# Palliative Care in Critical Illness/Injury
## *Communication Skills for Surgeons*

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## Palliative Care Overview

- Benefits of timely palliative care consultation (improved quality of care, reduced overall costs, avoidance of unwanted end of life care, decreased ICU and hospital length of stay, increases in longevity) have increased the demand for specialty palliative care providers. The increasing demand will soon out pace the supply of specialized providers. It is therefore imperative for surgeons to develop primary palliative care skills.

- This ACS module is focused on primary palliative care communication skills.

- **Main principles of palliative care**:
  - ***Effective communication***
    e.g. goal setting, prognostication, transitions in care

  - ***Relief of suffering***
    e.g. physical, psychosocial, spiritual
    A multidisciplinary approach is critical in addressing relief of suffering. Elicit the expertise of social workers, spiritual care providers, physical therapists, art therapists, music therapists, acupuncturists, etc. to provide holistic medical care.

  - ***Symptom management***
    e.g. pain, dyspnea, nausea, constipation, depression, anxiety, fatigue, delirium

- **Primary palliative care**: aligning treatment with goals of care, basic symptom management, and psychosocial support.

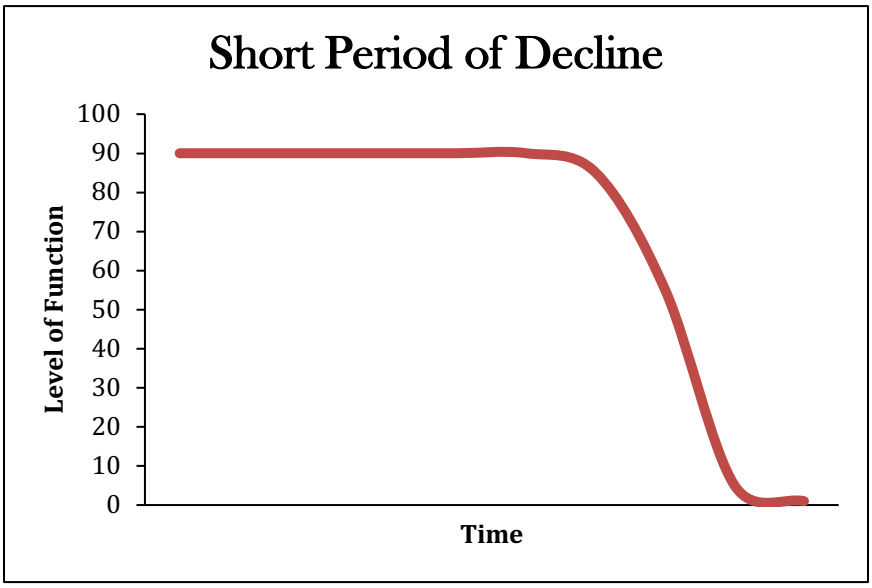
- **Secondary / specialized palliative care**: refractory symptom management (e.g. intractable vomiting, terminal agitated delirium, relief of dyspnea), addressing existential distress, navigating difficult family meetings, and managing medical team moral distress.

- **Palliative care vs. hospice**: Palliative care provides symptom management, psychosocial support, and assistance with medical decision-making to patients at all stages of serious illness, including concurrent disease-directed treatments. Hospice is palliative care reserved for patients who have decided to forego curative treatment and are in the terminal stages of illness.

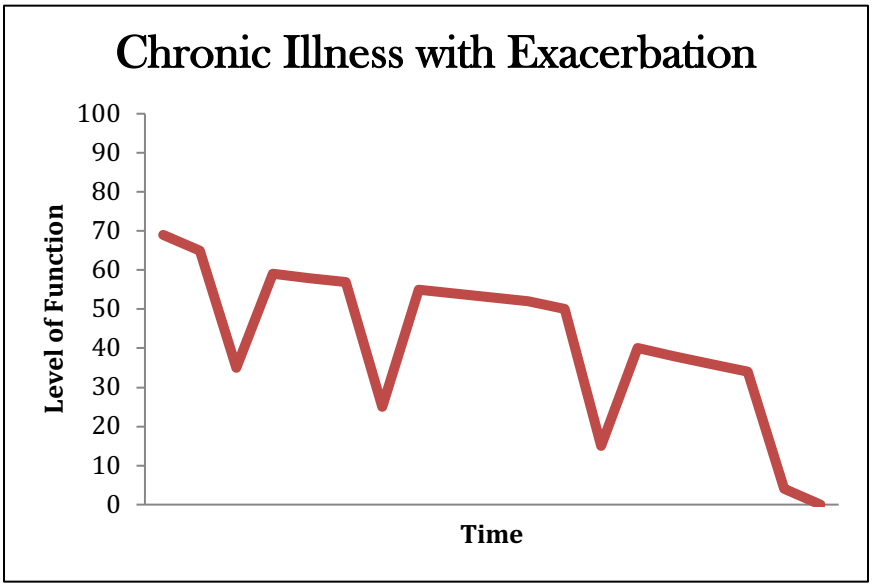
- **Introducing palliative care to patients and families**:
  *"Palliative care is specialized medical care for patients with serious illness / injury. Palliative care providers focus on the patient as an individual, and help to match their medical care to their goals and values."*

- *Illness trajectories*: Awareness of trajectories allows for more accurate prognostication and anticipation of needs. Drawing the expected illness trajectory for patients and families may facilitate advance care planning.

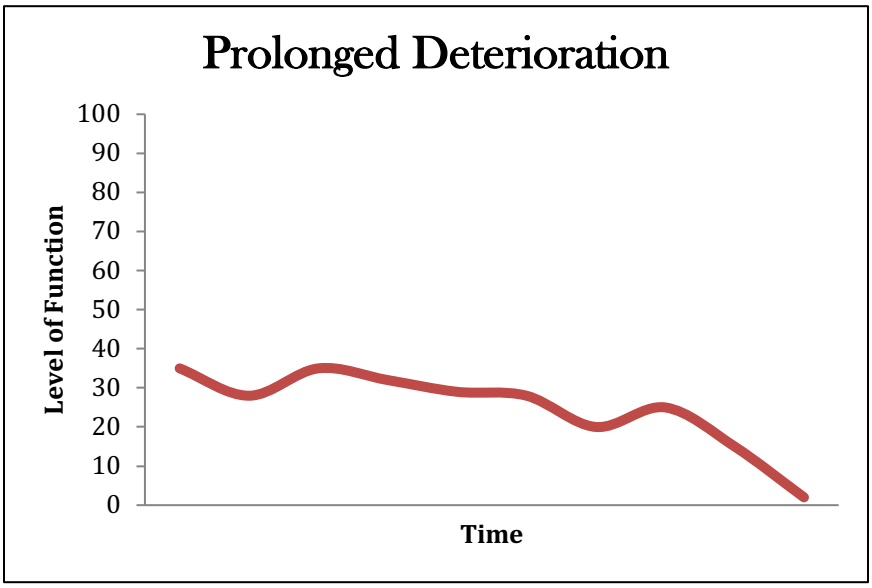
    1. Short period of decline (e.g. cancer)



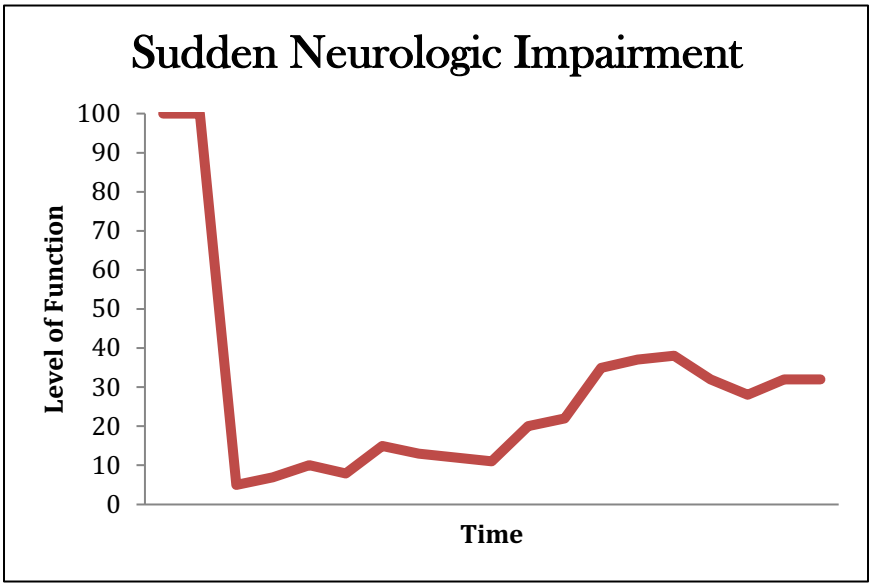

    2. Chronic illness with exacerbations (e.g. CHF, AIDS, COPD, liver failure)



3. Prolonged deterioration (e.g. dementia, multiple sclerosis, ALS, Parkinson's disease, frailty)




4. Sudden neurological impairment (e.g. traumatic brain injury, stroke, hypoxic ischemic encephalopathy)



## Conducting a Family Conference for Serious Illness

*Goal*: Delineate a patient's goals within the context of serious illness / injury and formulate a treatment plan so that the medical team can assist the patient in achieving these goals, while avoiding interventions that will cause suffering and not achieve stated goals.

**Table 1: Family Conference for Serious Illness / Injury**

| | | |
|---|---|---|
| **Pre-meet** | huddle with representatives from other teams to align perspectives, anticipate conflicts, and agree on treatment recommendations | |
| **Introduce** | introduce all meeting participants, ask for patient / family agenda, disclose medical team agenda | |
| **Assess** | evaluate their impression of the situation in order to know where to begin the medical update | "tell me what the doctors have told you about her condition" |
| **Update** | start with a **warning shot** (if disclosing serious news) + **headliner statement**, provide information in pieces and use lay language. ****Be ready for emotion**** | "I wish I had better news. His body is shutting down despite our best treatments" |
| **Empathize** | respond to emotion, avoid trying to fix it (see Table 2) | "this is a lot to take in and I can see you are upset" |
| **Prioritize** | turn conversation over to family to identify what is important to the patient (i.e. longevity, independence, comfort) | "if the patient were sitting here, what would they say about all of this?" |
| **Align** | align the medical care plan with patient's values. If family is uncertain, offer to make a recommendation | "based on what you have told me about your loved one's values, and based on our experience with patients with similar injuries, I recommend we transition to comfort-focused care" |

## Responding to Emotion

*Empathy*: the ability to understand and share the feelings of another

vs.

*Sympathy*: feeling of pity and sorrow for someone else's misfortune

**Benefits of responding to emotion / emotional cues**

- Patient / Family:
  - reduce the intensity of emotion
  - helps patient / family feel understood
  - helps patient / family process information

- Provider
  - allows provider to deal with the emotion instead of trying to fix it
  - allows provider to remain present in the conversation
  - reaffirms provider's commitment to caring for the patient

Recognizing emotional cues and responding with empathic statements is one of the most difficult skills in palliative care. For many providers, especially surgeons, addressing emotion head on does not come naturally. The NURSES pneumonic is designed to help build a skill set of responding empathically.

**Table 2: NURSES Statements**

| | | |
|---|---|---|
| **Naming** | name the emotion for yourself, then use a suggestive statement to verbalize it to the patient | "it sounds like your family is really worried about you" |
| **Understanding** | acknowledging statement that normalizes the emotion | "after hearing this kind of news many people feel a sense of hopelessness " |
| **Respecting** | can use in situations of conflict | "I really respect how your family is advocating for your mother" |
| **Supporting** | many patients fear abandonment along their journey | "I will be by your side no matter what you choose to do" |
| **Explore** | can use when the conversation is getting off track | "I sense you are frustrated, can you tell me about how you are feeling?" |
| **Silence** | allow space for the emotion to exist, become comfortable sitting in silence | |

## Code Status Discussion

A discussion of the patient's code status should take place within the context of a conversation regarding the patient's values and goals. The following is a suggestion for how to approach a code status discussion.

- *Introduce*
  "While we are discussing your treatment plan and **hoping for the very best** outcome, part of my job is to also **plan for the worst**. I know this is a tough topic (warning shot statement), but have you given any thought to the medical care you would want to receive if you **died in the hospital**?"

  *It is very important to use the word "died" in this conversation. Phrases such as "heart stopped" or "lungs stopped working" are not interpreted in a universal manner, and may convey a less significant, temporary medical problem.

- *Inform*
  "Of all the patients who die in the hospital and receive **CPR and life support machines**, 10% will live to be discharged from the hospital. The other 90% of people that die in the hospital and receive CPR and life support machines will not survive to be discharged from the hospital, and many of these people never come off of life support machines."

  *Television has convinced the public that CPR is very successful in reviving dead people. Avoid the trap of using medical jargon such as "defibrillator", "intubation", or "mechanical ventilation", as these words are not universally understood by non-medical people. On the contrary, most people do understand the concept of "life support machines".

- *Normalize*
  "Some people choose CPR and life support machines because **living as long as possible**, even on machines, is what is most important to them."

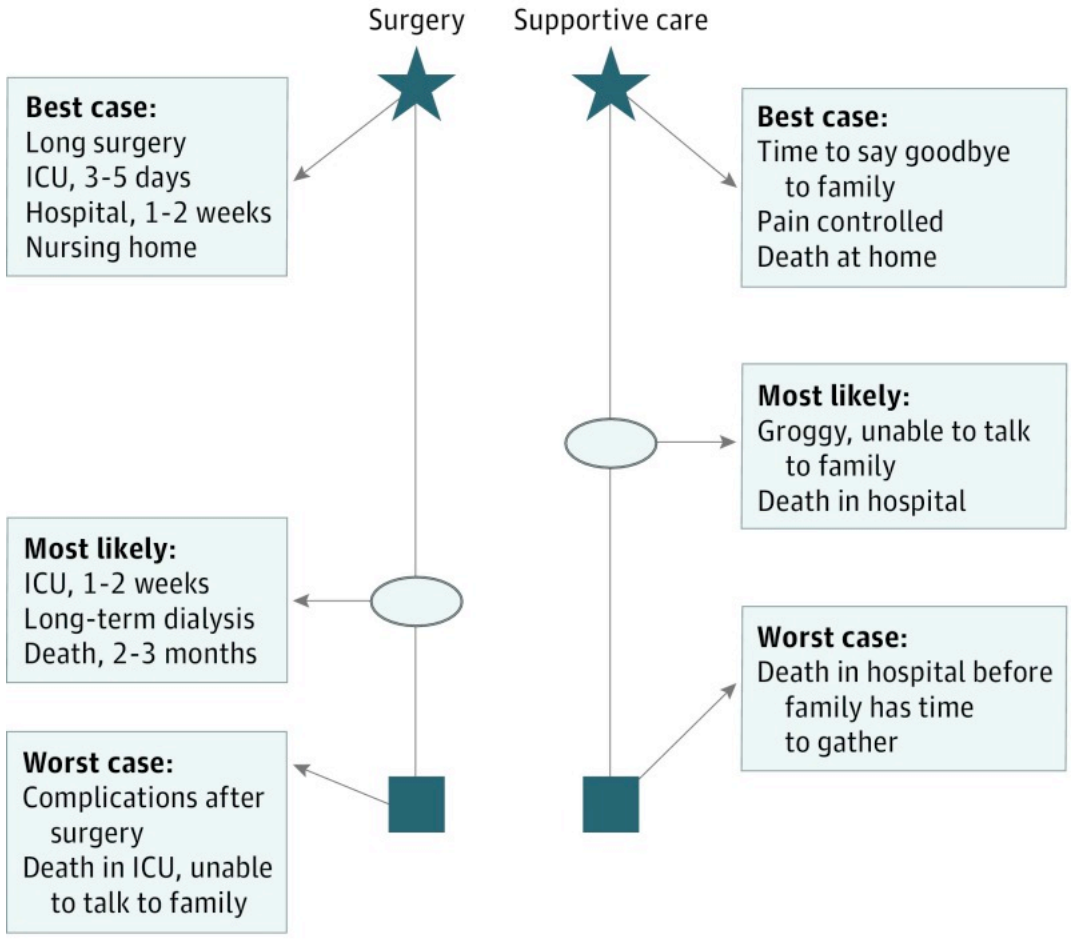
  "Other people choose no CPR and no life support machines because having a **natural and peaceful death** is most important to them"

  "Where do you stand on this?"

- *Recommend*
  "In your case, knowing that your functional independence is more important to you than living as long as possible, I recommend no CPR and life support machines if you die in the hospital, as I don't believe this would help you get back home living on your own."

## Approaching Uncertainty in Medical Decision-Making

The Best Case/Worst Case framework was designed by combining ***shared decision-making*** with ***scenario planning***. Within this framework, the surgeon combines a narrative description with a hand drawn graphic aid to set expectations of what is possible with different treatment options. Presentation of plausible scenarios within the boundaries of the best case and worst case scenarios allows the surgeon to paint a picture for patients / families that incorporates quality of life factors in the decision-making process.




Taylor et al. *JAMA Surg*. 2017

## Responding to challenging statements

- "***We only want to hear positive news***"
  - Important to earn their trust in the beginning
  - Start by discussing the "best case scenario"
  - When disclosing negative news down the line, limit to small pieces

- ***"Hoping for a miracle"***
  - Often these families are pegged as "in denial". Contrary to that belief, these people usually understand how bad the situation is, which is why they are "hoping for a miracle". It is easier for many people to voice their hope for a miracle than to verbalize their worst fears.
  - Key for provider is to find a balance between hope and honesty
  - Align with the family by accepting and endorsing their hopes
    "*we are also very much hoping for a full recovery*"

- "***They're a fighter***"
  - Recognize this statement as a coping mechanism
  - Use exploring statements to delineate what "fighting" means to that family
    "*Can you explain to me what fighting means to you*?"
  - Ask how the medical team can help the patient continue to "fight"
  - Align with the family by expanding their concept of fighting to include other ways people actively cope with illness
    "*I have heard that longevity is very important to your mother. Lets discuss how to achieve that while maximizing the quality of life she has left*."
  - Help the family discover what is possible for the patient within the context of serious illness / injury
    "*I understand that getting the patient home is something she is fighting for. Lets discuss how we can make that happen*."

- "***We want everything done***"
  - Start by acknowledging the statement
    "*I understand that you want the best possible medical care for your loved one*"
  - Use exploring statements to delineate what "everything" means to that family
    "*Can you help me understand what wanting everything done means to you*?"
    "*As you look to the future, is there anything you want to avoid*?"

## Multiple Choice Questions

1. **True or False: Palliative care is designed for patients with serious illness / injury at the end of life**.

   Answer: False- palliative care is designed for patients at all stages of serious illness, and is beneficial for patients undergoing life-prolonging treatments.

2. **Which is the best response to a mother that begins sobbing after disclosing serious news regarding her child's medical condition?**

   a) "Don't worry"
   b) "I'm sorry"
   c) Period of silence, followed by "I can see that you are devastated"
   d) Period of silence, followed by "I can't imagine how tough this is for you"

   Answer: d) When disclosing serious news, expect emotion to follow. Identify the emotion (sadness), allow space for the emotion, and respond with an empathic statement that helps to construct the emotion as tractable.

   Incorrect answers:

   a) "Don't worry" - attempt to fix the emotion
   b) "I'm sorry" - sympathetic statement, not empathetic statement
   c) Period of silence, followed by "I can see that you are devastated" – avoid using words that imply the emotion is unmanageable

3. **The best example of a "headliner" statement to open the "Update" portion of a family meeting is which of the following?**

   a) "I'm afraid I have some bad news. The infection is spreading despite our best efforts"
   b) "Last week we took her to the operating room, debrided the dead tissue, started broad spectrum antibiotics including Vancomycin and Zosyn, and now the white blood cell count is increasing"
   c) "The CT scan demonstrated an abscess in the muscle and gas in the overlying subcutaneous tissue"
   d) "I wish I had better news. We had to start vasopressors overnight"

   Answer: a) When disclosing bad news, prepare the patient / family with a "warning shot" statement followed by a simple "headliner" statement that provides an overview of the situation.

   Incorrect answers:
   Choices b), c), and d) provide too much detail and technical jargon that does not convey the overall clinical direction of the patient.

4. **Phrases such as "some people choose CPR and life support machines because they value longevity while other people choose no CPR and life support machines because they value a natural peaceful death" can be effective in achieving which of the following?**

    a) Encouraging the patient to choose what the provider thinks is best
    b) Normalizing the decision, while allowing the provider to remain neutral
    c) Scaring the patient into choosing DNR status
    d) Selecting resuscitation options such as "light code"

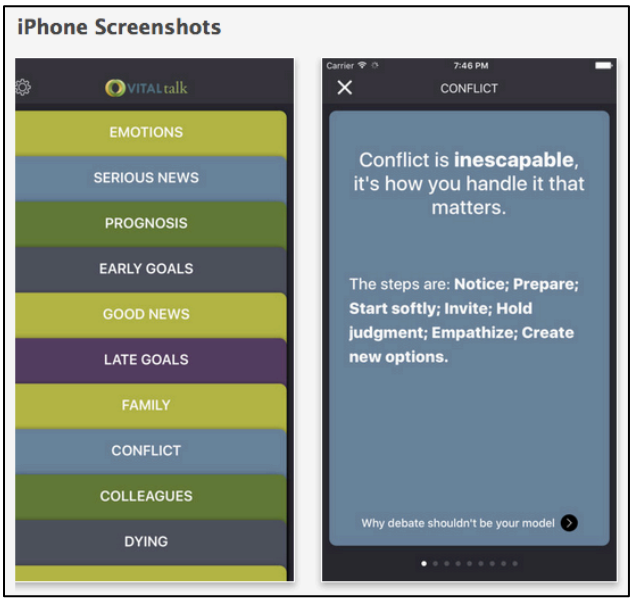
    Answer: b) Normalizing statements can be effective tools in many different situations, especially in cases involving patient / family mistrust of the medical team. By describing what different people may choose based on their values, providers remove their own biases and affirm their respect for patient / family autonomy.

    Incorrect answers:

    a) and c) are not patient-centered approaches
    d) The concept of "light code" is not universal between providers, patients, or families and should not be offered as a treatment option.

## Suggested Readings / Viewings

**VitalTalk** is a nonprofit collaboration that conducts NIH-funded research on effective communication skills in serious illness. The website was developed to disseminate evidence-based tools to help clinicians improve core communication techniques. Much of the content for this ACS module was derived from their resources at http://vitaltalk.org. It is highly recommended for fellows to watch the videos, use the quick guides for major learning topics, and download the **VitalTalk Tips app** (available at the Apple App Store and Google Play Store).




Brené Brown animated video on Empathy vs. Sympathy https://www.youtube.com/watch?v=KZBTYViDPlQ

Mosenthal AC, Weissman DE, Curtis JR, et al. Integrating palliative care in the surgical

and trauma intensive care unit: A report from the Improving Palliative Care in the Intensive Care Unit (IPAL-ICU) Project Advisory Board and the Center to Advance Palliative Care. *Crit Care Med*. 2012;40(4):1199-1206.

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