FACILITATING A "GOOD" DEATH:
Tools for expert end-of-life care for the dying hospitalized patient

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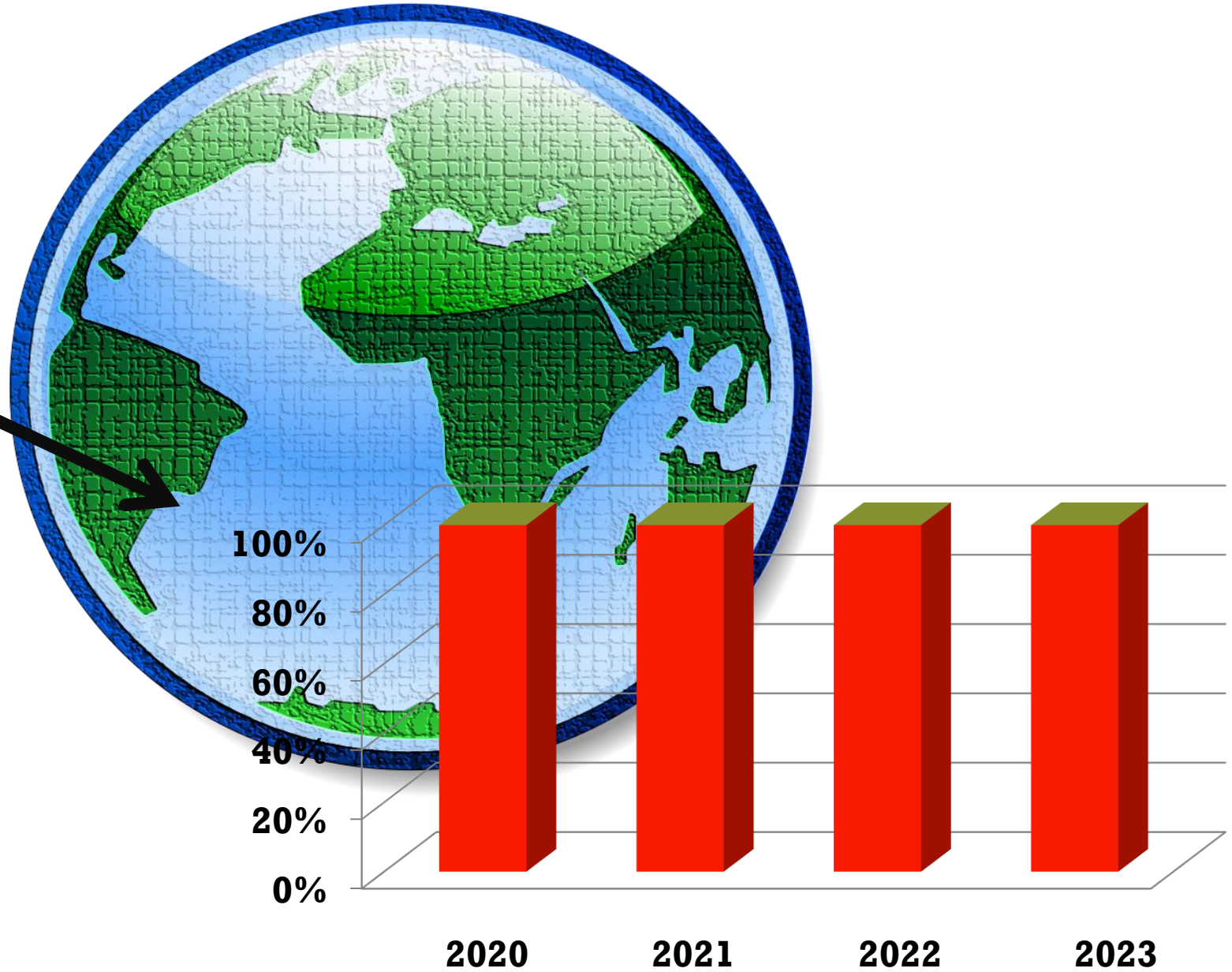
- I have no relevant financial or non-financial disclosures

Learning Objectives

- Identify helpful communication tools to use with patients and families at end-of-life.
- Recognize ways to facilitate goal setting.
- Describe approaches to enhance code status discussions.
- Understand medications for expert symptom management at end-of-life.

Likelihood of Eventual Death



What is a "good" death?

A good death is "one that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards of care."

(IOM, 1997)

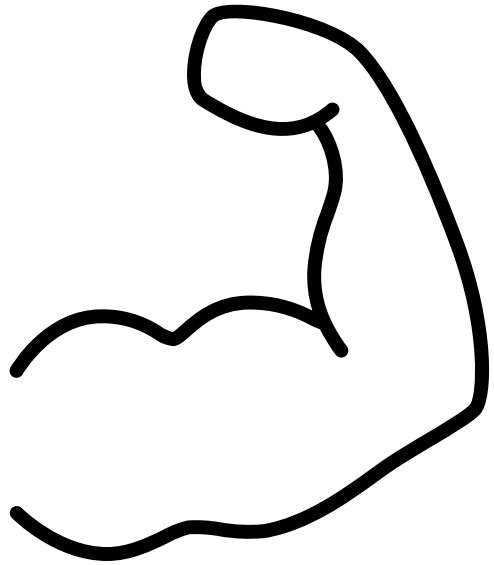
Place of death

- 15% of people die suddenly
- 85% die of prolonged illness
- 30% of individuals in the U.S. die at home
- Death in the hospital is associated with:
  Increased physical and emotional distress
  - **Decreased** quality of life
  - Prolonged grief disorder
- Hospital clinicians are at the front-line in facilitating a "good" death

(Bailey & Harman, 2018)

Meet Becky

37-year-old kindergarten teacher and mom of 2 young children who was diagnosed with esophageal adenocarcinoma 1 year ago, now with metastasis to the liver and bone who is admitted to your service due to increasing abdominal pain, nausea, and vomiting.



YOUR CHALLENGE

ESTABLISH GOALS OF CARE

How comfortable are you in communicating about goals of care?

Communication frameworks

NURSE:

Tool for responding to emotion

Naming	"You look sad today." "You look angry."	In general, naming the emotion turns down the intensity
Understanding	"This helps me to understand what you are thinking"	Shows that you acknowledge the emotion, but don't have to understand everything.
Respecting	"I can see that you have really been trying to follow our instructions."	You have done a great job with this.
Supporting	"I will do my best to make sure that you have what you need."	A powerful statement of support.
Explaining	"Could you share more in what you mean by that……?"	Asking a focused question prevents this from being too obvious.

Becky

1) Do your research:

Advance care planning documents?

Medical decision makers?

Previous notes/discussions

2) Set up conversation: (location, key stakeholders, positioning)

I'd like to talk to you about what is ahead with your illness so that we can do some thinking in advance in order find out what is important to you. This way we can align care with your goals. **Is that okay?**

3) Assess preferences and understanding:

Tell me about how much you know about your illness.

How much medical information would you like to learn from me?

Becky

4) Share information/prognosis

Is it okay if I share with you my understanding of your illness?

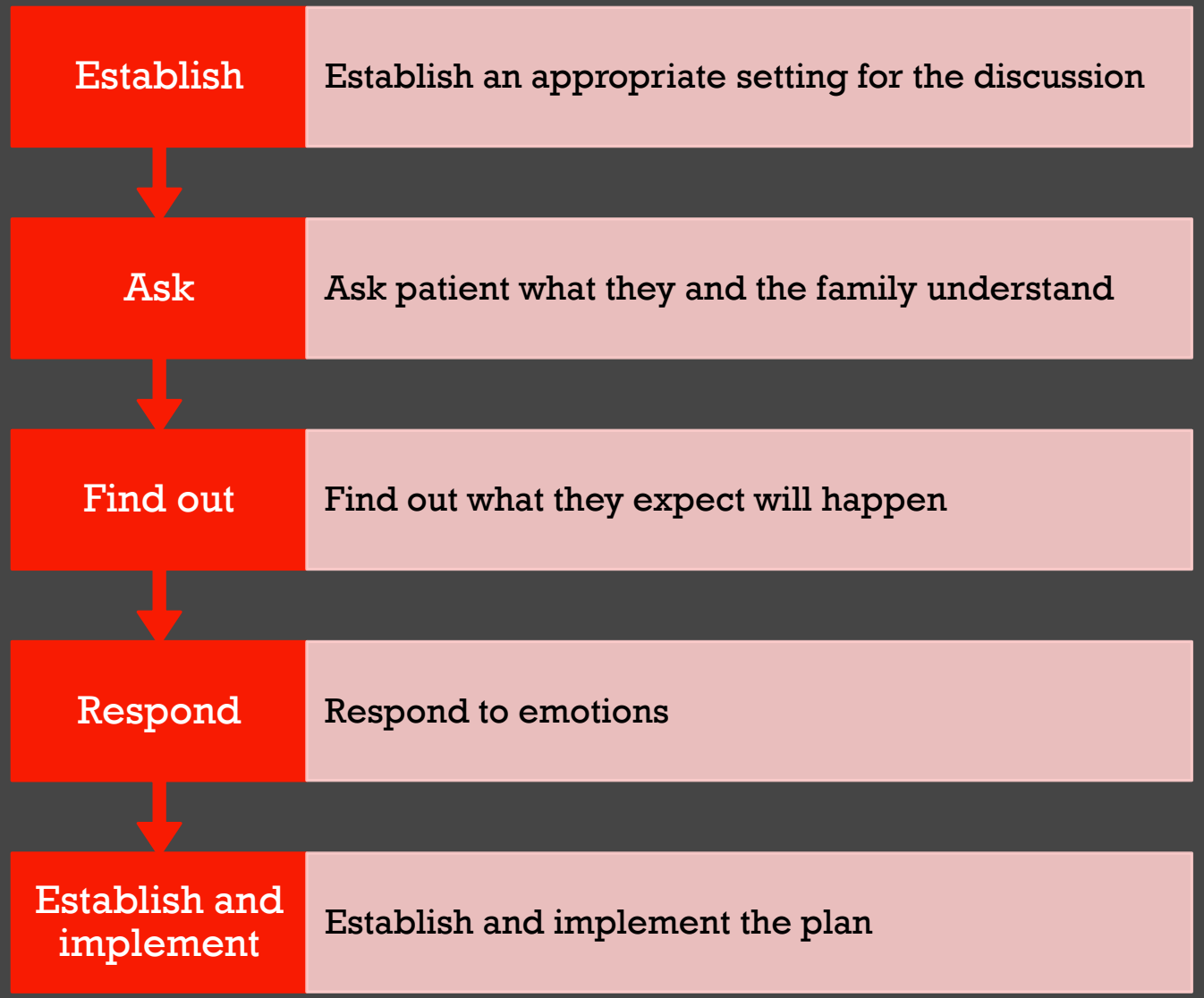
Create a Headline:

I wish that I could share that your cancer is responding to this chemotherapy, but I worry that your symptoms are related to an increase in the cancer burden.

(Insert pause and honor emotion)

Knowing this, I think that it is important to discuss how we should best care for you if your heart should stop or you should stop breathing despite our best efforts.

Discussing Code Status



(von Gunten & Weissman, 2015)

Discussing Code Status

Additional tips:

- Know the statistics
  - Only 10-15% of individuals that code while hospitalized survive to discharge
  - Statistics even poorer for those with advanced cancer, dementia, ESRD, etc.
- Speak general and then become more specific
- Talk about what life looks like if one might survive a code

(von Gunten & Weissman, 2015)

Discussing Code Status

Additional tips:

- Do not badger, then code status becomes a battle ground
- Explore emotions and feeling

  Helpful phrases:

  "What does code status mean to you? "

  "It sounds like you don't trust the medical system, could you share why?"

  "What could have been done differently if you did code? "

- Use innovative tools such as videos on code status

(von Gunten & Weissman, 2015)

Becky

4) Explore key topics (Goals/worries/strength/tradeoffs)

What are your most important goals if your health situation worsens?

What are your biggest fears and worries about the future of your health?

If you become sicker, how much are you willing to go through for the possibility of more time?

Becky

Becky **understands** that she has a progressive cancer and that she is early in a 3rd line chemotherapy regimen. She is **hopeful** that she will have response so that she has more time with her children and husband to help them get closure. She **doesn't want** to have pain or burdensome symptoms but **does not know when** she will not pursue treatment. She knows that she is not ready yet though. She will **think** about the code status.

Becky

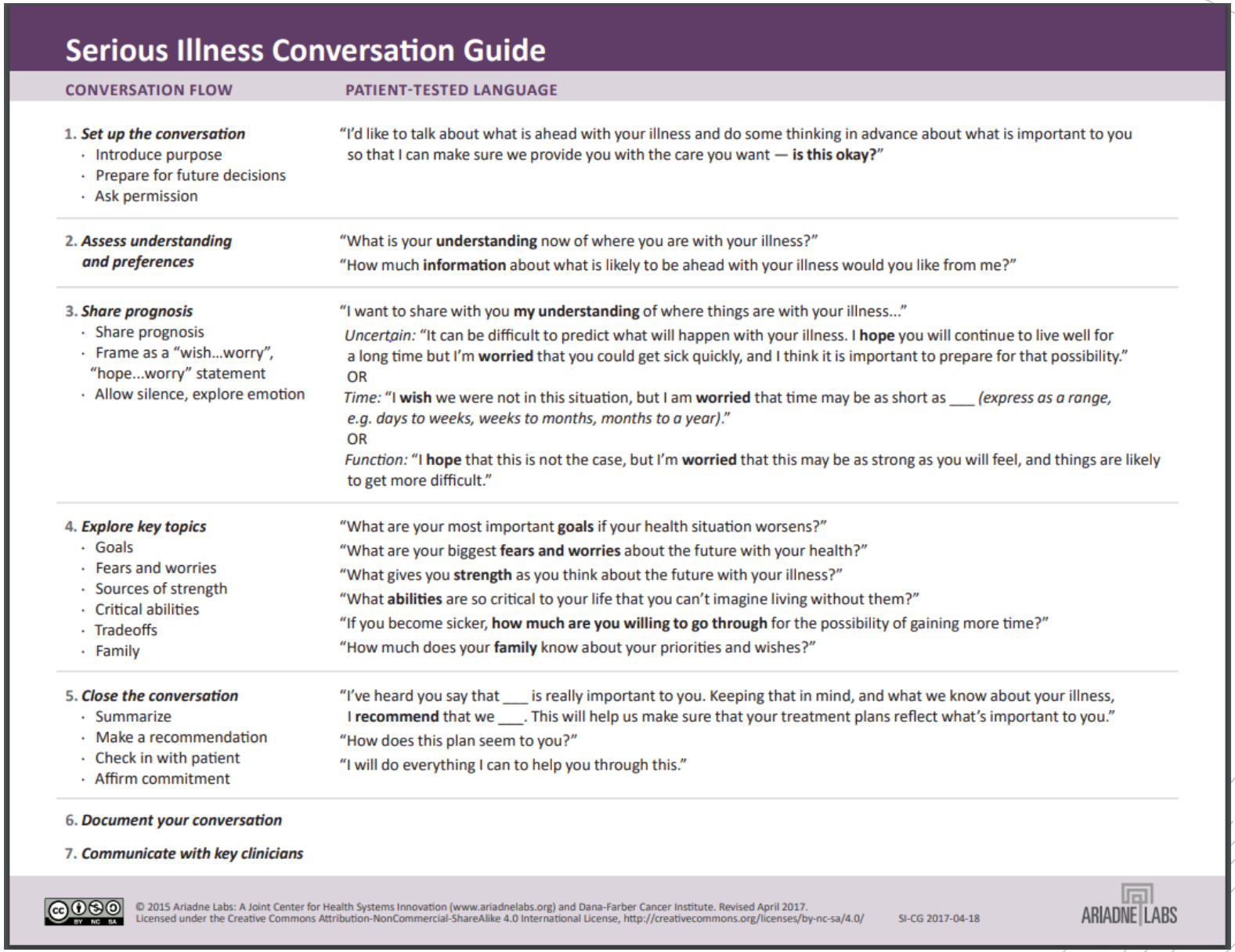
5) Close the conversation

I have heard you say that time is important to you now. We will focus on managing anything reversible contributing to the present symptom burden with a goal to discharge you soon to be with your family. However, if things change we will readdress you wishes to ensure our care is still in alignment with your goals and that they are attainable. How does this plan seem to you?

6) Document the conversation

7) Share conversation with key team members

CHEAT SHEET!



Serious Illness Conversation Guide

CONVERSATION FLOW	PATIENT-TESTED LANGUAGE
1. ***Set up the conversation*** · Introduce purpose · Prepare for future decisions · Ask permission	"I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want — **is this okay?**"
2. ***Assess understanding and preferences***	"What is your **understanding** now of where you are with your illness?" "How much **information** about what is likely to be ahead with your illness would you like from me?"
3. ***Share prognosis*** · Share prognosis · Frame as a "wish…worry", "hope…worry" statement · Allow silence, explore emotion	"I want to share with you **my understanding** of where things are with your illness…" *Uncertain:* "It can be difficult to predict what will happen with your illness. I **hope** you will continue to live well for a long time but I'm **worried** that you could get sick quickly, and I think it is important to prepare for that possibility." OR *Time:* "I **wish** we were not in this situation, but I am **worried** that time may be as short as ___ *(express as a range, e.g. days to weeks, weeks to months, months to a year)*." OR *Function:* "I **hope** that this is not the case, but I'm **worried** that this may be as strong as you will feel, and things are likely to get more difficult."
4. ***Explore key topics*** · Goals · Fears and worries · Sources of strength · Critical abilities · Tradeoffs · Family	"What are your most important **goals** if your health situation worsens?" "What are your biggest **fears and worries** about the future with your health?" "What gives you **strength** as you think about the future with your illness?" "What **abilities** are so critical to your life that you can't imagine living without them?" "If you become sicker, **how much are you willing to go through** for the possibility of gaining more time?" "How much does your **family** know about your priorities and wishes?"
5. ***Close the conversation*** · Summarize · Make a recommendation · Check in with patient · Affirm commitment	"I've heard you say that ___ is really important to you. Keeping that in mind, and what we know about your illness, I **recommend** that we ___. This will help us make sure that your treatment plans reflect what's important to you." "How does this plan seem to you?" "I will do everything I can to help you through this."
6. ***Document your conversation***	
7. ***Communicate with key clinicians***	

SI-CG 2017-04-18

ARIADNE LABS

(Ariadne Labs, 2015)

You can bill!

Advance Care Planning CPT Codes

- **99497**: "Advance Care Planning including the explanation and discussion of advance directives such as standard forms (including the completion of such forms, when performed), by the physician or other qualified health professional; first 30 minutes, face-to-face with the patient, family members and/or surrogate"
- **99498** *(add-on)*: Each additional 30 minutes

(Sudore, Lum, You, et al., 2017)

Becky

- It's now 1 month later, Becky is readmitted with AMS, significant lab aberrancies, once again disease progression is shown on imaging.

- Physical exam: lethargic, answering questions intermittently, shallow fast breathing with diminished breath , distended and tender abdomen, bilaterally lower extremity pitting edema, mottling?, jaundiced skin with scleral edema, thready pulses
- VS: BP 86/40, HR: 116, RR: 22

What do you say and to who?

Becky

1. Do your research:
   - Know prognosis/timeline/discuss with key clinicians
   - Look to see if other conversations were documented or if there is new paperwork completed
2. Set up stage

   Hello Brandon (surrogate decision maker). I had hoped things would be different. **Is it okay if we talk about how we best care for Becky?**
3. Assess understanding and address gaps

   How have things been going medically prior to coming into the hospital?

   Let me provide an update on how things are going now……
4. Share prognosis

I worry that Becky is dying and time is very short. Have you had any conversations with your wife on where she would want to be at end-of -life?

Location at End-of-life

Home versus Hospitalized

- What is the prognosis: hours, days, weeks, or months?
- What are the wishes of the patient?
- Who can care for the patient if the wish is to go home?
- What does hospice care look like in your region?
  - IPUs/responsiveness/ability to provide support
- Do you have a specialized floor/unit for end-of- life care or special protocols?

The “H” word

A model and philosophy of care that focuses on providing palliative care to patients with life-limiting illness, focusing on palliating patients’ pain and other symptoms, attending to their and their family’s emotional and spiritual needs, and providing support for their caregivers.

(Meier, D., McCormick, E. and Lagman, R. , 2018)

The “H” word


Hospice physician
Primary Physician
Hospice RN
Social Worker
Chaplain
Bereavement coordinator
Home health aides

Who qualifies?

Prognosis of 6 months or less.

When **patients and their families decide to forego disease-modifying therapies with curative/life-prolonging intent in order to focus on maximizing comfort and quality of life.**

2 physician certification

Benefits of Hospice

- Psychosocial, spiritual, and symptom support
- Support in home
  - RN visits
  - Chaplain/SW visits
  - Volunteers
- **Short-term** intensified care within inpatient Hospice units
- Respite care

Benefits of Hospice

- Medical equipment, supplies, and medications delivered to home
- Bereavement support
- Patients often die at home or inpatient unit with expert symptom management

Limitations of Hospice

Does not provide custodial care

Does not provide 24 hr caregiving

No frequent transfusions of blood products

Due to reimbursement, patients may be limited from seeing outside providers and seeking palliative interventions

Larger and non-profit hospice agencies may be more flexible paying for quality-of-life interventions such as routine lab work

Becky

4. **Explore key topics:**

   - What are you most worried about?

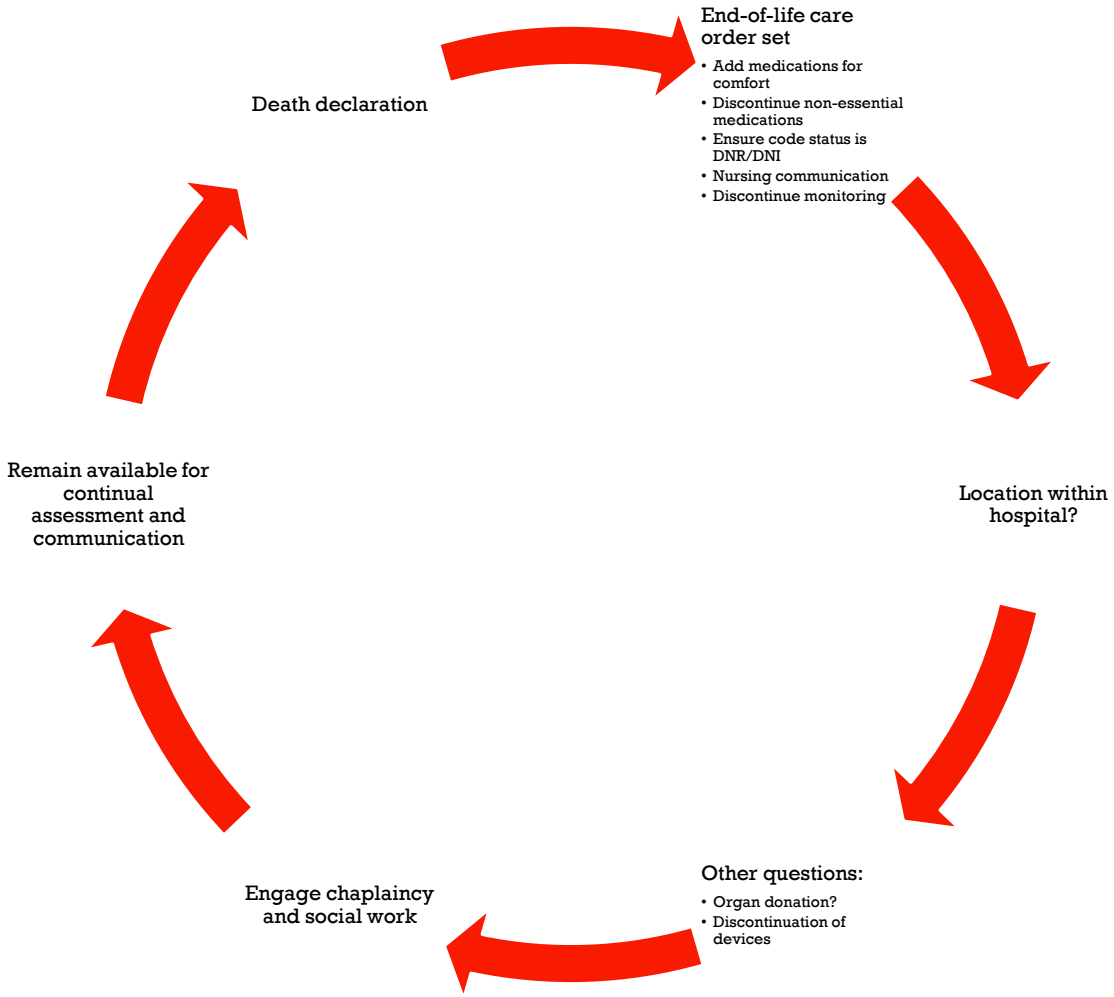
   Husband shares that he is worried that Becky will not make it home and does not feel like he can manage end-of-life symptoms while caring for their 2 kids.

5. Make a recommendation:

Based on what you have shared, I recommend that we proceed to **aggressively** focusing on comfort here in the hospital. I suspect that we only have hours, but Becky will leave us on her own time. Let's make arrangements to have those who care for her be present. I will adjust the orders to reflect our plan. I anticipate that questions will come up as we support Becky. Please ask them.

Caring for the dying patient

Next steps:


End-of-life care order set
• Add medications for comfort
• Discontinue non-essential medications
• Ensure code status is DNR/DNI
• Nursing communication
• Discontinue monitoring
Location within hospital?
Other questions:
• Organ donation?
• Discontinuation of devices
Engage chaplaincy and social work
Remain available for continual assessment and communication
Death declaration

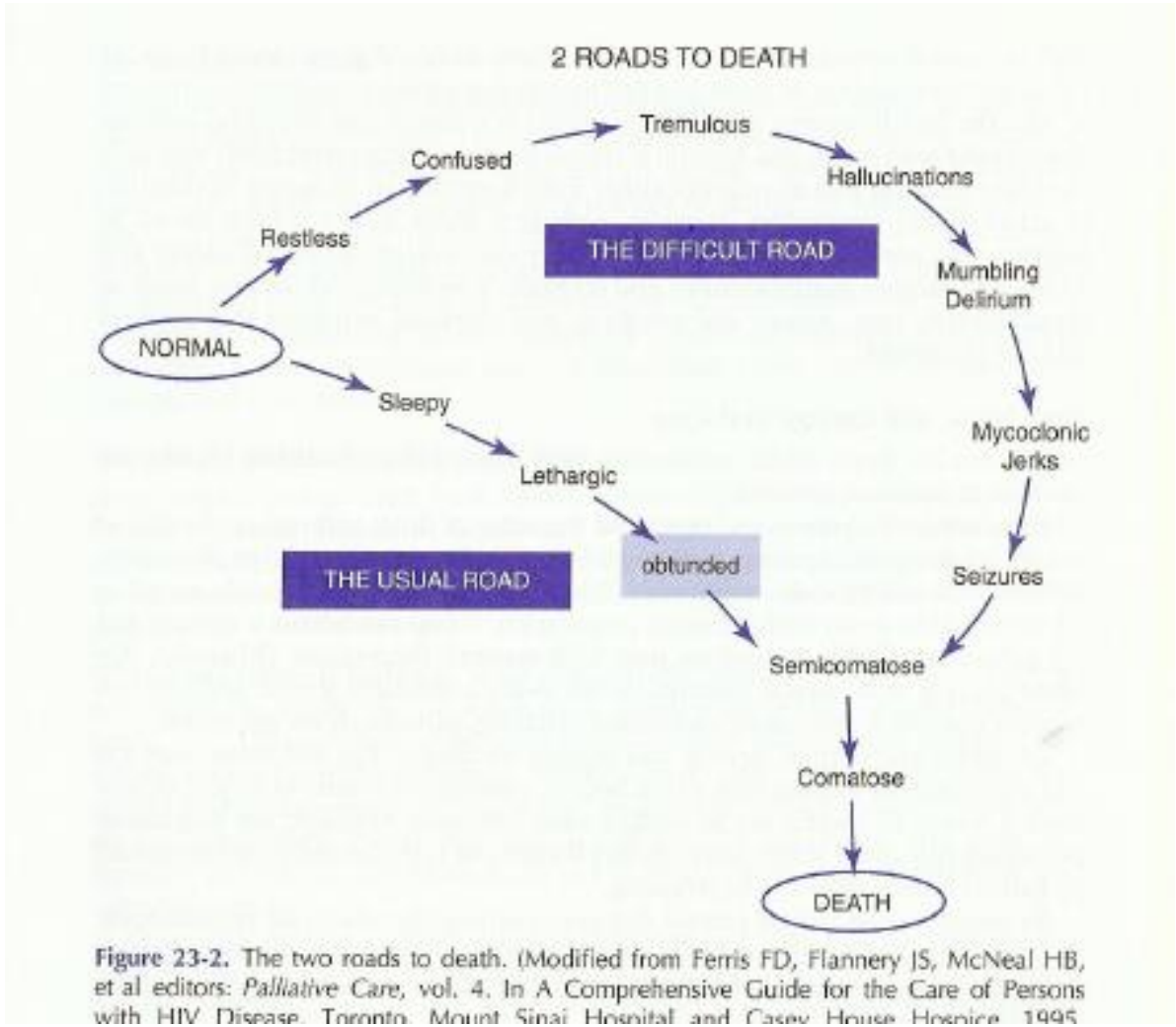


Figure 23-2. The two roads to death. (Modified from Ferris FD, Flannery JS, McNeal HB, et al editors: *Palliative Care*, vol. 4. In A Comprehensive Guide for the Care of Persons with HIV Disease. Toronto, Mount Sinai Hospital and Casey House Hospice, 1995

How do we die?

(The EPEC Project, 2003)

Stages of active dying

Early stage:

- Increasing fatigue, weakness → bedbound
- Loss of interest and ability to eat/drink
- Cognitive changes/ neurologic dysfunction
- Increasing sleepiness
- Decrease in speech

Middle stage:

- Further decline in mental status
- "Death rattle"

Late stage:

- Coma
- Decreasing perfusion → cool extremities
- Altered respiratory pattern
- Fever
- Loss of ability to close eyes

(Weissman, 2014)

Predictable symptoms

Signs	Mean (Median) time to death in hours
Death rattle	57 (23)
Respiration with mandibular movement	7.6 (2.5)
Cyanosis of extremities	5.1 (1.0)
Lack of radial pulse	2.6 (1.0)

(Morita et al, 1998)

How long?

- Once active dying begins, the time course is variable and hard to predict
  - Range: 24 hours to 10-14 days
- "Lingering" can be distressing to families
- Communication can help with these uncertainties
- Continue to engage with family and conduct a physical exam of patient
- Document that "patient is dying" not "prognosis poor"

What do you say?

Provide education about what is "normal"

- Progressive unresponsiveness
- Noisy breathing
- Inability to tolerate food and drink
- Purposeless movements or facial expressions

Explain changes as they occur

- Helpful phrase
  - "Is there anything you are seeing that worries you?"

What do you say?

Encourage family to nurture the patient

- mouth swabs, ice chips, lip care, eye care
- loss of senses: hearing, touch lost last

Reframe

- Helpful phrase:
  - "*He's starving to death*" becomes "*Fortunately, he's no longer feeling hungry or thirsty*."

Closure

Rituals

End-of-life symptoms

PAIN

DYSPNEA

NAUSEA

NOISY BREATHING

TERMINAL RESTLESSNESS

HEMORRHAGE

SEIZURES

Pain

- Pain can escalate or lessen at end-of-life
- Sublingual forms of opioids preferred*
  - Morphine starting doses:
    - 5 mg of PO/SL q 2 hrs prn
    - 7.5 mg PO q 2 hrs prn
    - 2 mg SC/IV q 1 hr prn
- Often discontinue extended -release pain medications
- If patients are on chronic opioids, then use 10-15% of basal daily opioid requirements in morphine equivalents q 4 hrs scheduled and continue prn q 2 hrs

(Bailey and Harman, 2018)

Equianalgesic doses

Morphine	Oxycodone	Hydromorphone	Fentanyl
PO 30mg IV 10mg	PO 20mg	PO 7.5mg IV 1.5mg	IV 100mcq

Opioid conversion

Pearls

- Calculating CI rates:
  - If there is a baseline opioid usage, then calculate usage and divide by the timeline
    - Example: Over the last 12 hrs it took 5 doses of IV morphine 2mg to keep patient comfortable
      - Continuous infusion= 10/12= 0.8mg/hr.
      - Bolus dose 0.4mg q 15 mins nurse push**
- Wait 15 mins for IV medication and 60 mins for po/sl medications to determine efficacy
- If dose is not effective, escalate by 25-100%
- Morphine causes drowsiness, sedation, loss of consciousness prior to respiratory depression
- Do not use morphine if CC < 30

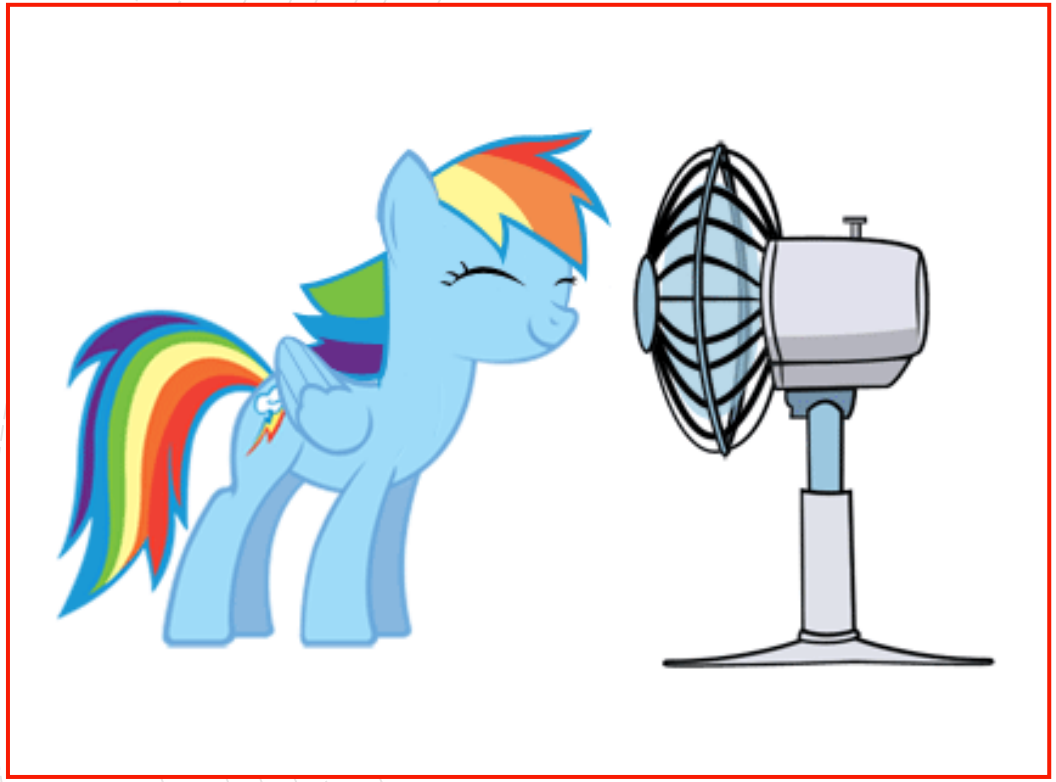
(Weinstein, Arnold, and Weissman, 2015)

Dyspnea

- Opioids, first line
  - Opioid naïve dosing:
    - Morphine 5-10 mg PO/SL or 2-4mg IV q 1-2 hrs prn
    - Continuous infusion of low dose opioid with PCA for nurse/family push may provide the best relief if constant dyspnea
  - May need higher dosing for opioid tolerant patients
  - Anxiolytics
    - Lorazepam 0.25mg or 0.5mg PO/SL or IV/SQ q 2-4 hrs prn

Bailey and Harman, 2018

Dyspnea



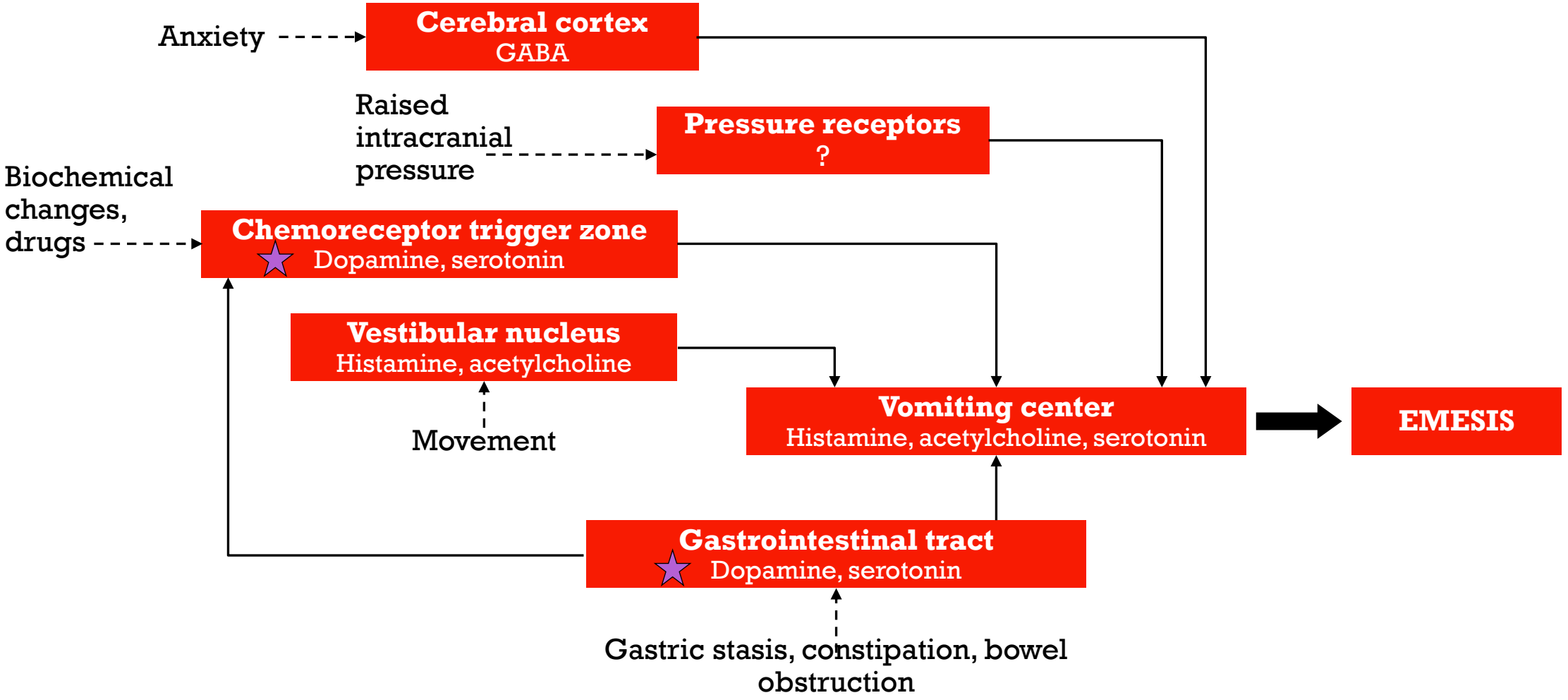
Non-pharmocologic interventions:

- Fan or open window
- Sit upright
- O2 trial
- Discontinue fluids

(Weissman, D., 2015)

NAUSEA:

EMETIC PATHWAYs



Redrawn from Glare P et al: Clin Interv Aging. 2011; 6: 243–259

Anti-emetic cheat sheet

capc Center to Advance Palliative Care

Drug Classes and Medications for Treatment of Nausea and Vomiting

Class	Mechanism	Indications	Drugs	Side Effects	Cost
Antidopaminergic therapies	• Block emetic pathways originating from the GI and CTZ • Antidopaminergic (D_2) • Direct pro-kinetic effect (metoclopramide)	Opioids, chemotherapy, toxins or drugs associated nausea and vomiting	• Prochlorperazine • Promethazine • Metoclopramide • Haloperidol	• Extra-pyramidal effects • Sedation • Hypotension • Contraindicated in bowel obstruction	Low
Serotonin receptor antagonists	Block emetic pathways occurring through vagal stimulation, 5-HT_3 receptors in the GI tract, and/or the CTZ	Chemotherapy, toxins (CTZ, GI tract) associated nausea and vomiting	• Ondansetron • Granisetron • Dolasetron • Tropisetron • Palonosetron (second generation)	• Constipation • Headache	Moderate
Antihistamines	Uncertain action at the vomiting center	Inner ear pathology, adjuvant to other agents	• Diphenhydramine • Hydroxyzine • Meclizine • Doxepin	• Sedation • Constipation • Confusion • Orthostatic hypotension • Dry mouth	Low
Anxiolytics – Benzodiazepines	Works via the cerebral cortex pathway	• Anxiety, PTSD post-chemotherapy • Useful as an adjunct	• Lorazepam • Oxazepam • Diazepam	• Sedation • Confusion • Falls and fractures	Low
Corticosteroids	• May relieve cancer associated nausea through effects on reducing inflammatory mediators, tumor edema, pressure on GI tract, and reducing intracranial pressure from tumor mass. • The exact mechanism in nausea and vomiting is unknown.	• Bone pain • Stimulate appetite	• Dexamethasone • Methylprednisolone • Prednisone	• Fluid retention • Increased blood pressure • Mood swings • Weight gain • Increased risk of infections • Thinning bones (osteoporosis) and fractures	Low
Cannabinoids	Cannabinoid receptors are widespread in the central nervous system and the mechanism of action is unknown	• Nausea unresponsive to conventional treatment • May be used in combination with other antiemetic therapies • Combination antiemetic therapy with dronabinol and prochlorperazine may result in synergistic antiemetic effects and minimize the toxicities	Dronabinol	• Tachycardia • Low blood pressure • Blood shot eyes • Muscle relaxation • Slowed digestion • Dizziness • Depression • Hallucinations • Paranoia	Moderate

Anti-emetic cheat sheet. CAPC. www.CAPC.org/documents/downloads. Accessed 1/17/22

Nausea (

Non-specific nausea

- Haloperidol 1mg po q 6- 8 hrs or 0.5mg IV/SC q 6-8 hrs
- Can titrate these doses upward
- Qtc prolongation is dose related and more likely in IV administration
- Dose reduction by 50% in adults > 65

Bailey and Harma, 2018)

Noisy breathing

"Death rattle"

Pooled oral secretions

More distressing to family than the patient*

Often no treatment needed

Helpful phrase:

"*I know that the breathing may sound uncomfortable, but [insert name] is not suffering.*"

(Bickel and Arnold, 2015)

Noisy breathing

- **Non-pharmacologic interventions:**
  - Reposition pt on side to allow drainage
  - Deep suctioning not helpful and adds to discomfort
  - Discontinue artificial hydration (IV/PEG) as these may contribute to respiratory secretions

- **Medications:**
  - Atropine Ophth Soln 0.1% 2 drops **PO** Q4hr prn
  - Glycopyrrolate 1 mg po or 0.2 mg IV TID

(Bickel and Arnold, 2015)

Terminal delirium

Can be hyperactive or hypoactive

If bothersome, can treat medically

Medication choices:

- Haloperidol 0.5 mg-2 mg PO/SL/IV q 1 hr prn until settled then schedule q 6-8 hrs
- Benzodiazepines can be helpful
- If delirium is refractory, can use chlorpromazine
  - Dosing 25-50mg q 2 hrs prn (up to 2,000mg) once find therapeutic dose, can give in BID dosing

Bailey and Harman, 2018)

Terminal delirium

Non-pharmaocologic interventions:

- Decrease sensory stimulation
- Crowd control
- Quiet room or soothing music familiar to patient
- Familiar faces

Harder to treat symptoms

Seizures

- Individualize care based on seizure history
- Lorazepam sublingual or SQ
- Can give medications per rectum if unable to take in po and unable to swallow
- IV seizure medications an option

Hemorrhage

- Reverse coagulopathies if able
- Dark sheets/towels
- Midazolam 2-10 mg IV/SQ or Lorazepam 2 – 4 mg IV/SQ
- Communicate with family/bedside staff to stay with patient in acute event

(Bailey and Harman, 2018)

Death Pronouncement

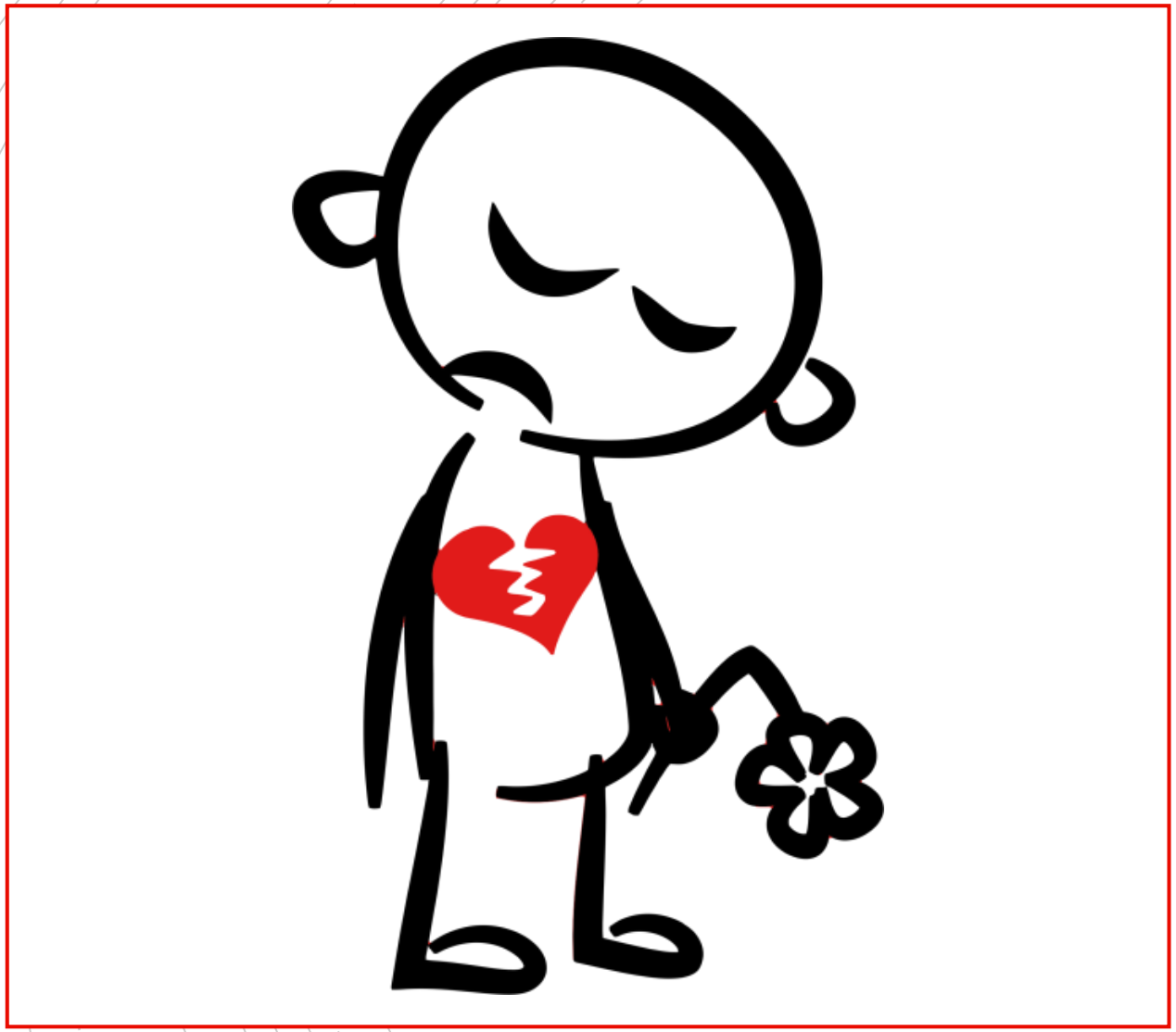
- **Introduce self and provide an empathetic statement**
- Examine respectfully
- Check ID bracelet and pulse
- Check pupils for position and response to light
- Check response to tactile stimuli
- Check for spontaneous respiration
- Check for heart sound and pulses
- Record time of death

Documentation

- Document date and time
- Document name of provider pronouncing death
- Provide brief statement of cause of death
- Note absence of pulse, respiration, pupil response
- Note if family present or informed
- Note family response if indicated
- Note notification of attending, pastoral care, social work or others as appropriate

Death Certificate

- Locate sample Death Certificate on unit
- Complete marked sections. Write neatly in black ink. Begin again if make an error (cross-outs not allowed)
- Document cause of death
  - Primary cause of death (Pneumonia)
  - Secondary cause of death (Advanced Alzheimer's Dementia)
  - Contributing cause of death (Agent Orange, Asbestosis)



Life after a loved one's death

- The end-of-life experience plays a role in how loved ones grieve
- Engage social work and chaplaincy
- Provide community resources for family
- Understand types of grief

Grief and bereavement

- Grief is a normal response to loss
- It involves processes and tasks at emotional, cognitive and behavioral levels
- Occurs in waves that lessen over time
- Often an anticipatory component for patient and family prior to death
- 10-20% of loved one experience complicated grief

Grief

Chronic Grief	Delayed Grief	Exaggerated Grief	Masked Grief
Normal grief reactions that do not subside and continue over extended periods	Normal grief reactions that are suppressed or postponed; the person consciously or unconsciously avoids the pain of the loss	Coping strategies may accelerate and even become destructive (e.g., increased smoking, EtOH, overworking, etc)	The person is not aware that the behaviors that are interfering with normal functioning are the result of the loss

Final thoughts

- Effective communication is key to facilitating a “good death”
- Expert symptom management is integral for a good end-of-life experience
- Many of the needs of a dying hospitalized patient can be expertly addressed with existing communication tools and medications

Resources

- Palliative Care Fast Facts- University of Wisconsin
  - https://www.mypcnow.org/fast-facts
- VitalTalk
  - http://vitaltalk.org/
- Ariadne Labs
  - https://www.ariadnelabs.org/areas-of-work/serious-illness-care/
- Center to Advance Palliative Medicine (CAPC)
  - https://www.capc.org/
- Beacon Project
  - BEACON | Palliative Care | Graduate School (cuanschutz.edu)

Questions?

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