# Palliative Care

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# Agenda

Goals of Care: Initial diagnosis of cancer and progression of disease

Pain Management: Best Practices

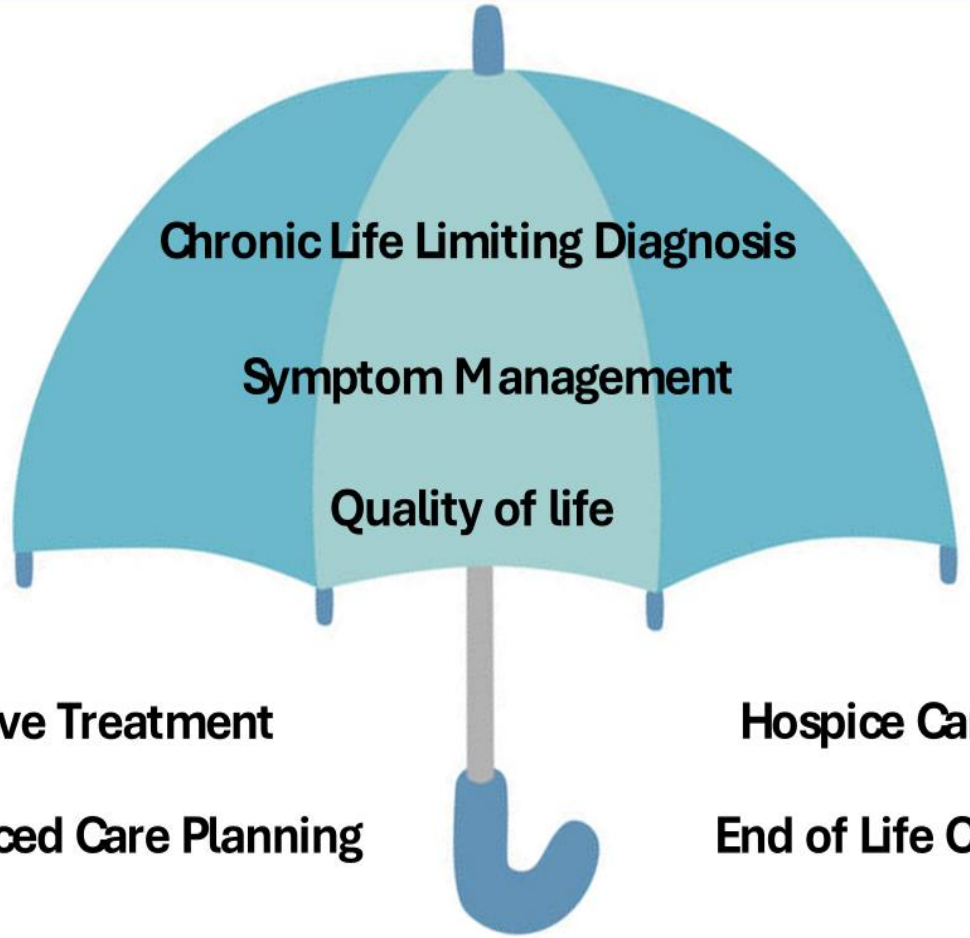
Moral Distress: How to identify and coping strategies


We only live once, snoopy.
Wrong! we only die once. We live every day!

# How to Introduce the Palliative Team to Patients and Families:

- An extra layer of support for patients with serious illness whose goals are to improve your quality of life
- A team designed to walk through this with you
- A team that can help with symptoms such as pain, nausea as a compliment to existing care
- Experts in managing symptoms
- A team that can help with patients and families cope with stress of illness
- Can help with advanced care planning for the future

# Palliative Care Umbrella




Active Treatment

Advanced Care Planning

Hospice Care

End of Life Care

In the beginning.....later in trajectory of the disease process

# Keys to Goals of Care Throughout

- Patient centered communication
- Empathy and truthfulness
- Understanding the illness and trajectory
- Plant seeds that goals can change if preferences and/or condition changes
- Early consults help with physical, psychological, spiritual and social accepts

What is most important to you?

What do you need/hope to accomplish?

What are you hoping for?

# Early Goals of Care (PAUSE)

- Pause
  - Make time for goals of care discussion early in pt's diagnosis
- Ask
  - Ask permission
- Uncover Values
  - Uncover values first
  - If your illness got very serious and might take your life, what would be most important
- Suggest
  - Suggest selecting a surrogate decision maker
- Expect Emotions
  - Expect emotions while discussing goals of care.
  - "In the past I have sometimes waited too long to have these discussions, then didn't know what my patients valued. I want to do better"

https:///vitaltalk.org

# Triggers for Repeat Goals of Care

- Disease progression
  - Increased tumor size
  - New metastases
  - Multiple failed lines of chemotherapy
  - Dose reduced chemotherapy
- Unexpected hospitalizations
- Pending surgical intervention
- Decreasing performance status

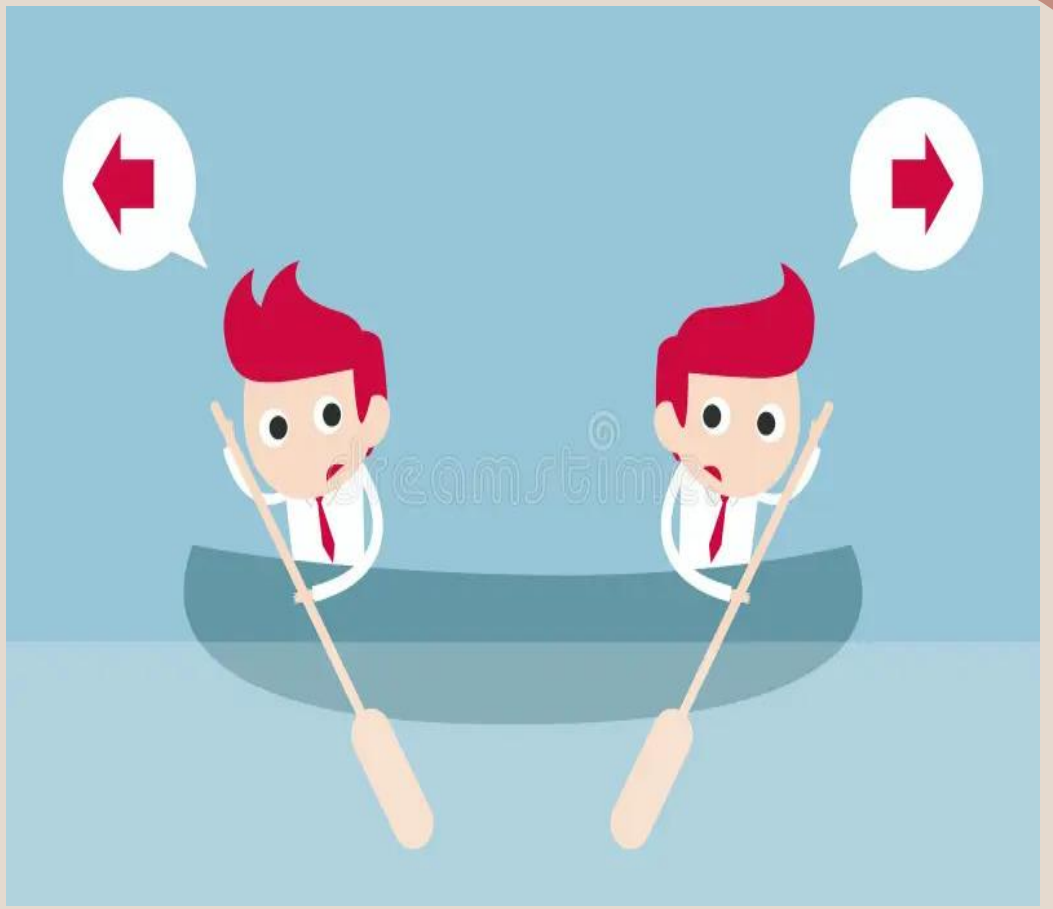
# Late Goals of Care Discussions (REMAP)

- **Reframe:** "the status quo is no longer working", or "we are in a different place"
- **Expect Emotion:** tell me what is going through your mind; empathy
- **Map Values:** what matters most before discussing treatment. Need to know patient's values. "Could we talk about you as a person?"
- **Align:** align yourself with patient's values. "I'm hearing that what is most important is time with your family"
- **Plan:** plan medical treatments that match your patient's values

https://vitaltalk.org

# Family Meeting: Conflict

- Recognize conflict occurs when patient and surrogate are not in the same place.
- Common Comments:
  - There must be some mistake
  - I know there are other treatments available
  - We want a second opinion
  - She is a fighter
  - She will never give up
  - There must be something more you can do



# Reasons Conflicts Happen

- Information Gaps
- Treatment Goal Confusion
- Emotions
- Family/Team Dynamics
- Relationship between the provider and the patient/surrogate

# Reasons for Conflict: Information Gaps

1. Inaccurate understanding of patient's medical condition (overly optimistic or pessimistic prognosis)
2. Inconsistent information (one dr tells you one thing and another something else)
3. Confusing information (use of medical jargon, multiple treatment options presented without a clear recommendation)
4. Excessive information (input from family/friends/clinicians providing information without full awareness of problem
5. Genuine uncertainty (ex predicting functional outcome from a brain injury in its immediate aftermath may be impossible)
6. Language/translation/cultural issues

# Reasons for Conflict: Treatment Goal Confusion

1. Inconsistent treatments and unclear goals, often due to provider/patient/surrogate emotional issue
2. Differing priorities about disease-directed treatment and comfort-oriented treatment between provider and patient/family
3. Lack of clarity about goals when several things occur at once (ex: cancer, infection, respiratory failure)

# Reasons for Conflict: Family/Team Dynamics

1. Patient/Family conflicted themselves and may want different things at different times, altered grieving
2. Dysfunctional family system, not supportive families
3. Surrogate lack of ability (mental illness, cognitive deficits)
4. Consulting teams disagree

Fast Facts #225

# Reasons for Conflict: Relationship between providers and patient/surrogate

- Lack of trust
- Past experiences on outcome where better than expected
- Genuine value differences (cultural, religious)

Fast Facts #225

# Goals of Care Discussion in 8 Steps

1. ASSESS KNOWLEDGE AND UNDERSTANDING
2. ASSESS WILLINGNESS TO RECEIVE INFORMATION
3. INFORM PATIENT OF PROGNOSIS AND ANTICIPATED OUTCOMES
4. EXPLORE EMOTIONS
5. DISCUSS HEALTH STATES THE PATIENT WOULD FIND ACCEPTABLE
6. DISCUSS TREATMENTS AND INTERVENTIONS
7. SUMMARIZE AND MAKE RECOMMENDATIONS
8. DOCUMENT THE CONVERSATION IN THE MEDICAL RECORD

HTTPS://WWW.ACPDECISIONS.ORG/GOALS-OF-CARE-CONVERSATIONS-A-BEST-PRACTICE-STEP-BY-STEP-APPROACH/

# 11 Tips for Palliative-Centered GOC

- Plan ahead of time for the conversation
- Establish rapport and ask permission to begin the conversation
- Use good communication skills to convey empathy and encourage engagement
- Employ shared decision making
- Incorporate high-quality, evidence-based patient decision aids, where appropriate
- Take the patient's health literacy into consideration
- Use plain language

https://www.acpdecisions.org/goals-of-care-conversations-a-best-practice-step-by-step-approach/

# 11 Tips for Palliative-Centered GOC

- Confirm patient's concerns and values by restating them as understood
- Use the Ask-Tell-Ask technique when discussing poor prognosis
- Allow for and manage emotions before moving forward with the conversation
- Revisit the discussion regularly, especially if the patient's health status changes

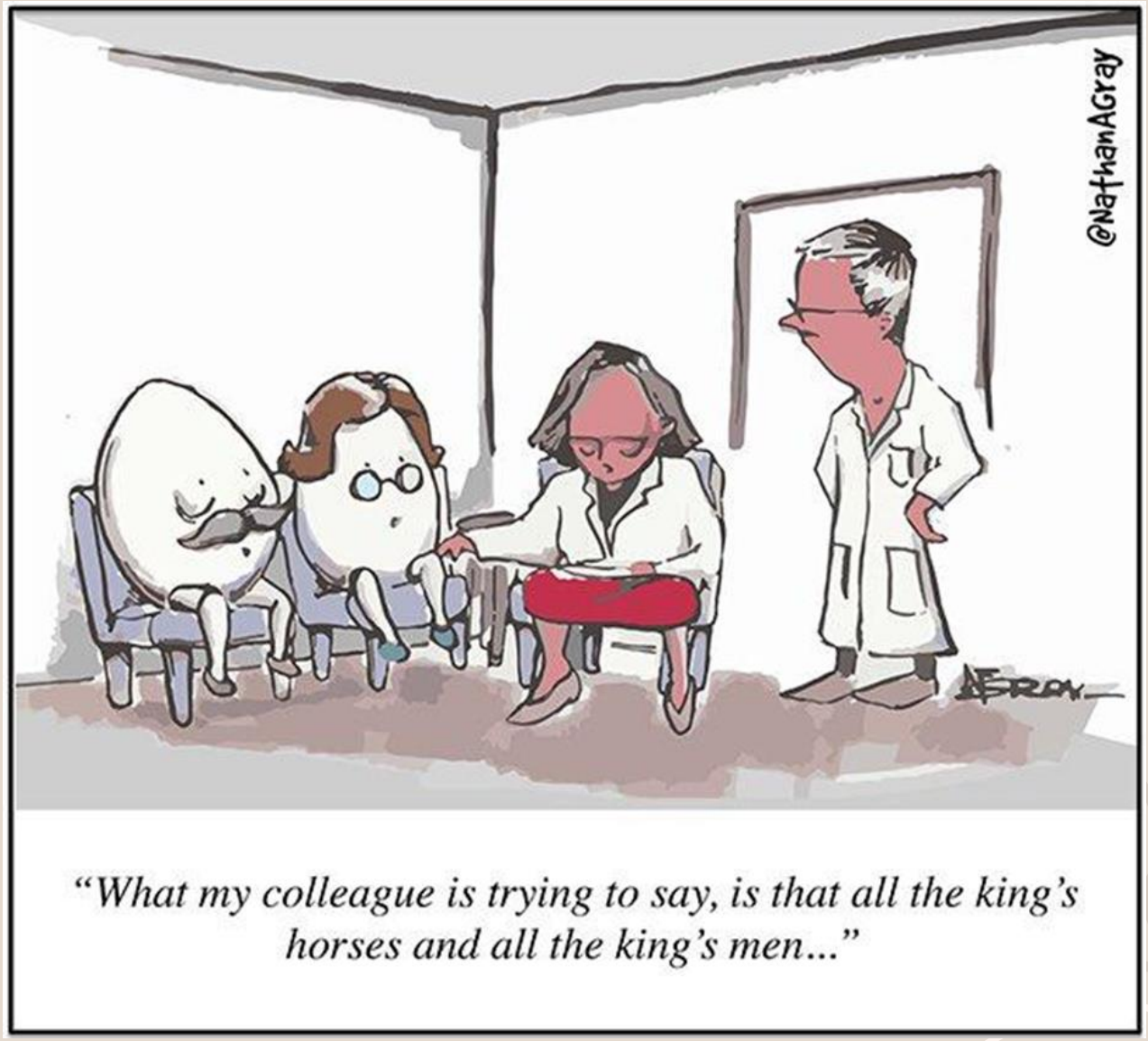
https://www.acpdecisions.org/goals-of-care-conversations-a-best-practice-step-by-step-approach/


"First the good news - we've all got to go sometime . . ."

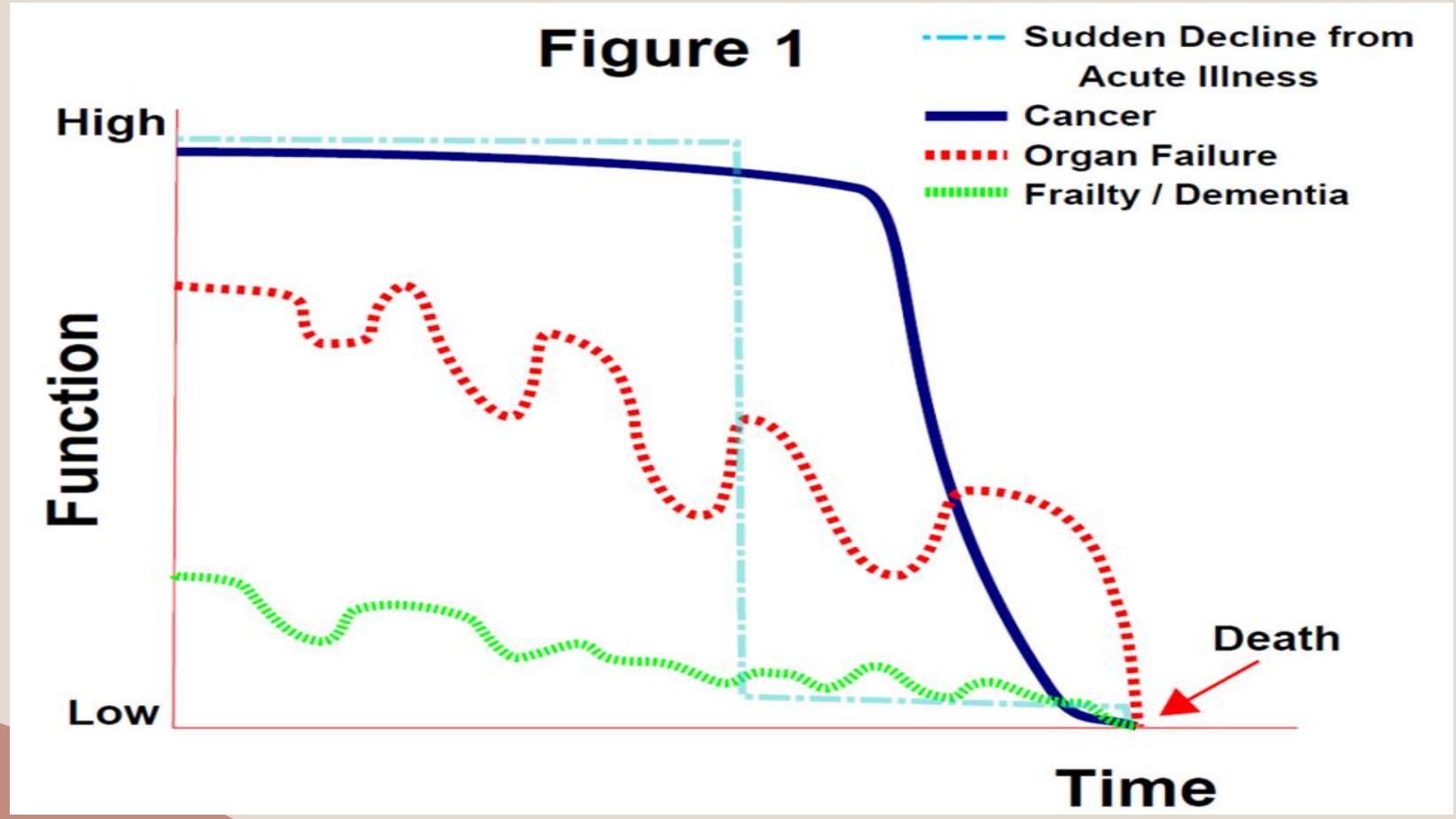
# Prognostication

- The surprise question
- Make survival estimates in timeframes (eg weeks to months)
- Best case vs worst case

- https://pmc.ncbi.nlm.nih.gov/articles/PMC6752241/



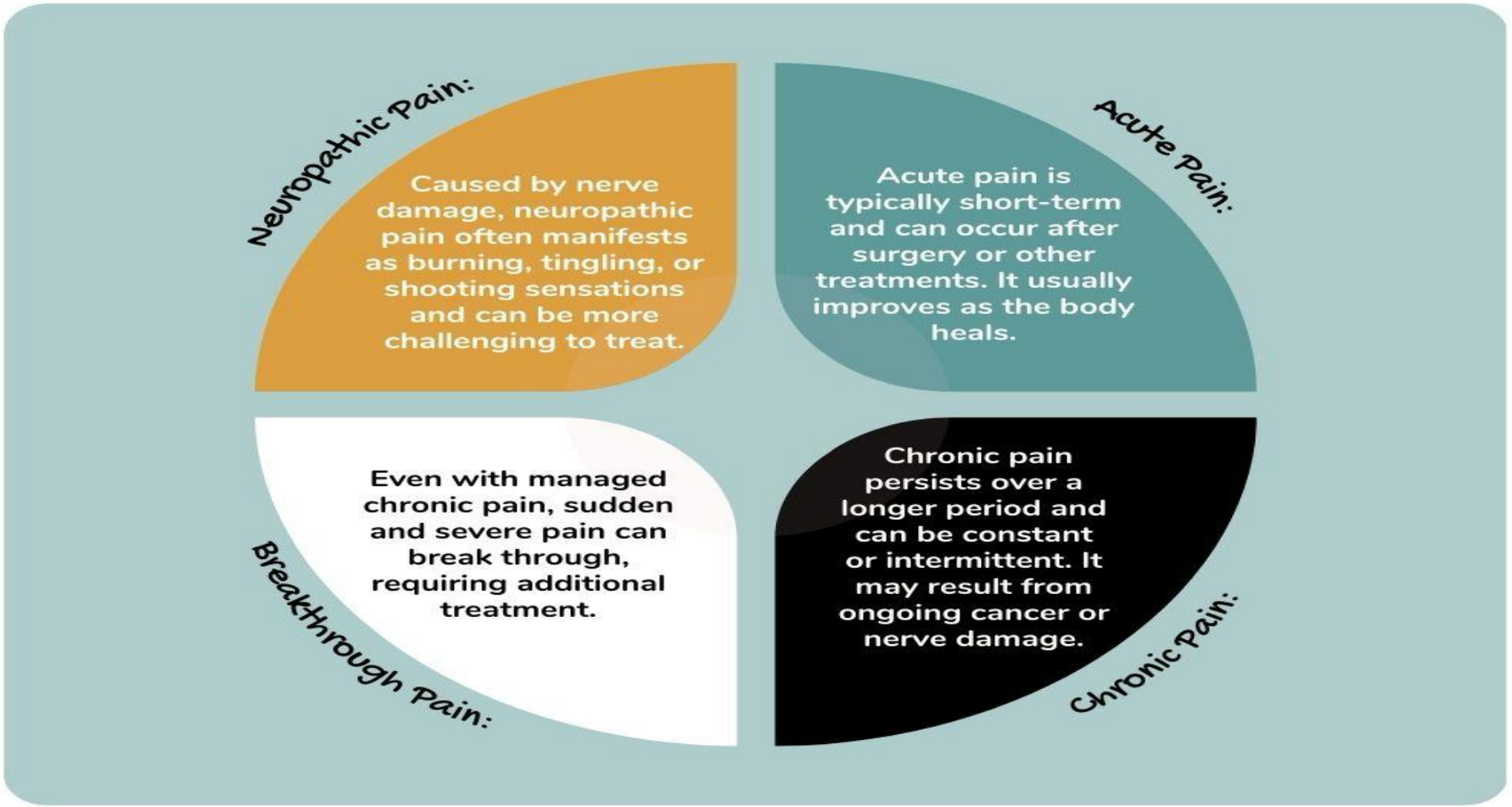
# Cancer Decline Trajectory

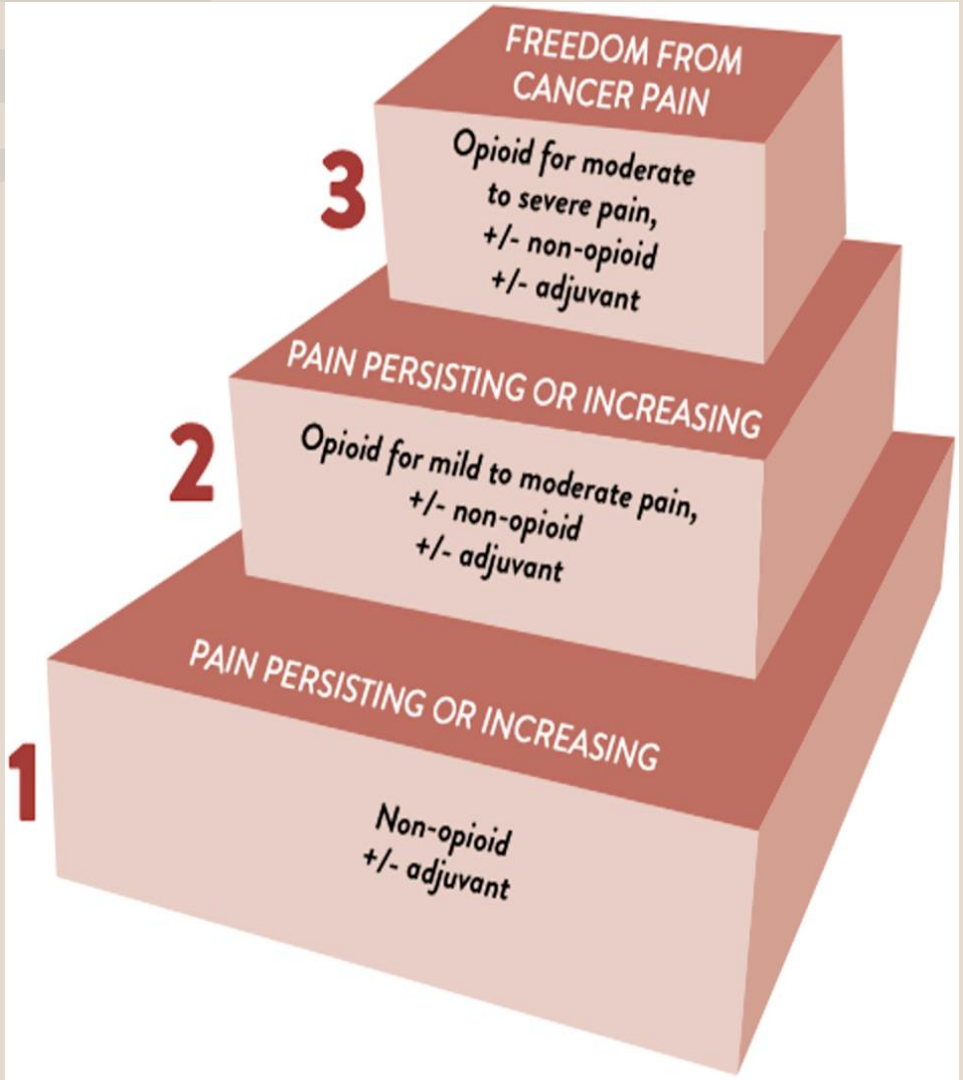



https://www.mypcnow.org/fast-fact/illness-trajectories-description-and-clinical-use/

# Pain

# TYPES OF CANCER PAIN






# Pain

- 35% of patients with cancer have moderate to severe pain
- 80% of patients with advanced cancer experience severe pain

https://www.ncbi.nlm.nih.gov/books/NBK554435/figure/article-31358.image.f1/?report=objectonly

# Non-Opioid Medications

- Tylenol
  - No more than 4 grams per day (8 extra strength tablets per day)
- NSAIDS
  - Avoid in bleeding risk, low platelet count, renal dysfunction
  - Caution in patients with diabetes, elderly, congested heart failure
- Steroids
  - Side effects: agitation, delirium, hyperglycemia, fluid retention, hypertension, increase risk of infection
  - Late side effects: adrenal insufficiency, myopathy, hyperglycemia, GIB, avascular necrosis, osteoporosis
- Antiepileptics
  - Dose adjust with renal insufficiency and elderly
  - Causes confusion, ataxia, sedation, and edema
- Antidepressants
  - TCA: caution with elderly and underlying cardiac disease, QT prolongation, sedation, delirium, constipation, urinary retention, and orthostasis

# Short Acting Pain Medications

- Advantages:
  - Helps manage acute pain
  - Helpful to determine correct doses of long-acting pain medicines
  - Used for breakthrough pain
- Disadvantages
  - Poor adherence
  - Repetitive dosing
- Examples:
  - Morphine IR, Roxanol
  - Norco, Tramadol, Oxycodone
  - IV Fentanyl, Dilaudid, Morphine

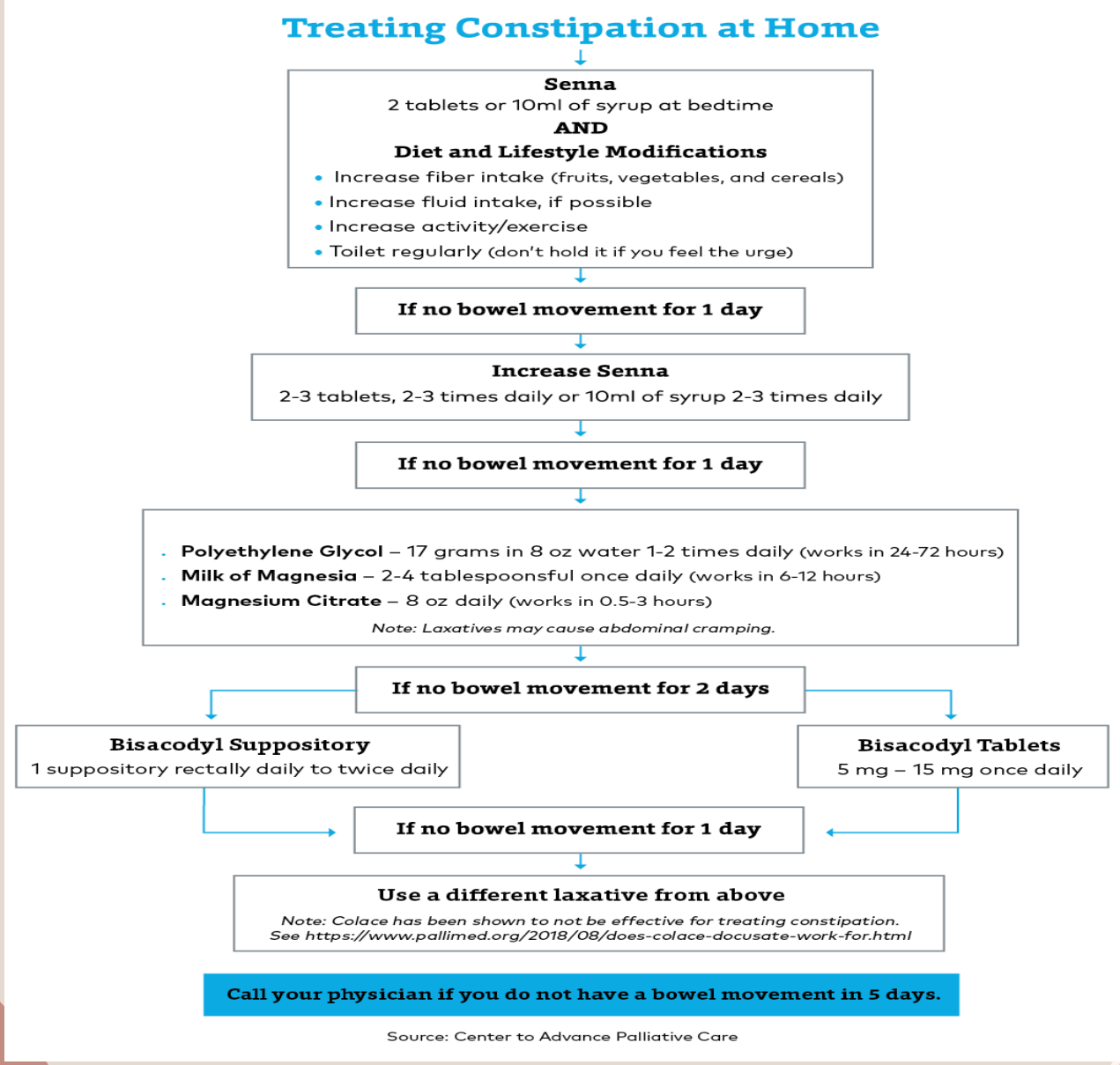
# Long-Acting Pain Medications

- Advantages:
  - Steady analgesic state in chronic pain
  - Improved med adherence
- Disadvantages
  - Not appropriate for rapid dosing
  - Cannot crush
  - Slower onset time
- Examples:
  - Morphine ER, Fentanyl Patch, Oxycontin, Methadone

# Pain Essentials

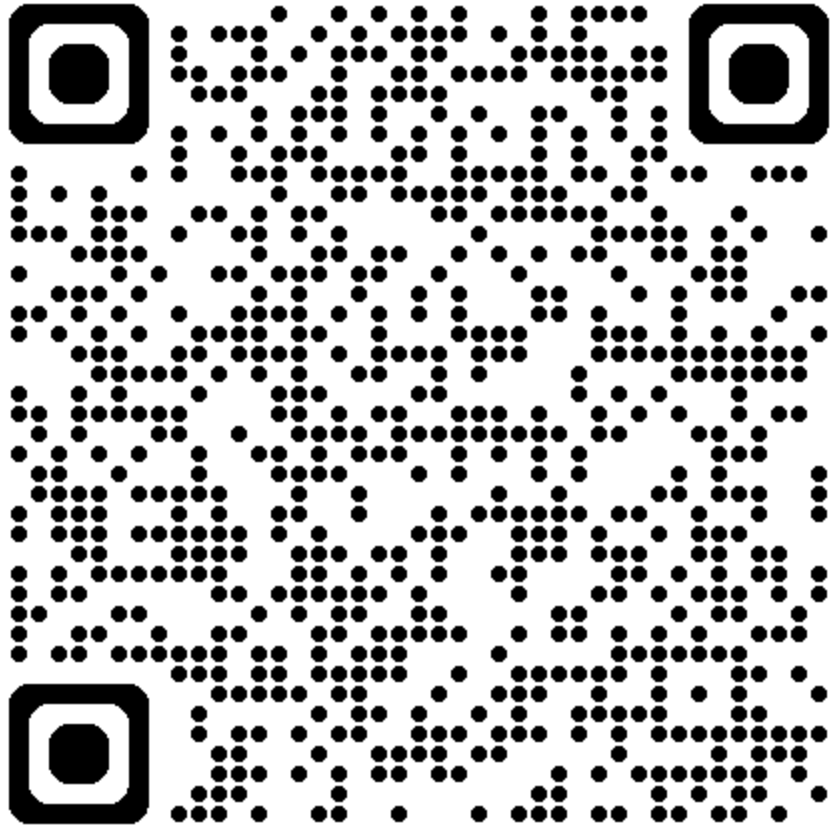
- Always start on bowel regimen
- Ensure patient and/or family have access to Narcan
- When not to drive
  - Starting a new medication/initial treatment
  - After dose changes
  - Adverse side effects: drowsiness, sleepiness, dizziness, confusion, poor coordination, or blurry vision
  - Combine with other substances (sedating meds, street drugs, etoh)
- After radiation and chemotherapy, may can decrease pain management

# Bowel Regimen



# OME- Oral Morphine Equivalent

- 1 mg IV Dilaudid = 20mg PO Morphine
- 20mg PO Oxycodone= 30mg PO Morphine
- 10/325mg Norco = 10mg PO Morphine
- 45mg PO Morphine = 12.5 mcg Fentanyl
- patch



# Moral Distress

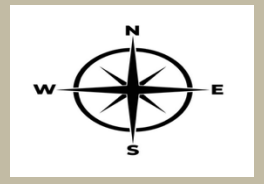
# Moral Distress

- Psychological disequilibrium between one's awareness of the morally appropriate action that a situation requires and the inability to act on it
- Inability to stop suffering, unclear goals of care and perceived futile treatments

# What am I experiencing?

## Moral Distress

When one knows the right thing to do, but constraints, conflict, dilemmas or uncertainty make it nearly impossible to pursue the right course of action.

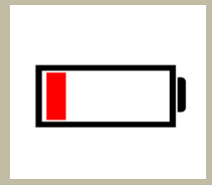



## Burnout

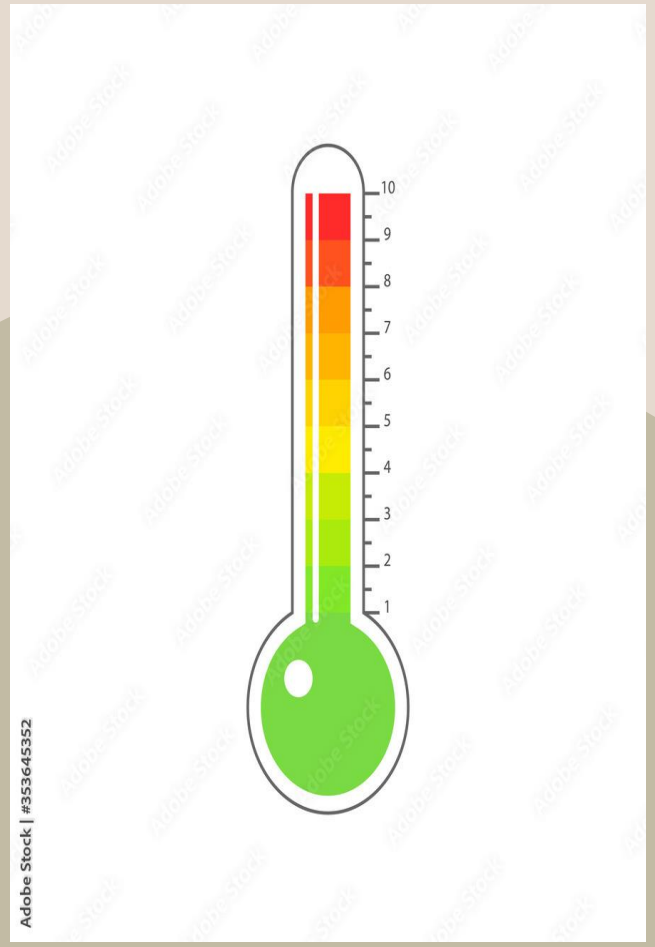
Physical, mental and emotional exhaustion caused by workplace stress leading to disengagement and depersonalization.

## Compassion Fatigue

Physical, mental and emotional weariness related to caring for those in significant pain or emotional distress.



# Asses Your Level of Moral Distress




## Moral distress symptoms

| | | | |
|---|---|---|---|
| **Emotional** | • Frustration<br>• Guilt<br>• Withdrawal | • Anger<br>• Sadness | • Anxiety<br>• Powerlessness |
| **Physical** | • Muscle Aches<br>• Neck Pain | • Headaches<br>• Diarrhea | • Heart Palpitations<br>• Vomiting |
| **Psychological** | • Depression<br>• Nightmares | • Emotional Exhaustion<br>• Decreased job satisfaction | • Loss of self worth<br>• Depersonalization of patients |

# Examples of Moral Distress

- End of life care: having to continue life sustaining treatments against a pts wishes or family values
- Ethical dilemma: situations where information is withheld from a pt or family for their own good
- Inappropriate care plans: disagreeing with a physician's treatment plan but feeling obligated to follow it due to hierarchical structures
- Lack of autonomy: experiencing situations where patients are unable to make informed decisions about their care due to cognitive impairment or cultural barriers

# The 4 A's of fighting moral distress

- Ask: ask for help to identify source
- Affirm: feelings are valid
- Assess: situation and solutions
- Act: use resources ethics system, building support systems, building support systems and advocating  for systemic changes, practicing self-care

# A Valuable Lesson for a Happier Life

- https://youtu.be/SqGRnIXpIx0?si=vuYdPkcC8_9rYsUU

# Nurses Testimonials

https://youtu.be/WziA88-n02k?si=De9xcg7gHYem2q86

I've been an ICU nurse for almost 10 years. I feel like moral distress is something that we deal with on a daily basis. It's very difficult to care for someone 12 hours straight and wonder if the things you are doing to them are causing more harm than good. You wonder- if the patient could speak for themselves, would they be okay with what I was doing to them? You see real suffering, and it truly hurts to know that you might be the one causing it.

In healthcare, we spend a lot of time intervening without considering if we SHOULD. We spend more time trying to buy more time for patients without considering the cost. We focus on quantity instead of quality. This becomes part of the dilemma that nurses face.

It has been increasingly more difficult over the years. Patients and families are less trusting of healthcare workers. We have an increase in violence against healthcare workers. Patients are coming in more complex than they ever have. Family members will post negatively about their experience in the healthcare system on social media. These have made the emotional weight we carry as nurses much more difficult to handle. Our hearts are breaking for the suffering people in the beds, all while defending our work and sometimes physically defending ourselves.

Back when I was a BICU RN, had a patient with Calciphylaxis. Was really bad and involved BIL upper thighs. After multiple trips to the OR to remove the damaged areas of tissue on her thighs, I had her in the Tank room to do Would Care. During would care, she experienced a moment of breakthrough pain and woke up crying, saying she didn't want to keep going through this anymore. Just to let you know, I had been taking care of her for three days straight, and each day, she had been taken to the OR for Excision. Seeing her, and listening to her, I notified the CN, and the Attending that day. The attending came and assessed the patient in the Tank Room..and made the decision to stop all sedation and provide minimal pain medication in order for the patient to wake up so her desires could be known. It was decided, after she fully awakened from sedation, that all treatment would stop as the patient wanted to go comfort care. Due, however, to family dynamics, the issue had to be presented to Legal.. In the end, the patient's desires were honored, she was made comfortable, and she was allowed to pass with dignity...pain free.

Only think I would have done differently is: I would have addressed and advocated for this patient sooner!!

I think the time that I experienced moral distress that I remember the most is when I was helping a team member who had a patient with stage 4 cancer and the patient was struggling with symptom management. The nurse had been calling the physician for help with pain medication and could not get anything else ordered for this patient with severe pain.  I called the physician and told him we really needed more pain medication for this patient. The physician said the patient was always asking for pain medication, but they would come assess the patient and make changes if they needed to.  The patient did have a history drug abuse in the past so it was understandable that the physician would feel that way, but the patient was really expressing and showing signs of severe pain. When the physician came to the bedside, I decided to round with him since the primary nurse was new and unsure how to handle the situation. The patient and patient's family member tried to explain symptoms and severity. The physician quickly stated they would "look into it" and left the room. Directly outside of the patient's room, the physician stated the patient was just drug seeking and the family member was crazy. I really experienced moral distress at that moment because I watched the patient "suffer" with severe pain and was nauseated and vomited all day and the physician did not believe their symptoms. I suggested consulting the palliative team because they could help the physician and patient with pain management. The physician agreed and consulted the palliative team. The team was able to change medications for the patient and get them comfortable. The patient's symptoms and pain were controlled by the next day, and the patient was able to go home the day after that. I feel like the physician was " burned out" with this patient and I was grateful they were open to allowing someone else to help. The only thing I might do different is educating the new nurses to seek help with situations like this sooner, so the patients don't have to wait as long for possible interventions.

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thank you