



Goals of Patient Care Form: discussion tips

"A large part of the task is helping people negotiate the overwhelming anxiety - anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances" [...] "There are many worries and real terrors." No one conversation can address them all. Arriving at an acceptance of one's mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany. There is no single way to take people with terminal illness through the process, but there are some rules [...] You sit down, You make time. You're not determining whether they want treatment X versus Y. You're trying to learn what's most important to them under the circumstances - so that you can [provide information and advice on the approach that gives them their best chance of achieving it. This process requires as much listening as talking. If you are talking more than half of the time, [...] you're talking too much."

"The words you say matter. According to palliative specialists, you shouldn't say, "I'm sorry things turned out this way", for examples. It can sound like you're distancing yourself. You should say, "I wish things were different". You don't ask, "What do you want when you are dying?" You ask, "If time becomes short, what is most important to you?""

"I'm worried" as good way to start the conversation about the issues you want to discuss and get patient's attention.

"Sacrificing time now for time later"

Atul Gawande's Being Mortal: Medicine and What Matters in the End



Words of wisdom from senior clinicians

Dr Tor Erclve, Emergency Medicine Consultant

“Just because modern medicine can do something doesn’t mean it is the best thing to do...”

“Concentrate on reversing the reversible to improve their quality of life, not more invasive treatments or investigations which would only prolong their suffering”

“Although we can’t reverse the underlying medical problem we can treat the symptoms...”

“With advancing age there is less reserve and they are unlikely to be able to cope with the stress of...”

I compare multi-organ failure with dominoes falling which is hard to stop once the cascade starts

Never offer the patient or next of kin HDU / ICU level care if it is not indicated or will not be available. It seems logical but clinicians often set their own trap by making this option available for those whom it should not be an option.

Similarly, when the NOK / patient / guardian want “maximum care”, it is up to us to decide what maximum. “Maximum care” is not an item on a shelf that can be purchased. It is the highest level of care which is appropriate for that patient.

When I feel it is appropriate (very selected patients), I am often happy to offer limited time PPV or peripheral inotropes in ED to show we have done everything to give the patient an opportunity to turn the corner. I set very clear time boundaries for the therapy when this option is chosen.

Don’t play God. Despite the limitations of care I have highlighted above, there are instances when one will need to recalibrate one’s own biases and boundaries. There are patients whose desire to live exceed those conditions which we would quantify as worth living- especially those with overwhelmingly supportive families which make these desires possible. Don’t presume to know what the home situation is like.

In contrary, there are those sinister families who prolong suffering of a loved one for pecuniary interests. They tend to want to conceal the realities of the home situation. They seem to go beyond what would normally be reasonable and they may present with an unusual affect, may ask unusual or insensitive / inappropriate questions and may even try to befriend staff for their anterior motives. They tend to be the type of people that activate your ‘spider sense’.

Dr Gayle Christie, Emergency Medicine Consultant

I feel people shrink away from discussing this because they simply don’t know how to do it. I think it’s important to be honest and not to dump the decision making on family members as I feel it can leave them feeling guilty, or opting for the “do everything”. I think as clinicians it’s important we explain what we feel would be in the patient’s best interests and why.



Dr Tim Paterson, Intensive Care Consultant

- *Prepare the space.*
- *Prepare yourself. Discuss with treating specialist, senior colleagues, nursing, allied health. Have a single “party line” that you will be the conduit for.*
- *The opening is important. Make sure all needed family/supports are present. Introduce everyone and their role. From there, you can:*
 - *Foreshadow the conversation. This allows those present to focus on what you’re saying rather than trying to guess what your purpose is, eg*
 - “Thanks for all coming in today. As you have probably gathered already, the news is not good”*
 - “I’d like to update you with how things are going. We won’t be making any major decisions today”*
 - “Things have really gone downhill in the last few hours, and it’s possible that your Dad may die at any time”*
 - *Ask for their understanding of the situation. Although the primary contact/patient may understand what’s happening, that doesn’t guarantee that everyone in the room does*
 - “Just so I know where we’re starting from, can you please explain to me what you’ve been told so far”*
- *Silence is ok!*
- *Some patients/families will want to take control and make the decision. Most won’t. All should be offered our recommended course of action, rather than asking them “what to do”.*

Dr Matt Anstey, Intensive Care Consultant

- *Always make sure you know who is in the room, and their relationships to the patient.*
- *If you can get information from other sources (especially long term GP, carers) that is really useful.*
- *Try and make sure you have a nurse come along for the conversation with the family.*
- *I try and make space for the family to talk as much as possible. So I start with simple statements like*
 - “It would help me if you were able to tell me what happened before [insert name - your loved one] came to hospital”*
 - “What do you understand has happened since they came to hospital?”*
- *If the opportunity arises, ask how the health of their loved one has been over the months prior to hospitalisation.*
- *Then ask, how do you think [their loved one] is doing? This gives two options*
 - 1. They recognise patient is deteriorating and makes the ongoing conversation easier*
 - 2. They don’t recognise the patient is deteriorating, and means you need to explain what is going on, and use clear phrases such as “your Dad is dying”, or “your mum has had a really bad brain injury”*

- *I also ask if they are visual people, and would like to see any scans to understand what is going on.*
- *I then point out that my role is to provide the medical opinion, and their role is to let me know what the patient would want, if they were able to have this discussion. We are not asking for their relatives' opinions as much as asking them to provide the patient's view.*
- *I also explain that, up to this point, we have been doing everything we can, but it is clear that there are things that we cannot fix.*

Dr Luke Torre, Intensive Care Consultant

Ultimately, we are trying to ascertain what the patient would want if they could make a decision. For critically ill patients they are often not able to do this due to a depressed conscious state. The way I would overcome that is by saying this to the family:

"If {patient name} was standing at the foot of their bed, looking at themselves, and heard all the information I have just told you, what would they say?" This is important as it takes away the guilt families often feel by making difficult decisions on behalf of family members. With this question, families often are reminded that this is actually what the patient would have wanted.

We should only provide the management options that are feasible and not futile. For example we should not discuss ECMOCPR for a patient having CPR who does not meet criteria for it.

As a clinician it is our duty to provide management options but ALSO to give a recommendation based on our experience and expertise. We are not waiters in a restaurant offering a menu and asking the diner to choose, we are experts providing the best advice we can to our patients and their families. When you consider what your recommendation is, ask yourself "if this were my loved one what would I do". The family doesn't have to agree or accept your recommendation, but you should provide it. That is not paternalism, that is professionalism.

When patients are clearly dying it is important to say "they are dying". It is not your fault it is the truth, we should always tell the truth. Another excellent question to ask for a dying patient is "would they want a priest or religious person to visit them?". This is useful as it solidifies in the family's mind that the patient is dying and it reminds families to fulfil this wish if it is important to the patient"

Never say "we must do something"

Never say "if we do this they may survive, if we do nothing they will die".



ASK

- *Understand what is important to the patient*
- *Understand what lifestyle limitations / treatments would be unacceptable to them*
- *Listen to patient's perception and understanding of the disease and treatment so far*

- *"What have you been told about your medical situation so far?"*
- *"To make sure we are on the same page, can you tell me what is your understanding of your illness?"*
- *"What are your thoughts about the future?"*
- *"Tell me what the last year has been like for you"*
- *"Could you tell me more about what is worrying you?"*
- *"I want to make sure that if you have questions or things you are worried about, we can help to address them."*
- *"You must have spoken to lots of people in the last few days. Can you tell me in your own words what you think is going on / what is happening"?*
- *"Has anyone spoken to you about what to expect from your disease and the kinds of treatments you would or would not want when you get really sick?"*
- *"Do you have a living will or advance directive, or know what these terms mean?"*
- *"Have you previously had an experience with serious illness, or has someone close to you had an experience with serious illness or death?"*
- *"If you were in this situation (again), what would you hope for? What would worry you most?"*
- *"Did this situation make you think about states of being that would be so unacceptable to you that you would consider them to be worse than death?"*
- *"What do you think your loved one would hope for / worry about?"*
- *"It's important that I understand your brother, so that I can make a treatment recommendation that he would agree with. How would you describe him?"*
- *"If you had to teach me about your Mum, what words would you use? What stories would you tell me?"*
- *Summarise: "So it sounds like your Grandma was a fiercely independent woman, who lived to help other people and play games with her grandkids. Does that sound right?"*

TELL

- *All reactions are acceptable: long silences, crying, outbursts. Try to learn to be comfortable with repeated and long pauses. Let them talk: if you are talking more than 50% of the time then you are talking too much.*
 - *Answer all questions honestly*
 - *Prognosis of illness*
 - *Treatment options: curative AND palliative Emphasize what WILL be done rather than what WILL NOT be done*
 - *CPR as a technical intervention with associated complications*
 - *Difference between ongoing care VS withdrawing therapy*
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- *Use the patient's name*
 - *Repeat / reinforce*
 - *Start at the level of comprehension and vocabulary of the patient and use nontechnical words: "spread" instead of "metastasized", "sample of tissue" instead of "biopsy"*
 - *Avoid excessive bluntness (e.g., "You have very bad cancer and unless you get treatment immediately you are going to die.") but be clear and succinct in what you say.*
 - *Give information in small chunks and check periodically the patient's understanding*
 - *Avoid using phrases such as "There is nothing more we can do for you" when in fact pain control and other symptom relief are very important*
 - *Use the words "may die", "will die"*
 - *Avoid using the words "futile", "futility"*
 - *"For a patient in the terminal phase and when explaining to the family the reasons why we are not providing artificial nutrition or hydration, I say something along the lines of 'The human body is designed very well to die peacefully and naturally so long as we don't interfere in the process. Sometimes, the more we do in terms of feeding tubes or drips only serve to complicate the dying process. I worry that we might be prolonging this for your loved one. I'm afraid the treatment isn't working.'" (Dr Anil Tandon, Palliative Care Physician)*
 - *We want to work out what is the right thing to do.*
 - *We are as certain as we can be.*
 - *Some things we can't be sure about but other things are very clear (focus on most certain facts).*
 - *I would like to discuss with you whether it is appropriate to keep on treating with X.*
 - *We want to avoid treatment that is overly burdensome / Ineffective / worse than the disease itself*
 - *We need to reset our focus to ensure that his time left is comfortable and dignified as possible.*
 - *We will do everything we can to ensure that your last days are as comfortable and as dignified as possible.*
 - *We are recommending making comfort a priority.*
 - *We want to stop doing unpleasant things that are not working.*
 - *We are recommending continuing good care while stopping*
 - *The treatments aren't working (this is actually a very powerful phrase)*
 - *Your Dad isn't ancient, but he's not 20 years old anymore. There are things that we do to a 20yo that we don't do to everyone, because they don't survive them.*
 - *Let's talk about what might happen to your Mum in the near future. She might slowly improve – although that's pretty unlikely. She might rapidly die over the next few days. Most likely is that she'll stay the same. Unfortunately, in their situation, staying the same is the same as getting worse.*

ASK

- NEVER ask "What do you want us to do?"
- Establish substitute decision-makers
- Align language with the patient's preferred mode of decision-making

- "What if, based on changes in your health, the doctors looking after you at the time recommend something different from what you have told your loved one(s)?"
- "Will you give your loved one(s) permission to work with your doctors to make the best decision possible for you, even if it may differ from what you said you wanted in the past?"
- "Are there certain decisions about your health that you would never want your loved one(s) to change under any circumstances?"
- "Can we talk about what we should do if things don't go as well as we hope?"
- "If your illness gets worse, what things would be most important to you?"
- Shared decision-making: "Based on what you've said, it seems to me that the most reasonable course of action is ..." (ie avoid asking "What would you like us to do?" to avoid placing the burden of the decision solely on the patient).
- Active decision-maker: "It is up to you to decide, but many people in your circumstances would consider it acceptable to ..." (i.e., legitimize the difficult option, but leave the patient as the final decision-maker).
- Passive decision-maker: "I recommend that we do the following ..." (ie declare the plan).
- "Who are you going to tell about this conversation?"
- "What do you need or want to do in the time you have left" (being at home with family, attending an important family event ==etc.)
- "Doctor, what would you do if this was your mother?"
 - "I really do not know what I would do if this were my mother, but based on what I know of your condition and your goals, I would recommend...."
 - "If this were my mother I would recommend...."
- "What other questions do you have?" (NOT "Do you have any other questions" as the former is an open question and the latter is a closed question).
- Was your Grandad a religious person? Would he have liked to see a priest?
- If your Dad was able to sit here with us, what would he say about the situation that he's in?
- There is no easy way here. What most people do is...

Addressing emotions with empathic responses: NURSE model

Name it

“...it sounds like you’ve been worried about what’s going on...”

Understand the core message

“...if I understand you correctly, you are worried about what to say to your family and how they will react...”

Respect / reassure at the right time

“...I’m really impressed that you’ve continued to be independent ...”.

Supporting

“... would you like me to talk to your family about this...”

Exploring

“... I notice that you’re upset, can you tell me what you’re thinking?”

“I can tell you weren’t expecting to hear this”

“It sounds like you are feeling overwhelmed by this”

“It’s natural that talking about this can be upsetting — for any of us. It’s okay to take some time.”

“I know that this isn’t what you wanted to hear. I wish the news were better.”

“You may have suspected that I was going to say something like that. It can still be a shock to hear it.”



The SPIKES model when breaking bad news

S - SETTING UP the interview

- Review the plan on how to start the discussion and the message you want to get across
- Anticipate difficult questions and expect to be faced with negative feelings, frustration or responsibility
- Arrange for some privacy; have tissues ready
- Involve significant others (patient's choice)
- Sit down - relaxes the patient and is also a sign that you will not rush.
- Avoid interruptions – phones, pagers (silent or ask a colleague to answer it)

P - assessing the patient's PERCEPTION

- open-ended questions to create a reasonably accurate picture of how the patient perceives the medical situation

“What have you been told about your medical situation so far?”

“What is your understanding of the reasons we did the MRI?”

- ✓ correct misinformation
- ✓ tailor the bad news to what the patient understands
- ✓ assess illness denial: wishful thinking, omission of essential but unfavorable medical details of the illness, unrealistic expectations of treatment

I - obtaining the patient's INVITATION

- Some patients want to know everything about their illness, some patients do not (offer to answer any questions they may have in the future or to talk to a relative or friend).

“Are you the sort of person who wants to hear all the details of your medical condition?”

- Discussing information disclosure at the time of ordering tests can cue the physician to plan the next discussion with the patient.

“How would you like me to give the information about the test results?”

“Would you like me to give you all the information or sketch out the results and spend more time discussing the treatment plan?”

K - giving KNOWLEDGE and information to the patient

“Unfortunately I've got some bad news to tell you”

“I'm sorry to tell you that...”

E - addressing the patient's EMOTIONS with empathic responses

S—STRATEGY and SUMMARY

Things you could say

It's a harder situation than most people think. (validates, normalises, encourages them to seek support)

Most people who have gone through this react similarly to you. (validates and normalises)

If I were in your situation, I'd feel very _____ too. (validates, normalises, assures)

Patients who are NOT ready for THE CONVERSATION

- A hypothetical situation: *"I know that you're a very positive person and things will probably go well this time around. If things down the track don't go so smoothly, we would like to know your thoughts?"*
- Hoping for the best, preparing for the rest: *"What are you hoping for at the moment? Would it be okay to talk about your concerns for the future in case things don't go as well as we hope?"*
- An 'I wish' statement: *'I wish I could guarantee that the antibiotics will work every time. What would be important to you if things were clearly getting worse?'*

What you should NOT say

Discounters (*"I am not comfortable with you like you are. I need to make it better so I will feel better."*)

- *I know how you feel. (You don't.)*
- *Time heals all wounds. (It doesn't.)*
- *You'll get over this some day. (The pain will decrease, but they will never "get over it")*
- *You must go on with your life. (They will the best way they can, and they don't need to be told.)*
- *You can always find someone worse off than yourself. (Not at the moment.)*
- *You must focus on your precious memories (Patient is still alive.)*

God clichés

- *It must have been his/her time.*
- *Some day you'll understand why. It was actually a blessing because God must have needed her more than you did.*
- *God never gives us more than we can handle.*
- *Only the good die young*