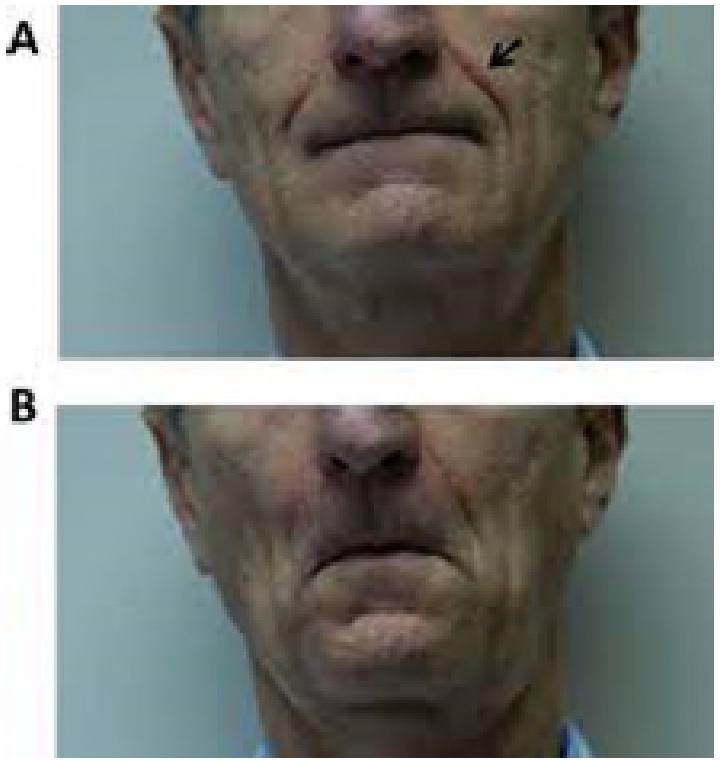


Palliative Performance Scale (PPS)

%	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Level of Conscious
100	Full	Normal activity, no evidence of disease	Full	Normal	Full
90	Full	Normal activity, some evidence of disease	Full	Normal	Full
80	Full	Normal activity with effort, some evidence of disease	Full	Normal or reduced	Full
70	Reduced	Unable to do normal work, some evidence of disease	Full	Normal or reduced	Full
60	Reduced	Unable to do hobby or some housework, significant disease	Occasional assist necessary	Normal or reduced	Full or confusion
50	Mainly sit/lie	Unable to do any work, extensive disease	Considerable assistance required	Normal or reduced	Full or confusion
40	Mainly in bed	Unable to do any work, extensive disease	Mainly assistance	Normal or reduced	Full, drowsy, or confusion
30	Totally bed bound	Unable to do any work, extensive disease	Total care	Reduced	Full, drowsy, or confusion
20	Totally bed bound	Unable to do any work, extensive disease	Total care	Minimal sips	Full, drowsy, or confusion
10	Totally bed bound	Unable to do any work, extensive disease	Total care	Mouth care only	Drowsy or coma
0	Death	—	—	—	—

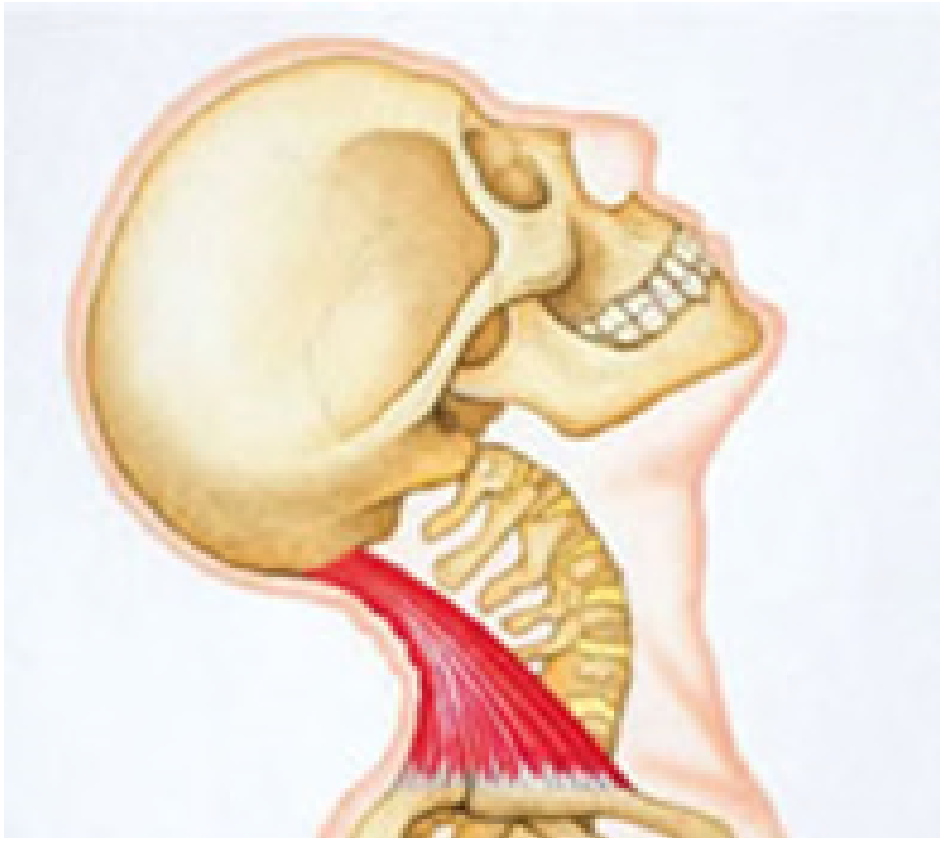
DROOPING OF NASOLABIAL FOLDS

PPS < 20% + drooping of nasolabial folds = 94% risk of death within 3 days

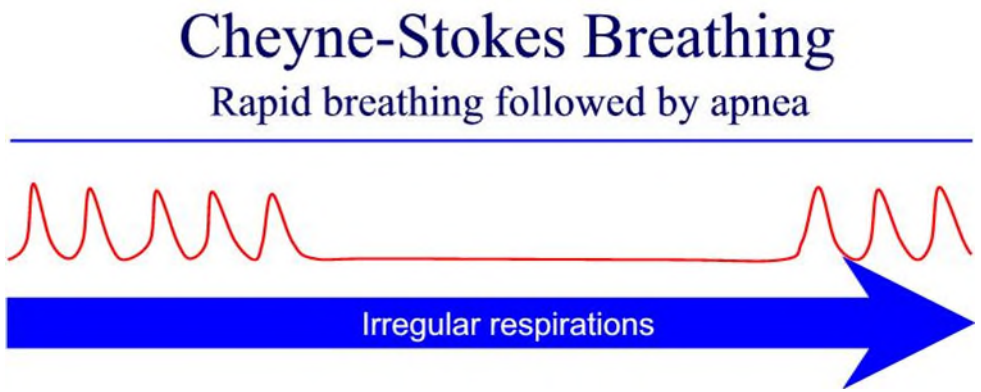


HUI D, ET AL. A DIAGNOSTIC MODEL FOR IMPENDING DEATH IN CANCER PATIENTS: PRELIMINARY REPORT. CANCER. 2015; 121(21):3914

HYPEREXTENSION OF THE NECK



CHEYNE-STOKES BREATHING



NON-REACTIVE PUPILS

DECREASED RESPONSIVENESS

< 2 DAYS BEFORE DEATH

DEATH RATTLE

Death within 16 hours

Prevalence: 60%

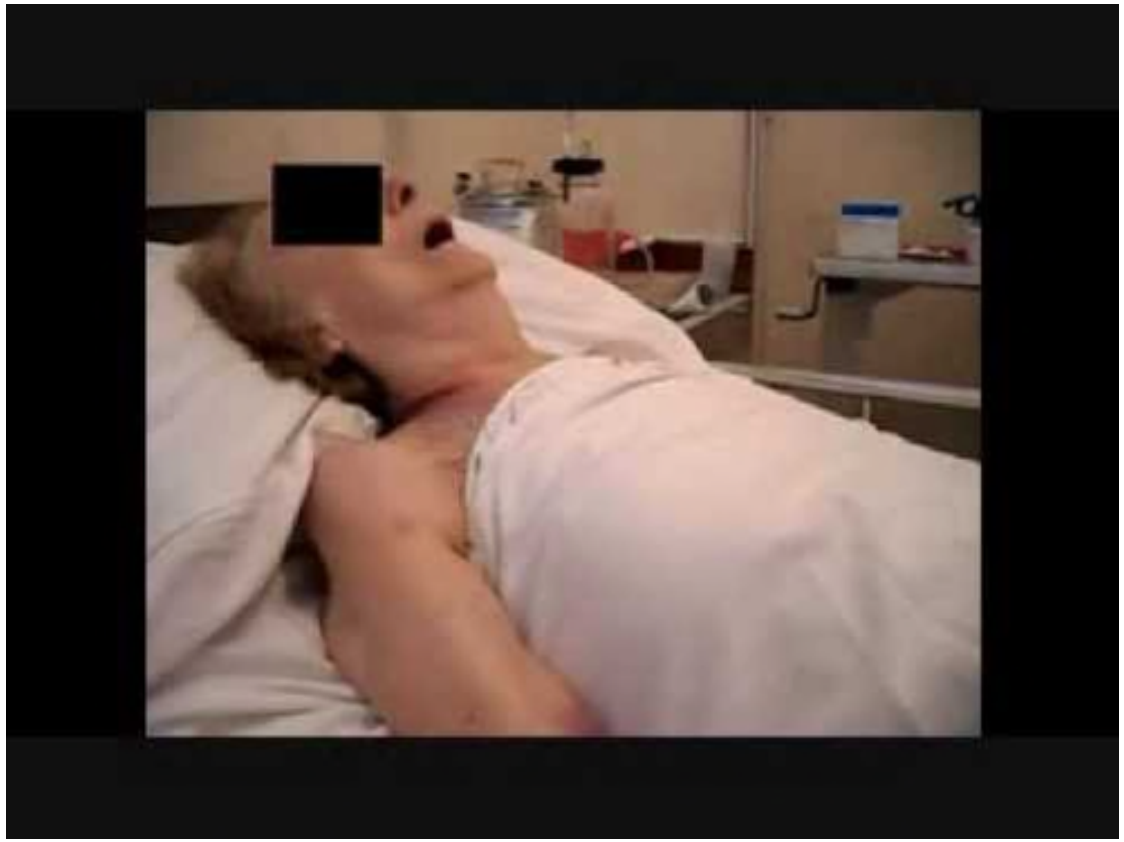
Swallowing dysfunction

Not correlated with respiratory distress

Treat: **repositioning**, oral swabs, hyoscyamine, atropine, **glycopyrrolate**, scopolamine, octreotide

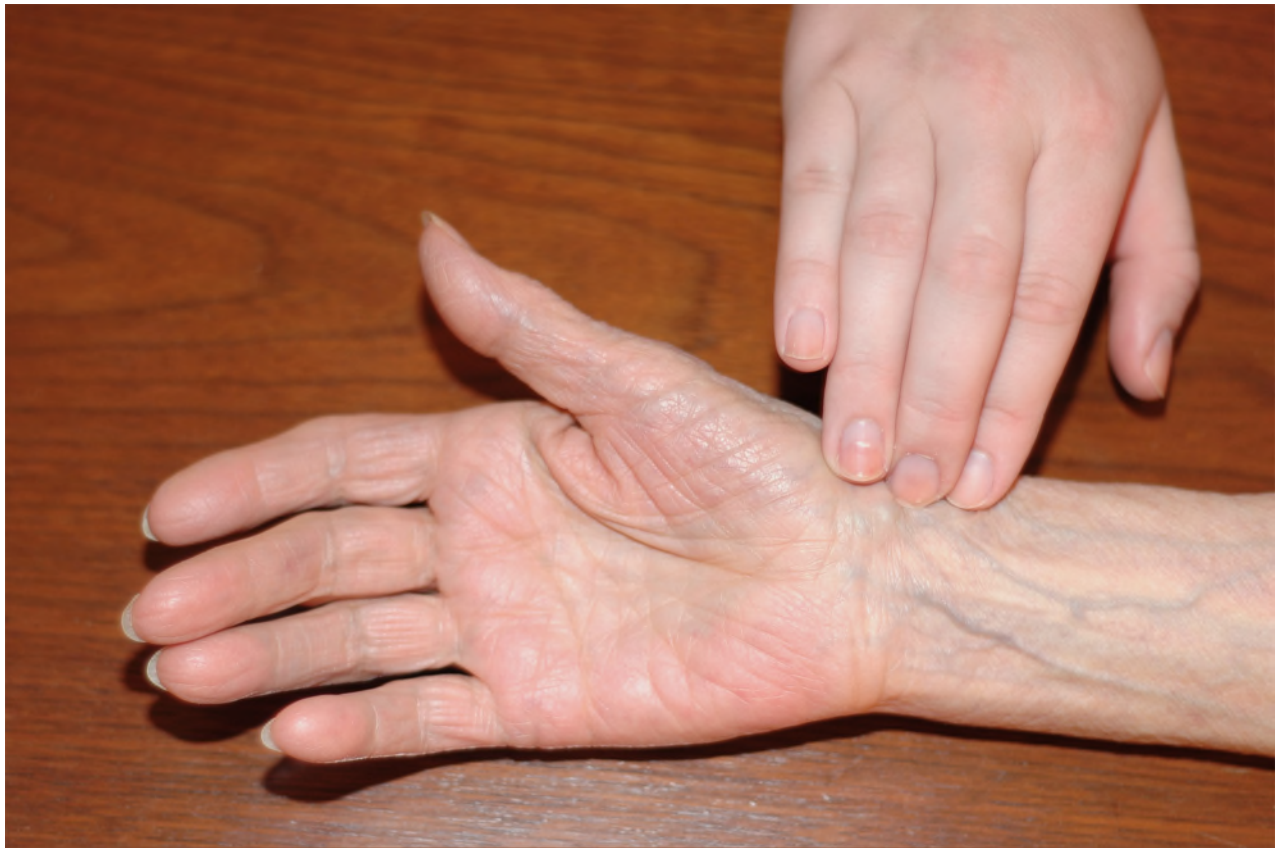
APNEA

RESPIRATION WITH MANDIBULAR MOVEMENT



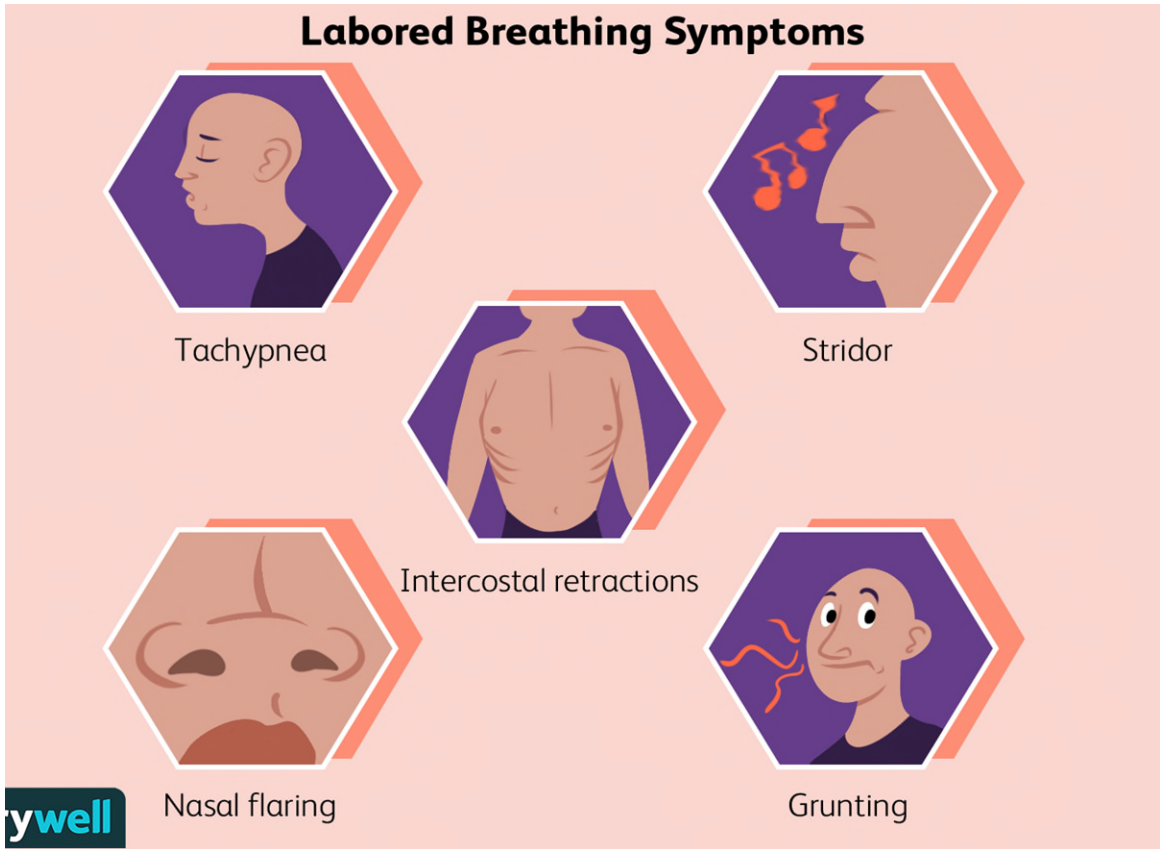
DECREASED URINE OUTPUT

PULSELESS RADIAL ARTERY



INABILTIY TO CLOSE EYES

GRUNTING


Labored Breathing Symptoms
Tachypnea
Stridor
Intercostal retractions
Nasal flaring
Grunting
ywell

FEVER

DIRECT CORRELATION

2 clinical signs of dying = 40% chance of dying

8 clinical signs of dying = >80% chance of dying

HUI D, ET AL. A DIAGNOSTIC MODEL FOR IMPENDING DEATH IN CANCER PATIENTS: PRELIMINARY REPORT. CANCER. 2015; 121(21):3914

DISEASE SPECIFIC SIGNS

CHF

CANCER

COPD

DEMENTIA

RENAL FAILURE

CONGESTIVE HEART FAILURE

Dyspnea

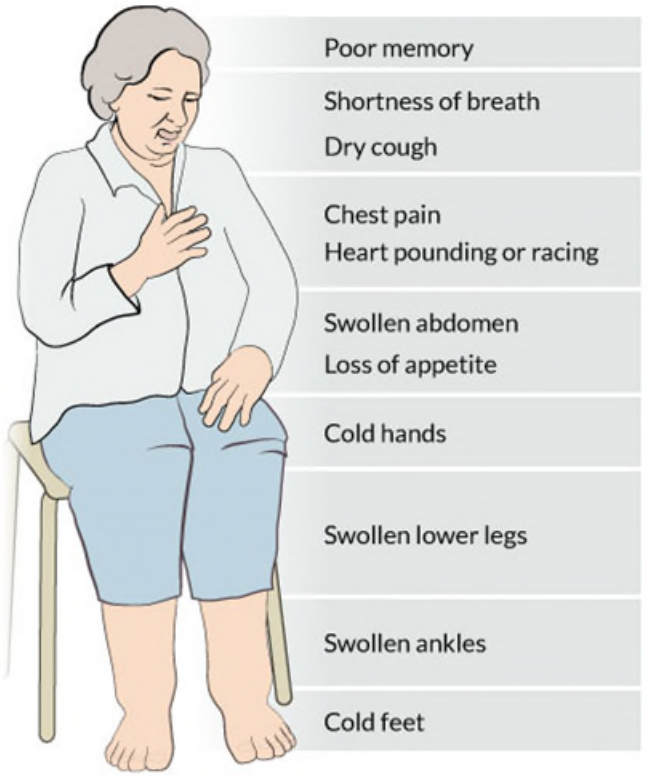
Edema

Cough/wheezing

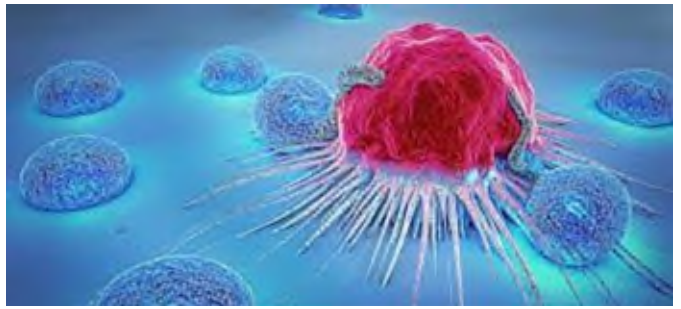
Delirium

Δ VS

Cardiac cachexia



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
- Dyspnea
- Anxiety/depression
- Delirium

DEMENTIA

Functional Assessment Scale (FAST)

1	No difficulty either subjectively or objectively.
2	Complains of forgetting location of objects. Subjective work difficulties.
3	Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4	Decreased ability to perform complex task, (e.g., planning dinner for guests, handling personal finances, such as forgetting to pay bills, etc.)
5	Requires assistance in choosing proper clothing to wear for the day, season or occasion, (e.g. pt may wear the same clothing repeatedly, unless super-vised.*
6	Occasionally or more frequently over the past weeks. * for the following **A)** Improperly putting on clothes without assistance or cueing . **B)** Unable to bathe properly (not able to choose proper water temp) **C)** Inability to handle mechanics of toileting (e.g., forget to flush the toilet, does not wipe properly or properly dispose of toilet tissue) **D)** Urinary incontinence **E)** Fecal incontinence
7	**A)** Ability to speak limited to approximately ≤ 6 intelligible different words in the course of an average day or in the course of an intensive interview. **B)** Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview **C)** Ambulatory ability is lost (cannot walk without personal assistance.) **D)** Cannot sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair.) **E)** Loss of ability to smile. **F)** Loss of ability to hold up head independently.

*Scored primarily on information obtained from a knowledgeable informant.
Psychopharmacology Bulletin, 1988 24:653-659.

RENAL FAILURE

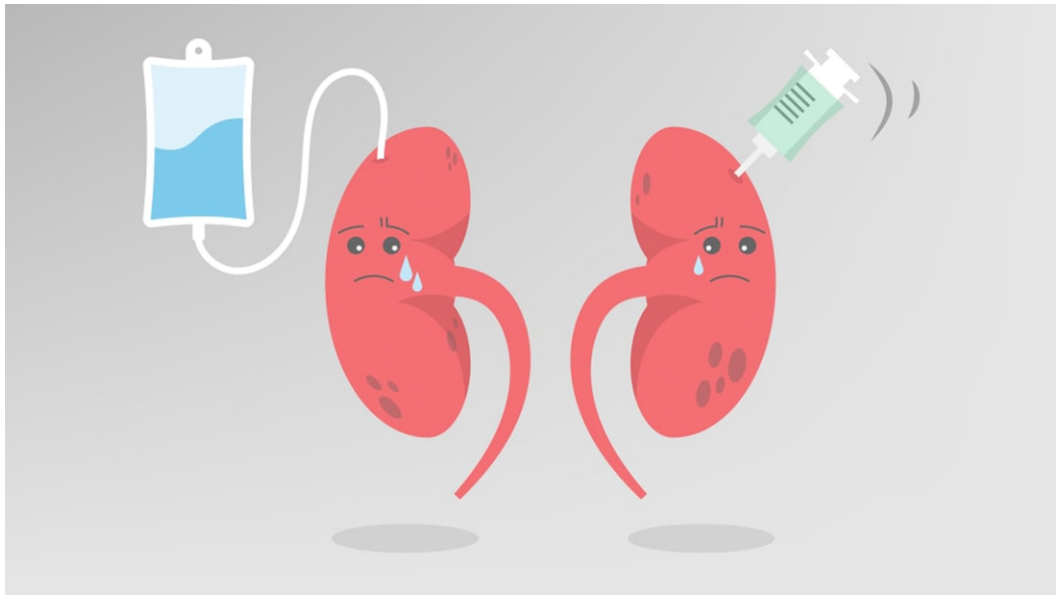
Uremia

- N/V
- Fatigue
- Muscle cramps
- Altered LOC

Pruritis

Edema

Oliguria



HUNGER & THIRST

Survival without food alone ~ 2 months

Survival without water ~ 8 – 21 days

Thirst

- Oral care
- Stop offending agents
- Medication management

HYDRATION

PROS

May add hours-days of life if given early (PC vs HO)

↓ delirium

Reduce fatigue

CONS

Pain

Congestion

Edema

IS MY LOVED ONE IN PAIN?

Pain does not necessarily ↑ as death advances

Monitor for nonverbal signs of pain

- “ouch” “stop”
- Crying, whining, 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 they can hear you

- Talk gently
- Explain direct caregiving
- Intermittent music/podcasts
  - sounds that may be desired by the person

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?

HAS MY PATIENT EXPIRED?

No one can predict the time of death

Death pronouncement – ABCs

Rigor mortis

Algor mortis

Liver mortis

“HIGH-QUALITY DEATH”

Preference for a specific dying process – 94%

- Home
- Being pain free – 81%
- Emotional well-being – 64%

More important to patient

- Religious/spiritual

More important to family

- Dignity
- Quality of life
- Life completion

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.

THANK YOU