



Difficult Conversations Guide

1st Edition

Julie J. Cooper, MD
Editor-in-Chief

Lillian Liang Emlet, MD, MS, CHSE, CPC, ELI-MP; Eric D. Isaacs, MD; Joanne Gould Kuntz, MD, FAAHPM
Senior Editors



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CHAPTER

1

Goals of Care Conversations in the Emergency Department (ED)

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DEFINITIONS

- **Serious Illness:** A health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregivers¹
 - The most common of these are cancer, organ failure (heart failure, chronic obstructive pulmonary disease (COPD), end-stage renal disease) and dementia/frailty.
 - This can also include an acute catastrophic event in a previously healthy person, such as trauma or stroke.
- **Goals of Care (GOC) conversations:** The ongoing communication that happens between a health care team and a seriously ill patient that aims to achieve goal-concordant care by:
 - Promoting autonomy and patient-centered care by understanding the patient's perspective and values;
 - Avoiding unwanted care and prioritizing valued care by aligning the treatment plan to these values;
 - Conferring psychological support for patients and their families.²
- **Surrogate decision-maker:** Someone who is chosen (by the patient prior to losing decision-making capacity) or assigned (based on legal statute) to speak for the patient and represent their values, goals, and wishes when they cannot speak for themselves³
 - Legal statutes vary by state, so be aware of your local laws and customs.

WHY THIS MATTERS

- The ED is often the first point of hospital contact for patients experiencing acute life-threatening conditions, exacerbation of chronic life-limiting illness, and in need of acute symptom management.
- In emergency medicine (EM) and throughout acute care, GOC conversations are erroneously considered interchangeable with “code status” conversations or discussions about specific treatments (CPR, intubation, central lines, etc.).
 - In fact, specific treatment recommendations are the outcome of a goals-of-care conversation and should reflect patient goals and values.
- High-quality serious illness conversations promote goal-concordant care throughout a hospitalization and can direct treatment during future visits.

WHEN TO USE

GOC conversations are indicated in the ED when:

- There is a change in clinical status in a patient with a chronic serious illness. This can include:
 - Acute and subacute changes in prognosis, such as sudden deterioration or exacerbation of the underlying serious illness.
 - Example: Patient with progressive malignancy on palliative/non-curative treatments presenting with sepsis and acute respiratory failure
- “The old plan isn't working” or current treatments are no longer effective or feasible. This is often characterized by repeat hospitalizations or frequent ED visits for sequela of the chronic serious illness, or when caregiving needs have exceeded the capacity of the caregiver.
 - Example: Patient with severe heart failure on maximal outpatient medical therapy now presenting for the fourth time in two months with shortness of breath and edema
 - Example: Elderly patient with progressive dementia/frailty with increased frequency of ED visits and hospitalizations due to falls, UTI, failure to thrive
- Acute, catastrophic illness in previously healthy patients does not typically prompt goals of care conversations in the acute setting, but rather requires skillful delivery of serious news and support of the resulting strong emotions.
- A patient is likely to undergo an invasive procedure, resuscitation, or treatment (intubation, dialysis, thrombolysis) with a high risk of complications.

STEPS FOR A SUCCESSFUL GOC CONVERSATION⁴

Subsequent chapters will address in detail each step in the GOC conversation. This is an overview of the complete process.

Step	Purpose	Example Language
<u>Reframe</u>	<p>Deliver a clinical update.</p> <p>Deliver serious news.</p> <p>Put the current visit in the context of the larger chronic illness.</p> <p>Help the patient or surrogate understand what to expect.</p>	<p>“What have you heard so far?”</p> <p>“Is it ok if I tell you what I am seeing?”</p> <p>“This might be difficult to talk about.”</p> <p>“I’m afraid I have some serious news to share.”</p>
<u>Expect emotion and empathize</u>	<p>Emotional thinking is faster and more powerful than the cognitive processes needed to receive information and make decisions.</p> <p>Take time to show you are fully present.</p> <p>Allowing space for emotional processing and making your empathy visible builds trust with patients and surrogates.</p>	<p>“I can see how hard this information is for you to hear.”</p> <p>“We are here to support you every step of the way.”</p> <p>“She is so lucky to have you here to advocate for her.”</p>
<u>Map patient goals and values</u>	<p>The patient is the expert in what matters most to them, the medical team are experts in the available treatments to try to achieve those goals.</p> <p>Confirm prior documented advance care planning conversations and treatment limitations.</p> <p>We have to find out what is most important in order to make a goal-concordant treatment plan.</p>	<p>“Given the situation, what is most important to you?”</p> <p>“What are your concerns when thinking about the future?”</p> <p>“We want to work together to make sure she is getting the kind of care she wants. One thing I see in her record is that you previously discussed avoiding procedures like CPR and breathing machines. Has that preference changed?”</p>
<u>Align with the patient’s values</u>	<p>Show your work, explicitly link the values you have elicited to the plan you are going to propose.</p>	<p>“From what you have told me, it sounds like the most important things to you are…”</p>
<u>Plan medical treatments that align with values</u>	<p>Propose a medical plan that aligns with values and seek feedback on that plan.</p> <p>Recommend treatment limitations if they are not goal concordant.</p>	<p>“Given those goals, here is what I would recommend we do next.”</p> <p>“These are some treatments I would not recommend at this time.”</p> <p>“What are your thoughts?”</p>

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PEARLS AND PITFALLS

- Do not address individual treatments (intubation, CPR, central lines) without first addressing goals and values. These interventions should be presented as a recommendation based on goals and values.
- Decisions around potentially life-prolonging treatments such as CPR or intubation sometimes need to be made in minutes.
 - In these cases, confirming existing treatment preferences may need to happen before a more complete GOC conversation (ie, a patient with prior DNI orders experiencing acute respiratory failure and the decision to initiate mechanical ventilation can't wait).
 - In these cases, after confirming the surrogate and giving a brief clinical update, it is appropriate to directly confirm previously documented preferences.
 - Even if these choices have been previously established, bringing them up can be emotionally taxing and should be done with empathy and support.
 - If there is not clear agreement or understanding, the default is often to pursue life-prolonging treatment until goals can be clarified. Treatments can always be scaled back when appropriate.
 - After the situation is stabilized, give a new reframe and proceed with the goals of care conversation.
- Having the right people involved in your GOC conversations as soon as possible can save time and reduce conflict.
 - The patient (when able) and the surrogate are the most important participants, but always check to see who else should be involved and do your best to include them by phone or in person when feasible.
- These conversations do not always happen in one sitting.
 - When clinical situations are complex, the larger arc of a GOC conversation may not happen entirely in the ED.
 - When your conversation reveals there is too much uncertainty to confidently make a goal-concordant plan, the default may be to “do more” or offer a trial of more intensive therapy.
 - Each conversation should build on previous ones to help engage and deepen the understanding between the patient, family, and care team.
- Make sure to document your conversations in a place they can be accessed by everyone on the downstream care team.
 - This helps facilitate goal-aligned decisions and prevents contradictory messages. It also allows for future conversations to pick up where the last one left off.

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Delivering Serious News

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WHY THIS MATTERS

- Serious news in the ED setting can be defined as any information that adversely and seriously affects an individual's view of their future.¹
 - Delivering serious news in the ED is sometimes purely informational, such as the disclosure of a new diagnosis or finding.
 - In other cases, it involves reframing the current situation by giving a clinical update in the context of the bigger picture.
- Effective delivery of serious news or reframing the current clinical situation is the foundation of all serious illness conversations, and is the basis on which treatment plans are formed.
- Delivering serious news is stressful, particularly in the ED, where it is made more difficult by the frequency of interruptions and the lack of a prior patient-doctor relationship.²
- Effective delivery of serious news assists with the emotional adjustment to the news, as well as a patient's or surrogate's long-term relationship with clinicians.

WHEN TO USE

Situations necessitating a structured framework for serious news delivery may include:

- Sudden or unexpected condition
 - Major trauma
 - Sepsis
 - Stroke or TIA
 - Suspected malignancy
 - Pregnancy or miscarriage
- New diagnosis of a chronic illness
 - Multiple sclerosis or demyelinating disease
 - Diabetes
 - Seizure
 - Heart failure
- Progression of an existing chronic illness
 - Worsening of known malignancy
 - Progression of organ failure (renal failure, heart failure, respiratory failure, progression of neurologic disease)
 - Frailty with multiple hospitalizations
- Progression of illness or new illness that might impact future level of care
 - Ambulatory dysfunction or injury that requires rehabilitation
 - Progression of dementia that may require skilled nursing facility placement or home caregivers

Death notification is a special case when it comes to delivering serious news. It is covered in detail in Chapter 7.

The SPIKES Protocol³

Step	Purpose	Example Language
Setting	<p>Ask who the patient might want to have with them to hear an update.</p> <p>Consider a conference room/family room or placing privacy screens if patient is in a shared care space.</p> <p>Silence all monitors as able.</p> <p>Tell your colleagues you will be stepping away for a moment.</p> <p>Sit down; be as present as possible.</p> <p>Involve at least one other member of your team, such as a nurse, social worker, or chaplain who can assist with resources and next steps if you need to step away.</p>	<p>“Is there anyone else you would like to include in the discussion?”</p>
Perception	<p>Assess the patient’s understanding of the clinical situation.</p> <p>This allows you to make sure you are adding to what they already know.</p>	<p>“What have you heard about your test results so far?”</p> <p>“What have other clinicians told you about what to expect with this condition?”</p> <p>“What did the last team tell you about what we were looking for on the CT?”</p>
Invitation	<p>Ask permission to engage in conversation about a sensitive topic.</p>	<p>“We have your test results back. Would it be OK to talk about them now?”</p>
Knowledge	<p>Plan what you are going to say before you enter the room. Practice saying it out loud if needed.</p> <p>Keep the initial information concise and big-picture oriented; you can always give more information or clarification later.</p> <p>Consider using a warning phrase.</p> <p>Share the medical information in a concise manner without medical jargon, and include what it means for the patient/surrogate.</p>	<p>“Unfortunately, I have some serious news.”</p> <p>“The ultrasound shows the baby is in the fallopian tube and not in your uterus. This means the baby cannot survive and you may need surgery.”</p> <p>“Your CT showed a blockage that is causing your vomiting. This means the cancer has grown despite the chemotherapy.”</p> <p>“He has a serious infection that is affecting his organs. Because his immune system is weak this could be life-threatening.”</p>
Emotion/Empathy	<p>Allow space and time for information to be digested.</p> <p>Watch for an emotional reaction like tearfulness, a look of sadness, silence, shock, or anger.</p> <p>Identify the emotion experienced by the patient by helping to name it.</p> <p>If a patient appears emotional but is silent, use open-ended questions to ask what they are thinking or feeling.</p>	<p>“I can see this information is really overwhelming.”</p> <p>“I can’t imagine how hard this is to hear.”</p> <p>“You have been such a great advocate for your sister.”</p> <p>“We are here to support you every step of the way.”</p> <p>“Would you be willing to share how you’re feeling about all of this news?”</p>
Strategy/Summary	<p>Ask permission to discuss the next steps.</p> <p>Summarize what was discussed. Inform them of the team members and resources available to support them.</p> <p>Develop a plan moving forward and answer all questions they have.</p> <p>This can be short term planning or longer-term planning.</p>	<p>“Would it be OK to talk about where we go from here?”</p> <p>“I’ll check back in an hour to see how he is responding to the treatment.”</p> <p>“The next step is that the specialist will come down to give their recommendations.”</p> <p>“He’ll be admitted to the hospital, I’ll put in the orders for a bed upstairs and the admitting team will come see him and give you more information.”</p>

PEARLS AND PITFALLS

- Take a moment to acknowledge that delivering serious news can be personally taxing, and learn what you need to do to prepare yourself before and care for yourself after.
- Most serious news should be delivered along with additional information that gives it context or meaning.
 - Use plain language and avoid medical jargon.
- Confirm the patient's or family's preferred method of communication and spoken language preference.
 - Use in-person interpreters, if available.
 - Consider briefing the interpreter of the content of the conversation in advance of the conversation.
- Some responses to strong emotions can be maladaptive; make sure to provide emotional and physical space for a wide range of reactions and protect yourself in the event a patient or surrogate becomes agitated or violent.

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Demonstrating Empathy and Responding to Emotion

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WHY IT MATTERS

- **Acknowledging and responding to a patient’s/surrogate’s emotional state is a crucial step that helps build trust and move your partnership toward a space where they can receive new information and make decisions.**
- Engaging patients in difficult conversations, such as hearing serious news or thinking about the future, can elicit strong emotional responses.
 - **The limbic system (emotional brain) is faster and more powerful than the prefrontal cortex (rational brain).**
 - When the brain is in “survival mode” due to high stress, the prefrontal cortex is offline and not able to participate in decision-making.

WHEN TO USE

- It is critical to first recognize emotion, as **responding to emotion** allows you to connect with the patient or surrogate before moving to presenting information or making decisions.¹ Emotion can present in an encounter as:
 - **Overt emotion** that is clearly visible as verbal and/or nonverbal cues, such as crying or pacing. Rather than avoiding these strong emotions, pause and acknowledge them before continuing.
 - Example: “I can see how upsetting this is to hear.”
 - **“Masked” emotion** that may be expressed through cognitive statements or questions. This may manifest as concerns about individual test results, details of treatment options or prognosis. In these cases, it’s important to recognize the emotional undertone, even if the patient or surrogate seems focused on facts.
 - Example: “It sounds like you’re feeling worried about what these results mean.”

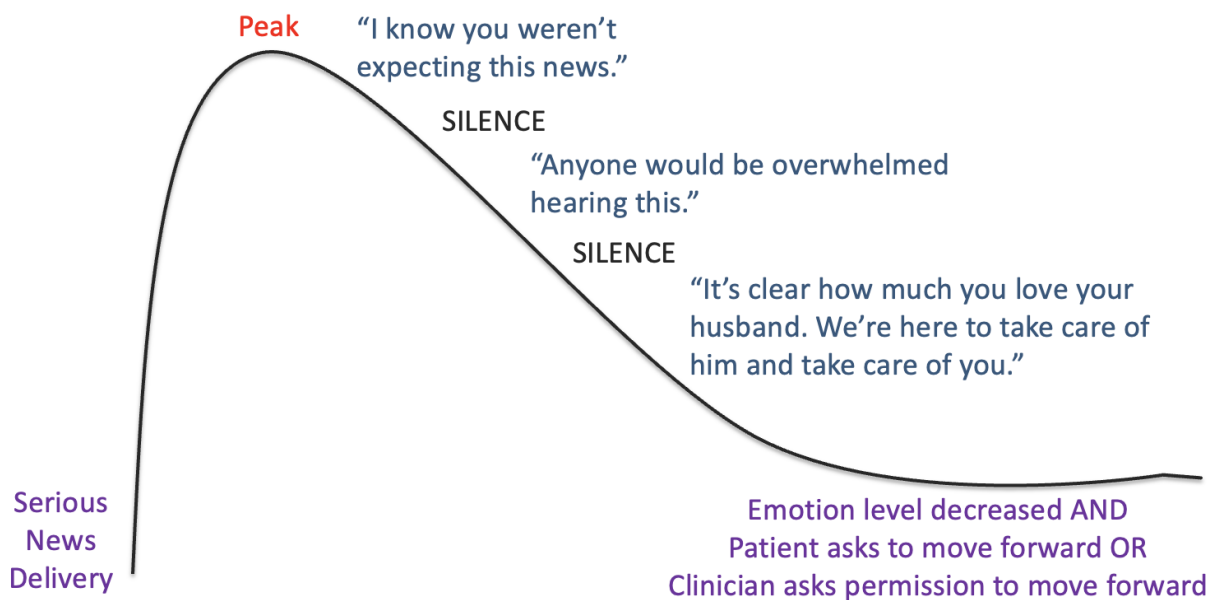
STEPS

After recognizing the emotion, you may still have trouble finding those “perfect words” to express your empathy. **NURSE** is a mnemonic for statements that help with verbally responding to emotion.^{2,3}

NURSE	Example Language	Tip
Name Put the emotion into words to directly acknowledge it.	“I wonder if you’re feeling upset, or even angry?” “I can see this situation is very overwhelming.”	Suggest, don’t declare. People don’t like being told how they’re feeling.
Understand Show that you’re trying to understand the patient’s experience.	“I can see how much this is weighing on you.” “I can’t imagine how scary this is.”	Avoid stating you understand what they are going through (you don’t), but show you are trying to imagine their emotional state or situation.
Respect Acknowledge effort and perseverance.	“You’ve done everything that has been asked of you.” “We are so glad you are here advocating for your ____.”	Try offering respect or praise to caregivers as well.
Support Offer your presence and/or expertise.	“I’ll be here to help guide you to make sure we honor your priorities.” “Our team will be here with you every step of the way through this treatment.”	Some patients want action, while others want to be heard - if what you first offer doesn’t connect, try something different.
Explore Use open-ended questions to encourage further sharing.	“Could you tell me more about what worries you?” “I’m curious. What’s running through your mind right now?”	Exploring prevents you from making assumptions and can uncover the underlying emotion when it is not obvious. The answers can give you an indication that the patient/ surrogate has heard the information and can guide the conversation further.

PEARLS AND PITFALLS

- Verbal acknowledgment of emotion doesn't make the emotion go away, it allows processing so that the prefrontal cortex (rational brain) can start to function again and engage in decision-making.
- Non-verbal responses to emotion such as leaning in, calm tone of voice, eye contact, and facial expressions also demonstrate engagement with the emotion.
- Silence allows space for patients to process information and express their emotions.
 - Avoid trying to fill silences with more information.
- "I Wish" statements can supplement NURSE statements and allow you to accept a patient's response without necessarily agreeing with it.⁴
 - Example: "There must be something else you can do!" (masked emotion)
 - Response: "I wish there was a treatment that could cure your cancer."
- Very strong emotions require more than one empathic response. (Figure)
 - Do not move on to next steps or action items until you see and hear signs that their emotion level has de-escalated.
 - This may show in your patient or surrogate's body posture, tone of voice, and words of agreement.
 - Ask permission to pivot to the next portion of the conversation.
 - Example: "Would it be OK if I shared with you what to expect next?"



(Figure courtesy of Dr. Tara Bamat, Children's Hospital of Philadelphia)

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Prognosis and Trajectory

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WHY THIS MATTERS

- **Prognosis** refers to the expected outcome of a disease. **Trajectory** refers to the assessment of how the patient has done in the past and how they are likely to do going forward.¹
- Many ED clinicians do not feel able to share information about prognosis, either because they do not have a relationship with the patient/family or a perception that they don't have enough data.
 - In fact, we are often well-positioned to gather timely and key information, even in the ED.
- While we deal with significant uncertainty when a patient presents to the emergency department, recognizing trajectories and sharing information about prognosis is critical because patients and caregivers can participate in making treatment decisions based on their understanding of their prognosis.²
- Sharing a realistic prognosis allows patients to make informed decisions about the kinds of medical care they would prefer. It can:
 - Help patients and families frame discussions with other key decision-makers;
 - Help patients and families understand the difference between treatment options that are likely to be curative or reversible and those that are likely to extend *quantity* of life at the expense of *quality*;
 - Help set the stage for discussions regarding preferences and supports other teams that may become involved during the course of the patient's care.

WHEN TO USE

- Sharing concerns about prognosis should happen while giving the medical update or delivering serious news .
 - Reframing the current situation involves delivering news and adding meaning. Prognostic information is often part of the meaning.
 - Example: “She has a severe infection affecting multiple organs. I'm worried that with her underlying dementia and other medical problems she could be sick enough to die during this hospital stay, even if we provide maximal treatments.”
- Common examples of times where prognosis may be shared as part of the serious news delivery:
 - Patients who are acutely ill within the setting of life-limiting illness (e.g. advanced cancer presenting with sepsis, advanced dementia presenting with recurrent aspiration, end-stage liver disease presenting with GI bleeding);
 - An injury or diagnosis that is likely to prevent them from returning to their prior level of functioning and independence;
 - A new serious illness for which ICU-level care and support may be recommended.

CONSIDERATIONS

- Ask permission to share information about prognosis.
 - Remember there are often cultural and psychosocial considerations about the best way to deliver information about prognosis.
- Baseline function is an important predictor of recovery.
 - Information about baseline function (eg, weight loss, decreased PO intake, decreased appetite, decreased awake time) can quickly be gathered by history and exam.
 - The palliative performance scale (PPS)^{3,4} is a common tool used to quantify performance status and can be helpful even in the acute setting to define this baseline function.
 - The PPS assesses functional status across multiple domains (eg, ambulation, ADLs, PO intake, level of consciousness), with more functional impairment indicating lower chances of survival.
- For most chronic progressive illnesses, the overall trajectory is of progressive decline, after an acute illness or hospitalization they would not be expected to recover to a level higher than they were prior to the hospitalization.
 - There are disease-specific trajectories that are well defined and combined with functional status can help place a patient on their overall trajectory:
 - Acute emergencies (eg, PE, stroke, trauma): these can accompany a steep decline but also come with the most uncertainty early on, use caution when having prognostic conversations in these acute presentations, especially in previously healthy patients;
 - Cancer: slow decline with swift and fatal complications leading to death;
 - Chronic organ failure: series of acute illnesses followed by recovery to slightly lower functional status than prior (eg, CHF, COPD, liver disease, renal disease, MS, Parkinson disease);
 - General frailty and aging, dementia: slow and gradual decline in function.

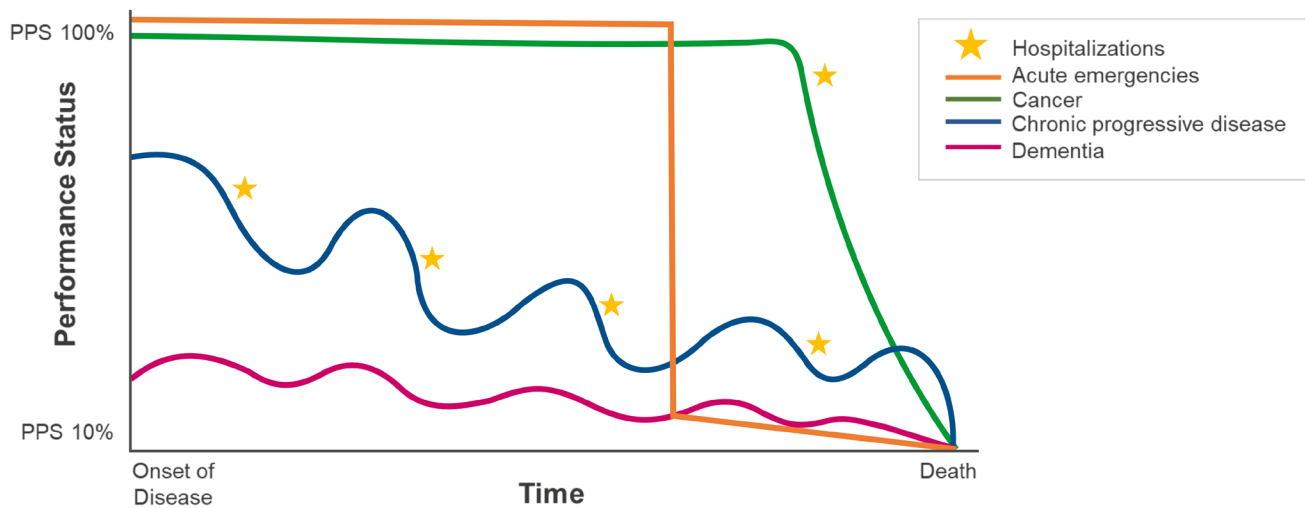


Figure 1. Illness trajectory models of acute emergencies, cancer, chronic progressive disease, and dementia. Note that chronic progressive disease (eg, CHF, COPD, liver disease, renal disease, MS, Parkinson disease, etc.) has periods of acute decline during exacerbations with gradual loss of functional status. In contrast, dementia has a trajectory of slow decline leading to death, and both cancer and acute emergencies include rapid declines leading to death.

- One way to communicate prognosis as part of serious news delivery, especially if the short-term trajectory could go several ways, is using a framework of “best case, worst case.”
 - As an experienced clinician you can likely predict a few potential trajectories and tell a story about what they might look like to help prepare the patient.
 - Example: “The very best case scenario is that we see a good response to our treatments here in the ED and her vital signs improve. In that case I would expect her to be admitted to the hospital for ongoing treatment and possibly be able to be discharged home or to a rehab.”
 - Example: “In the worst case scenario, despite all the treatments we are giving its possible that her body won’t be able to overcome this infection and I’m worried she is sick enough that she could die this hospitalization.”
 - Example: “In your mom’s case, I think the most likely scenario is that she will need admission to the ICU, we will give her time to respond to the antibiotics and other medications and we give her body time to recover from the infection. This would be the beginning of a long road and I would anticipate she could be in the hospital for up to a week or two with a long recovery after. I wouldn’t expect her to recover to a level better than how she was prior to coming in.”

PEARLS AND PITFALLS

- If you are unsure of the patient’s prognosis, do not guess. Instead, communicate your worry about the patient’s condition more broadly to help the patient/family/decision-maker understand the gravity of the situation and that they may need to make important decisions in the near future.
- If estimating prognosis surrounding time frames, use “bucket” estimates rather than specific numbers.
 - Example: “If things continue the way they are now I worry that he may have [hours to days] [days to weeks] or [weeks to months].”
- You may need to reframe provocative questions such as “How long have I got?” toward exploring the underlying emotions and values.
 - Example: “I wish I had a specific answer for you. Tell me more about what is worrying you.”

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Values Mapping

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WHY THIS MATTERS

- Each patient has a unique set of values and goals that impact their health care preferences.
 - Goal-concordant care requires that the health care team learns about what is most important to an individual patient and creates a medical plan in line with those goals and values.
 - The patient is the expert in what matters most to them; the health care team are the experts in what medical treatments are available to meet those goals.
- **Many clinicians have been taught to offer a treatment-based approach (which we do NOT recommend)** by offering a “menu” of available therapies and asking the patient to choose.
 - Example: “If her kidneys continue to get worse, she will need dialysis. Is that something she would want?”
 - Example: “If your heart were to stop, would you want CPR?”
- **We recommend a values-based approach**, which is a huge paradigm shift for most physicians. It means first exploring and understanding what is most important to the patient, then using that information to make a recommendation about next steps in treatment.
 - Example: “I hear you say that it has been really stressful for your husband the past few times he has been admitted to the hospital. It sounds like it is taking longer and longer each time for him to recover. I would like to prioritize medical plans that could help him be at home whenever possible.”
 - Example: “It sounds like if time is short, you wouldn’t want to be in a position where you couldn’t speak for yourself. It also sounds like you would not want to rely on machines. So, I would recommend we focus on your comfort and what matters most to you. I would not recommend artificial life support like a breathing machine to keep you alive if you weren’t able to participate in your care anymore.”
- While every patient will have different goals and values for their care, some common examples of values uncovered in these conversations may include:¹
 - Be cured/recover
 - Live longer
 - Improve or maintain function/quality of life/independence
 - Focus on comfort
 - Achieve life goals
 - Remain at home
 - Accomplish a particular goal/witness a particular event
 - Attend to spiritual needs
 - Avoid being a burden
 - Provide support for family or caregivers
- **This step of the goals of care discussion should guide the treatment plan to align with the patient’s goals and build rapport and trust between the clinician and the patient or their surrogate.**
 - Making recommendations unique to the patient’s individual values shows that you listened and puts your recommended treatment plan on a stronger foundation.
- Discussing what matters most to a patient also helps to build trust and allows you to understand cultural differences to provide equitable care.²

WHEN TO USE MAPPING (THE “M” IN REMAP): ELICITING VALUES

- Mapping out values should happen after a patient has received a clinical update and is in an emotional space where they can participate in the discussion.
 - Eliciting patients’ values should always take place **PRIOR** to recommending a treatment plan.

STEPS

- **Introduce the idea of Mapping** so the patient and their family members understand the purpose of your questions.
 - Example: “It’s important that we work together to make the best treatment decisions for you. In order to figure out next steps we need to learn more about what’s important to you, your previous experiences, and what treatments would be completely unacceptable.”
 - Example: “Would it be OK if we talked about what matters most to your mother? During times like this, there are details that would be helpful to know so that we can best take care of her. Once we know this, we can match her goals with further treatment plans that align with her values.”
- **Identify patients’ goals** using the **VALUES** framework:

Category	Description	Examples (top box = talking to the patient, bottom box = talking to a surrogate)
V ital Goals	Ask about their priorities and hopes	“Given this news, what’s most important right now?”
		“Given this situation, what are you hoping for?”
		“Hearing this news, if your mother were able to talk to us, what would she say is most important to her right now?”
		“When thinking about the future, what would you want to prioritize for your son?”
A ctivities	Ask about the things they want to keep doing	“Would you be willing to share what activities are most important to you right now?”
		“What brings the most joy and meaning to your life?”
		“When thinking about the next weeks to months, what would your father say about what he’d like to be able to do?”
		“If your father were here in the room with us right now, how would he describe a good day?”
L imits	Ask about if there is anything they would consider unacceptable <i>*We recommend asking this at the end, and consider prefacing that this is a difficult question to ask*</i>	“What would be an unacceptable quality of life?”
		“What abilities are so critical to your mother that she couldn’t imagine living without them?”
U ncertainties	Ask about their worries and concerns	“When thinking about the future, what worries you the most?”
		“After hearing this news, what concerns would your husband say he has?”
E xperiences with illnesses	Ask about their experience with serious illnesses or end-of-life care	“Have you or your family ever had an experience with a serious illness before?”
		“Thinking about the last time your daughter was in the hospital, would she want to do anything different this time?”
S trength & Support	Ask what helps them through their illness	“What gives you strength in these times?”
		“What things have helped you in other difficult times with your illness?”
		“What gives your wife strength? How does she cope?”
		“Who else supports your mother through her illness?”

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- **Align** with your patient by summarizing what you learned. **Reflect back and paraphrase what they said to you so the patient or family knows you were listening closely.**
 - Example: “What I’m hearing is your mother enjoys time with family, physical independence, and would want to allow a natural death. Did I get that right?”
 - Example: “Let me know if I’ve heard you correctly: You are having difficulty tolerating the chemotherapy recently and aren’t sure how much more you can endure, and also it’s really important for you to get to your son’s graduation at the end of year.”
 - Example: “I hear how important the grandkids and travel are to you, and that even if you were in a wheelchair, you would find it wonderful to spend time in the garden. Did I get that right?”

PEARLS AND PITFALLS

- For any VALUES question there may be more than one response. You can use questions such as “Tell me more about that” or “What else?” to expand their answers.
 - Don’t assume you know exactly what someone means the first time.
- When talking with surrogate decision-makers or parents in the case of pediatric patients, **center the discussion on the patient and their values** (rather than those of the surrogate).
 - Example: “If your loved one was awake and could understand everything that is happening, what would they say is most important?”
 - Example: “Has your loved one told you what situations or treatments they would find unacceptable going forward?”
- For most people, several things are likely to be important. **You will need to ask at least 3 or 4 value-based questions to arrive at a proposed treatment recommendation.**
- Talking about goals and values evokes vulnerability. Strong emotions may come up at any time in the conversation, so remember to respond to emotion using NURSE empathetic statements.
- As you are asking your VALUES questions, be sure to remember or jot down the answers, the data you collect will be the foundation of your proposed treatment plan.

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Making a Plan

Recommending Next Steps Including Surrounding Code Status

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WHY THIS MATTERS

- Serious illness care is not one-size-fits-all. Personal and cultural values affect treatment and end-of-life preferences.
- Patients and their surrogates are experts in what matters most to them.
 - We are the experts in translating those goals and values into a medical plan.
- The plan initiated in the ED matters and often determines the trajectory of subsequent hospital care.

WHEN TO USE

- Treatment plans should be proposed only after delivering a clinical update, identifying goals and values, and summarizing what you have heard.
- This framework is relevant for conversations both with patients and surrogates.

STEPS

- Summarize the values mapping that you just completed.
- Next, ask for permission to talk about treatment recommendations.
 - *Example: Thank you for sharing that information about your dad. Is it OK to talk about where we go from here?*
- Offer a treatment recommendation. Lead with treatments you would recommend.

Values/Goals	Treatment Plan	Recommendation
Live longer. Continue disease-modifying treatment. It can be used when there isn't enough prognostic information to recommend specific limits.	Full treatment Curative intent	Consider any available medical interventions, critical care, surgery. These interventions can always be reassessed as more information becomes available. [jump to Example 1 below]
Balance quality of time with quantity of time. Avoid unhelpful interventions or specific interventions that are not aligned with goals. Allow time to see if something is working or if the acute situation will improve.	Non-escalation Trial of therapy	Non-escalation may include avoiding ICU level of care, avoiding invasive treatments if they are unlikely to be effective, and limiting time in the hospital when possible. Trial of therapy may include any number of treatment options, but with clear time parameters for the trial and clear signs to monitor that would tell the team if the treatment is helping. [jump to Example 2 below]
Prioritize quality of time and comfort over all else.	Comfort	Focus only medical interventions that promote comfort and well-being. Manage symptoms aggressively. This case may be appropriate for hospice consideration. [jump to Example 3 below]

Example Case: The patient is an 85-year-old non-ambulatory person with 3 hospitalizations this year, now critically ill with sepsis. You have already given a headline, responded to emotion, and mapped values. Below are 3 examples of a treatment plan that may be recommended based on different values.

EXAMPLE 1 (FULL TREATMENT)

Mapping shows the surrogate believes the patient would want to prioritize being alive over all else, even if they may become fully dependent on activities of daily living and may require full-time care.

- Full treatment: “Based on what you’ve shared, we would recommend intensive treatment focused on recovering from this illness and prolonging his life. This means intensive treatments, like a ventilator in the ICU. I am still worried about him, and more discussions about his care can continue in the hospital. How does that sound?”
- If there is any disagreement, consider attending to any underlying emotions. Use a phrase like “Tell me more about that” to explain areas of disagreement.
- “I will ask our Palliative Care/Supportive Care specialist team to consult. I want to make sure we continue to respect his wishes, and I have found they provide a lot of support to patients and families going through difficult times.”

EXAMPLE 2 (NON-ESCALATION/TRIAL OF THERAPY)

Your mapping shows that prior to this hospitalization, the patient was still enjoying some activities, but he and his family have concerns about his overall quality of life. He had a prior ICU stay, when he had to go to acute rehab afterward and it was very hard on him. He wouldn’t want to go on living less able than he is now.

- “It sounds like your loved one would be willing to come into the hospital for treatment, but not have highly invasive treatments like life support machines or resuscitation that would leave him more dependent. Do I have that right?”
- “I’d recommend we admit him for IV antibiotics and treatment, but if he gets worse we will focus on comfort rather than putting him on life support machines or doing CPR if his heart stops.”
- “I wanted to let you know about a specialist team called Palliative/ Supportive Care who will be consulted on your loved one’s care. They routinely follow patients with serious illness so that we make sure we are respecting these choices and prioritizing his quality of life.”

EXAMPLE 3 (COMFORT)

Your mapping shows that the patient and his family are aware of the functional decline he has experienced and he has expressed that he is tired and doesn’t want to keep going on bouncing in and out of the hospital. They would ideally like him to be able to be at home and get the care he needs there.

- “It sounds like your dad would not want to have more treatment to prolong life, but instead focus on comfort at this time. Do I have that right?”
 - If yes: “We can focus on your dad’s comfort. I’ll have our Supportive/ Palliative Care team assist with making sure his symptoms are well-controlled and that your family has support at this difficult time.”
 - If death is imminent: “We can keep your dad comfortable in the hospital using medications to ensure he doesn’t suffer.”
 - If it’s important that he be at home but may require additional home health resources to facilitate this: “We can ask our hospice team to come and make sure his symptoms are well controlled at the end of life, (when that happens), and that you have the support you need as a family.”

After all of these recommendations, wait for a response. If there is any disagreement, consider attending to any underlying emotions. Use a phrase like “Tell me more about that” to explain areas of disagreement.

- Thank the surrogate and elicit questions.
 - “Thank you for having that difficult conversation with me. What questions do you have for me?”

DISCUSSING SPECIFIC TREATMENT LIMITATIONS

- Code Status
 - You may have been taught to ask patients directly about their code status, but specific interventions like CPR, intubation, and central lines are actually just part of a larger medical plan to try to meet the patient’s goals.
 - We don’t ask patients to decide what antibiotics they should be on or what floor of the hospital they should be admitted to, so asking them to choose these treatments, in particular, can feel uncomfortable for both the patient and the clinician.
 - If a patient’s current goals include trying to prolong their life even with tradeoffs or a trial of therapy to look for response, these may be goal-concordant interventions (even if they are not interventions you would choose for your own loved one).

Values/Goals	Treatment Plan	Example Language Surrounding Code Status
Live longer	Full treatment Curative intent	<p>“I’m hearing that right now it would be important for us to do everything we can to try to prolong life even if that meant more invasive life support.”</p> <p>“In that case, if his heart stops or he is unable to breathe on his own we would perform CPR and place him on a ventilator. We can always reassess if we think these treatments are helping and choose to stop them at any time if they are not.”</p>
Balance quality of time with quantity of time	Non-escalation Trial of Therapy	<p>“Based on what you told me, I hear that he would want us to give him a chance to get through this infection, but also that he would not want to be on machines for a long time.”</p> <p>“I think we should try IV medications like blood pressure medicines and IV antibiotics for a few days and reassess. We will let his body’s response guide us. However, if he were to get sicker and his heart stopped, we would allow him to die naturally so he wouldn’t ever be on machines.”</p>
Prioritize quality of time and comfort over all else	Comfort	<p>“I hear you say that if her time were short, she would want to focus on the quality of that time.”</p> <p>“I’m going to recommend that all of our treatments prioritize her comfort. We will avoid putting her on life support machines or performing CPR and instead focus on her comfort and allowing her to die naturally.”</p>

■ Patients with previously documented treatment limitations

- While many patients have prior documented treatment limitations (ie, prior DNR/DNI status in the hospital, POLST form on file, advance directive forms, documentation from outside facilities), these orders are not always backed up by meaningful and up-to-date goals of care conversations.
- Prior documented treatment limitations are part of the medical plan; don’t bring them up until you have completed the rest of the conversation (given an update, explored goals and values, and are ready to integrate these prior limitations into today’s plan).
 - Bringing up existing treatment limitations can still be emotionally laden and should occur in the context of overall goals of care.
 - Example: “Based on what you’ve told me, giving him a chance to get through this infection is important. I see that he had previous discussions in the chart that stated he wouldn’t want machines like dialysis, ventilators, and CPR. We want to confirm that this is what we will honor in addition to the treatment plans we’ve discussed so far.”
- Remember that preferences and priorities change over time and as illness progresses; this is why we recommend addressing goals and values at every visit BEFORE committing to a plan.

PEARLS AND PITFALLS

■ Enter these conversations without an agenda or a preferred outcome in mind.

- The plan will be a product of shared decision-making between the health care team and the patient.
- We often assume that patients with serious or life-limiting illness presenting to the ED are looking to pursue maximal life-sustaining treatment.
- Conversely, health care staff may be biased toward guiding patients with serious illness to pursue comfort measures even if that is not in line with the patient’s current goals.

■ Rather than assuming you know the best treatment plan for the patient, link it to the goals and values you heard from them.

■ Summarize big-picture goals before talking about therapeutic interventions.

■ Our job is to help patients match their goals to the benefits and risks of therapies. Avoid offering a long list of therapies and the benefits and risks of each.

- Focus on shared decision-making rather than emphasizing that a treatment would not work or would cause harm.

■ Lead with treatments you will offer; later, you can discuss treatments you will not recommend based on their stated goals and values.

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Death Notification

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WHY THIS MATTERS

- Death notification in the ED involves navigating highly emotionally charged conversations with the deceased patient’s next of kin.
 - They may have varying degrees of involvement in the patient’s life or awareness of the patient’s clinical course and recent events.
 - The clinician may have incomplete information.
 - The death of a patient affects the treating clinicians and team.
- If done by an unskilled clinician, this conversation can prolong and intensify grief of families, as they remember not only what is said but also *how* it is said.¹
- Inadequate training in communication skills contributes to the stress experienced by physicians after the death of a patient.²
- The two most important things to communicate are that the patient died and that you care.

WHEN TO USE

- When a patient dies prehospital or in the ED and next of kin must be notified in person (or by phone when needed).
- Death notification should be performed by or closely supervised by the most experienced member of the medical team, rehearsed ahead, and less experienced learners should be carefully prepared before and supported during the conversation.
 - This often requires a pre-huddle with those who will be participating, including physicians, nurses, chaplains, social workers, family support people, and interpreters as applicable.

GRIEVING³

Theme	Example Language
GATHER all necessary next of kin and needed information.	<p>Find a private location separate from the deceased patient’s room.</p> <p>Information to review prior to the encounter includes:</p> <ul style="list-style-type: none"> ● Name of the deceased and correct pronunciation. <ul style="list-style-type: none"> – Enlist law enforcement or prehospital resources if identification is in question. ● Prehospital details including which next of kin may have been on scene and what they witnessed. ● If law enforcement are involved, the level of contact with the deceased patient that next of kin may be permitted to have after the notification. <p>Chaplain, charge nurse, social worker, or other staff can help set up the room and get advance information about whom to expect.</p> <p>Make sure tissues available, and offer other comfort items if available.</p> <p>If there is a large number of next of kin, have staff identify a smaller group to hear the initial notification.</p> <p>Don’t start a meeting while important people are on their way. This may lead to you repeating information and disrupting the flow of conversation. It is better to delay the meeting to allow all people to be present.</p>
RESOURCES: Utilize your staff and resources appropriately.	<p>Preparing for very strong emotions means preparing for a variety of possible responses to the news.</p> <ul style="list-style-type: none"> ● Unfortunately, this can sometimes manifest as violence toward staff. ● Keep your personal safety in mind. Be aware of your positioning between patients and any exits, and always have another staff member with you; consider having security on standby. <p>Additional interprofessional team members in the room with you can help discuss certain topics, such as a need for a medical examiner or coroner investigation, funeral home planning, etc.</p> <p>If using an interpreter, include them in the pre-meeting so they are aware of the conversation’s context and can prepare to give bad news as well.</p> <p>Notify other team members that you will be in meeting so they only page or call you for critical actions and prevent interruptions.</p>

Theme	Example Language
<p>IDENTIFY: Introduce yourself as the physician to everyone in the room and have them introduce themselves.</p>	<p>“I’m Dr. _____, I’m the emergency physician caring for _____. For my knowledge can you briefly tell me how everyone is related to the patient?”</p> <p>Introduce the rest of the team in the room as well.</p> <p>Refer to the patient in present tense rather than the past tense.</p>
<p>EDUCATE: Explain to everyone in the room the events leading up to the patient’s death.</p>	<p>Include pertinent events, both prehospital and in the ED, recognizing that next of kin may have been present prehospital.</p> <p>Avoid open-ended questions such as “Tell me what you know.” Keep it brief, and avoid medical jargon or too many details to prevent information overload.</p> <p>Avoid a long lead-in.</p> <p>“I understand he was in a severe car accident where he ran into another vehicle on the highway. The paramedics were called out and helped to get him out of the car. He had signs of a severe head injury and internal bleeding. Despite the paramedics doing everything they could to treat him and get him here, his injuries were too severe. I’m so sorry to tell you that he died.”</p>
<p>VERIFY: Confirm to family and friends that patient has died.</p>	<p>Use the words “dead” or “died” rather than euphemisms such as “passed away,” “is gone,” or “didn’t survive.”</p> <p>If using a translator, inform them of the need to translate the exact words rather than use euphemisms.</p>
<p>_____ [space]: Give space, and pause after saying “dead” or “died.”</p>	<p>Nobody will remember anything you say afterwards, and it is important that this critical piece of information is received and understood by all present.</p> <p>Expect emotion that may be expressed in a variety of ways, both verbal and physical. Sadness and overwhelm are common, but prepare to address survivor guilt or even anger.</p> <p>You will likely need to allow for a longer pause than you feel comfortable with.</p> <p>The first thing you say after this pause should be a verbal expression of empathy. This is the time to make your caring visible, both verbally and nonverbally.</p> <p>Avoid trying to provide reassurance with statements like “They are in a better place” or “It will be OK.” Just allow space for the emotions as they come up.</p> <p>“I’m so sorry for your loss.”</p>
<p>INQUIRE: Ask if there are any medical questions (after an appropriate pause).</p>	<p>Be honest about knowledge deficits; avoid the urge to give definitive answers if you are unsure.</p> <p>Common questions such as “Did they suffer?” are often an expression of emotion rather than an inquiry about a medical detail. Consider responding with a NURSE statement or offering to share your hope that they did not suffer.</p>
<p>NUTS AND BOLTS: Transition to logistical tasks (autopsy, organ donation, funeral arrangements, and personal belongings).</p>	<p>Learn the local procedures in your department to be able to appropriately inform next of kin what to expect.</p> <p>Delegate this task to a staff member, such as a social worker or charge nurse, so you can transition back to other patient care.</p>
<p>GIVE: Give them the opportunity to grieve as a family.</p>	<p>If a family is allowed to see the body, ensure it is clean and covered and the room is tidied as best you can. Let them know what to expect regarding medical equipment or visible injuries.</p> <p>Give appropriate bereavement resources or the contact information for chaplain or social work if available.</p>

Theme	Example Language
Telephone notification	<p>Do your best to identify the most up-to-date emergency contact.</p> <p>Ensure the person is in a safe space to receive the death notification, such as a private location, and is not driving or operating other equipment.</p> <p>“I’m Dr. _____ calling from _____ emergency department. I’m caring for [patient’s full name]. Is this _____? I have you listed as their emergency contact. How are you related to them? Were you aware they had come to the hospital?”</p> <p>“Are you in a place where you can receive some important news? I’m afraid I have some serious news to share; is anyone with you?”</p> <p>Never deliver news via voicemail; rather, leave your contact information and try again later. If you ask them to call back, make sure clerical staff or the charge nurse are aware of the nature of the call. If your shift ends, consider making the outstanding notification part of your handoff in case next of kin call later.</p> <p>Coordinate with a social worker or charge nurse to have a follow-up phone call to discuss logistics/ administrative tasks.</p>
Law enforcement involvement, medical examiner, coroner	<p>This varies by department and jurisdiction. Learn your local procedures so you can educate the next of kin appropriately.</p> <p>If the death is part of a law enforcement procedure, you may need to disclose that family and friends are not allowed to touch the body.</p> <p>Cases of pediatric deaths, suicide, other unexpected or violent deaths often involve legal investigations. This can become an additional layer of challenge for the clinician and invoke even stronger emotions on the part of next of kin.</p> <p>In cases of crimes or victims of abuse, avoid expressing opinions regarding what parties are to blame or suggesting a definite cause of death if it isn’t known.</p> <p>It is acceptable to disclose that this is the official policy of the county/city due to the unclear circumstances of the patient’s death and is aimed at giving the family more information as to how the death occurred.</p> <p>It is ideal to provide contact information for the liaison of the authority (medical examiner, coroner, etc.) who will be taking custody of the body.</p>
<p>Family presence during resuscitation (FPDR)</p> <p>Family-witnessed resuscitation</p>	<p>This is a benefit for families in providing closure, understanding the gravity of a patient’s illness, and managing grief. One study showed that 100% of families would do it again if given the opportunity.⁴</p> <p>Institutions with policies on FPDR do not report increased litigation.⁵</p> <p>Limit to 1-2 family members present, speak to them outside the room about what to expect, confirm their desire to be present, and reiterate their ability to leave at any time.</p> <p>“This can be difficult to witness. For some families it is helpful to have understanding and closure, for others it can feel overwhelming and is not the right choice for them. If you want to leave the room at any time, just tell me and we’ll bring you back to the family room and keep you updated as we have been doing.”</p> <p>Do not offer FPDR to individuals who are combative or overly disruptive. Use your judgment.</p> <p>Assign a dedicated ED team member to facilitate, be with family, console, and answer questions regarding process and terminology. This frees up the clinicians to continue providing care during the resuscitation.</p>

Theme	Example Language
Pediatric death ⁶	<p>People who lose a child through an acute and unanticipated event commonly need to understand the events leading up to death, to be able to say goodbye to their child in some meaningful way, and to be able somehow to carry the child forward in their lives. Your role in telling the family about the death of their child can help them accomplish these tasks.⁶</p> <p>Establish relationships with key family members early; this can include step-parents, foster parents, kinship guardians, etc.</p> <ul style="list-style-type: none"> • Pediatric patients may have minor siblings in the hospital or at home. Families should be offered support in disclosing the death to the patient's siblings and in supporting bereaved siblings. <p>Family-witnessed resuscitation may be especially important in this group and is generally recommended when feasible.</p> <ul style="list-style-type: none"> • Parents may desire to touch or hold the child's hand during termination of resuscitation. <p>In pediatric death, you are likely to be called to balance the needs for accurate forensic information with the compassionate care of the family whose child just died. Pediatric death is almost universally the subject of legal investigation.</p> <p>Always attempt to contact the primary pediatrician or child's medical home; it should not be the family's responsibility to disclose the death to the rest of the care team.</p>

PEARLS AND PITFALLS

- Sometimes, despite the best preparation, the first question when you open the door to speak to next of kin will be something like “Did she die?”
 - It is understandable and appropriate for emotions to run high, but still best practice for you to control the pace of the conversation and make sure information is delivered in a controlled way.
 - **Example:** “I can see how worried you are. I'm Dr. ____, the emergency physician taking care of _____. I'm here to give you an update and just want to confirm who everyone is so I can give you the best information.”
- Death in the ED is emotionally taxing for clinicians and staff. The death notification task itself adds an additional layer of emotion and often involves witnessing profound grief first hand.
 - A simple moment of silence at the time of death can allow staff to catch their breath, acknowledge the profound nature of death, and honor the patient and their next of kin.
 - Debriefing with a trusted colleague or professional such as a chaplain can also help in processing the strong emotions that come with death in the ED.
 - Before seeing new patients or resuming other tasks in the ED, take a few moments for yourself to acknowledge your own emotions and anything the situation may have brought up for you.
- Bereaved families should receive:
 - Written information regarding the process for an ME case and what to expect.
 - The name and phone number of a person in the ME office who will serve as a contact.
 - Contact information for the ED physician (or delegate) if there are questions in the future.
 - Name and number of a hospital contact, preferably a social worker or chaplain.
 - Instructions related to their personal safety and wellness. (Are they safe to drive home? Are they alone? Who can be called to provide support?)

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Navigating Conflicts

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WHY THIS MATTERS

- Conflict is a natural part of the human experience, especially when it comes to conversations specific to illness, treatment options, or the health care system. The ED is particularly predisposed to conflict for numerous reasons, including:
 - Clinician factors (heavy patient loads, boarding and overcrowding, burnout);
 - Patients/family member factors (acute illness, limited access/understanding of health care system);
 - Fatigue/exhaustion (long wait times, long shifts, and 24/7 staffing).
- Difficulty navigating conflicts can:
 - Create mistrust between the health care team and family members;
 - Impede clinical decision-making;
 - Delay lifesaving or suffering-limiting interventions;
 - Harm interprofessional relationships and contribute to clinician burnout.

WHEN TO USE

- Consider and anticipate when conflict may likely arise, such as situations involving:
 - Multiple surrogates with differing opinions;
 - Unexpected news or sudden changes to plans;
 - Lack of health literacy among patients and surrogates;
 - Uncertainty in diagnosis;
 - Discordant expectations;
 - Cultural differences or limited English proficiency causing miscommunication;
 - Resource limitations causing crowding, delays, need for transfer;
 - Social determinants of health are impacting the patient.
- Recognize signs/symptoms of conflict arising:
 - Raised voices;
 - Heightening of emotions;
 - Closed-off body language (crossed arms, lack of eye contact, shaking head);
 - You notice yourself becoming irritated/frustrated.

STEPS

Theme	Steps	Example Language
Trust Build a foundation.	Start from a nonjudgmental place. Seek to understand rather than assume intention behind actions/words.	“What have you been told so far?”
	Express appreciation for the other person’s opinion.	“Thank you for sharing that...”
	Ask for permission to address conflict.	“Could we talk about some of the things that are happening here?”
Emotional awareness Recognize and reflect. Respond with empathy.	Recognize patient/surrogate and your own emotions. Take a moment to pause; what emotions are coming up? What internal/external factors might be affecting each of you in this moment (life stressors, large patient load, fatigue)?	“This situation is really difficult.”
	Reflect and name emotions.	“What I’m hearing you say is this experience has been frustrating.”

Theme	Steps	Example Language
Ask questions Be curious and open to learning something new.	Avoid the cycle of action/reaction. If the other person announces a firm position, you might be tempted to defend your position or dig in. Practice curiosity instead.	“Can you tell me more about what you mean by...?”
	Reflect and ask for the other person’s perspective. This demonstrates active listening and gives an opportunity for the other person to clarify their emotions/stance.	“It sounds like you are frustrated that you have been waiting for a bed upstairs, since it is loud here. Is that right?”
	Explore interests. Identify conflict and seek to find shared motivation.	“It sounds like you would like to have your mother moved upstairs so she can get some rest. I would love to help her get some rest.”
Make a plan together.	Ask permission to add your perspective.	“Would it be OK if I share a concern/recommendation?”
Align interests.	Summarize and share concerns/ perspective.	“It sounds like we both want your mother to get a bed upstairs and get some rest.” “I worry there may not be an available bed for several hours.”
	Brainstorm together.	“Could we talk together about some ways we can help her get some rest while we are waiting for a bed?”

Here, we focus on strategies from the University of Washington TEAM framework (Figure 1) and the book, *Getting to Yes: Negotiating Agreement Without Giving In*.

PEARLS AND PITFALLS

- Listen to understand rather than to respond.
- Remember to summarize and clarify the final plan or resolution.
- Remember that not all “conflicts” are conflicts. Not every situation where people have differing opinions should be considered a true conflict, and sometimes a difference of opinion can lead to a better outcome when handled constructively.

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Disclosing Medical Errors

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WHY THIS MATTERS

- Medical errors are inevitable in the practice of medicine and emergency medicine.
- **A medical error is defined as an erroneous act or omission that could result in an adverse effect on a patient.**
 - Medical errors:
 - Can result in a range of outcomes, some benign and others catastrophic;
 - Are multifactorial and are often due to the complexity of modern medicine, the need to make high-impact decisions utilizing limited information, and systemic burdens on providers (stress, high workload, fatigue);
 - Can result from a flaw in the execution of a sound medical plan, the wrong plan to achieve a patient aim, or a “near miss”;
 - Although a “near miss” may not result in patient harm, it is similarly important to report and disclose these events;
 - Medical errors are underreported and are a significant cause of death in the United States.
- **Honest, timely disclosure of medical errors (including near-misses) bolsters the relationship between doctor and patient and fulfills an ethical responsibility in maintaining truthfulness and patient autonomy.**
 - Lack of disclosure results in heightened patient anxiety and distrust.
 - It may increase exposure to malpractice litigation.⁵
 - A retrospective study noted fewer lawsuits and legal costs after the implementation of a medical error disclosure program.⁶
- Medical disclosure of unanticipated outcomes of care has been required of medical organizations since 2001 under Joint Commission (JCAHO) Patient Safety standards.⁷

WHEN TO USE

- **Medical errors should be disclosed when they are identified and as the clinical circumstances/consequences are fully understood.**
 - A patient must be updated about the medical consequences of a medical error as soon as possible, even if the full circumstances surrounding the error are being investigated.
 - Subsequent disclosures between the provider team and the patient will be required to update the patient on the specific cause as this becomes clear (ie, inter-professional communication failure, interruptions, labeling error, etc.).
- Decisions about the timing of disclosure are made in conjunction with institutional resources (department leadership, risk management office, hospital administration, patient advocate, etc.).¹

STEPS

- While most physicians recognize the importance of disclosure, there is variability in how “full disclosure” is done in practice.
 - Many physicians explicitly apologize to patients after medical errors, but the amount of disclosure varies directly with the clinical significance of the error.⁴
 - Barriers to full disclosure include physician embarrassment/shame, fear of precipitating a malpractice lawsuit, and discomfort with the disclosure process.
- **Most patients consider “full disclosure” to include:**³
 - **Disclosure of all harmful errors;**
 - **An explanation as to why the error occurred;**
 - **How the error’s effects will be minimized;**
 - **Steps the physician (and organization) will take to prevent recurrences.**

1. **Come to consensus on the circumstances of the incident.** This may require discussion with the hospital team and/or institutional representatives.
2. **Establish who should be present at the disclosure meeting.** Include pertinent team members and patient advocates. This may include institutional representatives, such as hospital legal representatives or risk management staff.
3. **State that an error has occurred.** Be clear with your words (ie, say “error” or “mistake”).⁴
4. **Offer a factual description of the error and its clinical implications.** Avoid medical jargon.
5. **Offer a sincere apology.**
6. **Describe any system review efforts to prevent similar future errors.** Many systems utilize Communication and Optimal Resolution (CANDOR), a process in which health care institutions/practitioners can respond to unexpected events that cause patient harm. It is a “patient-centered approach” that emphasizes early disclosure of adverse events and proactive methods to achieve amicable resolution.³
7. **Reassure the patient that the results of an investigation into medical error will be fully disclosed at the earliest opportunity.**

DISCLOSING MEDICAL ERRORS (MISTAKE)

Step	Purpose	Example Language
Muster the facts.	Determine initial information surrounding medical error.	
Invite participants.	Include patients, their proxies/advocates, and institutional representatives	<p>“We’d like to have an important meeting with you about your medical care. I’d encourage you to invite anybody who helps you make medical decisions, such as a family member or your health care proxy.”</p> <p>“It’s standard that at meetings like this we include members of our hospital staff, including (introduce members of team).”</p> <p>“They are here to ensure that what we discuss here today can be used to help provide safer patient care.”</p> <p>“Our hospital requires that they are present to help protect its employees.”</p>
State the error.	Clearly disclose that a medical error occurred.	<p>“There was a medical error with your care.”</p> <p>“There was a mistake made with your care.”</p>
Tell patient the known details.	Describe the error and medical consequences.	“I’m very sorry this happened.”
Apologize.	Express sincere regret.	
Know and provide next steps.	Describe institutional review process (this may fall to other team members with deeper knowledge.)	
Expect further disclosure.	Determine how to report future results of investigation.	“More information will become available in the next few days/weeks. We want you to know the full details about what happened as soon as possible. How would you like for us to share this information?”

PEARLS AND PITFALLS

- It is important to distinguish between medical error and statistical risk of adverse outcome.
 - Errors occur when there is a failure of systemic safeguards, or an avoidable deficit in requisite provider knowledge, skills, or judgement.
 - Statistical risk is an adverse outcome without identifiable deficits.⁹
- It is normal to feel guilt, fear of repercussions, and a loss of self-esteem when medical errors occur.
 - As “second victims,” we may feel as though we have failed our patients and begin to doubt our clinical skills/knowledge base.^{10,11}
- Methods to help support those experiencing Second Victim Syndrome include:
 - Building a culture that de-individualizes medical errors;
 - Improving access to immediate peer support programs;
 - Engaging an interdisciplinary team in event analysis;
 - Identifying local institutional resources/support in such circumstances.
 - Employee Assistance Programs (EAPs) often provide resources, including free/complimentary counseling and assessments for employees under such duress.
 - Peer support programs exist to offer psychological first aid with active outreach following patient safety events.
- “Apology laws” are state-specific legislation that legally protect providers during disclosure of medical errors. Some laws prohibit medical error disclosure as admission of guilt in lawsuits, others protect apologies but not the information provided.

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