

## Communicating the transition to palliative care

The communication goal is to guide the patient to understand the goals of care relevant to the palliative approach, focusing on maintaining quality of life. Importantly is that it is at the patient's pace; this may be a **communication process** rather than a one of conversation. Remember, you may be breaking bad news here.

Strategies: the sequence of steps used to achieve the communication goal; Skills: verbal utterances that assist in the completion of each strategy; Process tasks: often non-verbal behaviours or other aids to complete each strategy effectively

STRATEGIES	SKILLS	PROCESS TASKS
1. Recognise patient's cue or emergent clinical reality	Declare your agenda items Negotiate agenda Check patient understanding	Ensure setting appropriate to this discussion Consider goals of care
2. Establish understanding of disease progression, treatment efficacy & prognosis	Check patient understanding Invite patient questions Make partnership statements	Deepen understanding of patient's predicament Correct misunderstandings Sustain supportive environment Tailor amount of information to patient's need Acknowledge reality
3. Discuss patient's values & priorities; negotiate new goals of care based on the patient's values & priorities as well as the burden versus benefit ratio of available treatments	Endorse question-asking Check patient understanding Reinforce joint decision-making according to the patient's preferred level of involvement	Introduce palliative approach: Contrast cure with care Emphasise living in the present Emphasise 'always something to do to help' Commit to continuity of care Establish quality of life goals of importance Acknowledge (ie: anti cancer & palliative treatments can be given simultaneously)
4. Respond empathically to emotion	Ask open questions about the emotional response & coping Empathise by clarifying, acknowledging, or emotions	Promote hope over grief or despair Emphasise the living over the dying
5. Negotiate the shift to discuss the process of dying	Make a 'take stock' statement Check patient understanding Categorise information Ask open questions	Ask permission or check readiness to discuss dying Describe relevant elements of good symptom control Provide tailored information
6. Promote understanding of change & illness transitions	Validate Summarise Validate patients efforts Express a willingness to help	Consider patient's response to family Consider spiritual/religious needs Address specific cultural needs. Contrast open awareness of end of life issues with avoidant copying style Promote consideration of advantages & disadvantages of treatment choices
7. Address caregiver's concerns	Ask open questions Endorse question asking Make partnership statements	Identify value of respite from caregiver role Consider role of community volunteers, health aides etc Examine instrumental care or nursing care needs
8. Effect referral to palliative care services where appropriate	Ask open questions Endorse question asking Make partnership statements	Identify value of respite from caregiver role Consider role of community volunteers, health aides etc Examine instrumental care or nursing care needs
9. Close consultation	Summarise Check patient understanding Endorse question asking Review next steps	Remind patient regarding the availability & commitment to care Affirm progress & focus on continued living Document discussion & inform relevant team members/others

Some communication techniques for responding to emotions in end of life care communications

TECHNIQUE	EXAMPLE
Silence	When a person is upset, just being there & shared silence is a way of providing space, safety, support & communicates that it is OK to be upset
Validation	"From what you have said, it is understandable that you are feeling <i>angry</i> after all that has happened"
Empathy	"It sounds like you really have had a rough time of it..."
Name or acknowledge the emotion	"You seem sad" "I can see that you are very angry"
Encourage expression	"Do you feel able to tell me more about how you are feeling?"
Paraphrase/Repeat back	"If I understand you correctly, you are feeling angry because you were told that your mother's pneumonia would respond to antibiotics..."

Some alternate approaches to some common (and less helpful) communication approaches used

*Although many of these examples relate to cancer, their principles are relevant across other advanced disease & end of life issues*

APPROACHES TO AVOID	WHY THIS APPROACH IS PROBLEMATIC	ALTERNATE APPROACHES
“There is nothing more than can be done”	Although chemotherapy, for example, may no longer be helpful, other treatments, symptom management or intervention approaches which can proactively support quality of life	“Although we cannot offer treatment to shrink this cancer, we can improve your quality of your life by managing the symptoms that are currently making you feel so awful. Could I discuss this with your further?”
“At the moment he is too frail. He would need to gain more weight for us to consider giving him more chemotherapy in the future.”	What does the family (and patient) understand about this? Have goals of care for end of life been deferred under the illusion that chemotherapy is still an option in managing or curing the patient’s cancer at a future date IF he puts on weight. Is this a realistic goal? The outcomes may be that the patient becomes coerced to eat more (by the family) with the key focus on eating rather than palliative care & quality of life issues. When then faced by cachexia as time goes on, the patient may feel he is to blame (or blamed by family) for having not tried hard enough.	“Your father has lost considerable weight due to the cancer that has spread, despite our best treatments. Further chemotherapy will not help him.... We have other ways of helping him to be at home & as functional (as he said was important to him) for as long as is possible. Would it be helpful to you to discuss this further?”
<p>“If your heart stops, would YOU want us to do everything?”</p> <p>“If your heart were to stop, you would not want us to institute heroic measures, would you?”</p>	<p>Cardiac arrest is described as an isolated mechanical problem, disconnected from multi-organ failure (such as usually associated with advanced disease). Responsibility for the DNR decision is placed squarely on the patient (you), in contradiction to the philosophy of shared decision making. The poor efficacy of resuscitation in end-stage disease is often not discussed, although in the Clinicians mind, implied; ‘to do everything’ is a euphemism for CPR. The patient is unlikely to fully understand the illusion of this ‘choice’.</p> <p>The opposite of heroism is cowardice. No one would want cowardly measures instituted, so this question has a coercive tone. On another level, ‘heroic measures’ is a medial euphemism for ineffectual CPR in a dying patient. The patient may not understand this hidden meaning.</p>	<p>“What do you know about CPR in general? Have you known of anyone who required CPR? What was that experience like? (<i>Ascertaining the patient’s knowledge about CPR facilitates patient education &amp; correction of CPR misperceptions</i>).</p> <p>“Although CPR can help people with heart attacks, who are otherwise quite healthy, it generally causes more harm than good for people such as yourself when their disease/condition is advanced” (<i>this could be followed by use of silence for the patient to consider/respond to what has been said so far</i>). Does the patient want you to explain more about this? “May I share my thoughts about how useful CPR might be for you? My recommendation is that CPR would not be helpful. It will not reverse your (<i>condition</i>). If we were able to resuscitate you, it may result in you being unwell enough to need to stay in hospital (negotiate information about risk based on patients information needs; this may include the risk of being on ICU on a breathing machine) rather than, for instance, having a natural death at home (if that were the patients hopes) when their time comes. The patient may want to talk about the future &amp; dying or may wish to leave this for now.</p>
“His illness has progressed and is now advanced”.	The words <i>progressed &amp; advanced</i> have positive connotations in our society. In this context are the progress & advancement terms euphemisms for the fact that the patient will likely die of their illness in the near future?	“I’m afraid that his illness has worsened.” (pause for a response. If none, negotiate to give further information in terms of what that means). Avoid using euphemisms/jargon & check the persons understanding of the message you are relaying.

<p>“He has failed to respond to his treatment”</p>	<p>The patient should not be blamed for the failure of treatment</p>	<p>“The treatment did not work. Unfortunately, this cancer is very aggressive....”</p>
<p>“If I talk about end of life care planning, the patient will give up hope”</p>	<p>There is no evidence that talking realistically about death results in loss of hope, provided that the patient is open to this discussion. Not being given opportunity to talk about dying can, by contrast, cause a ‘conspiracy of silence’, that can leave the patient feeling isolated &amp; with a sense of hopelessness. It is more likely that talking about it will allow the patient to prepare &amp; feel more supported through acknowledgement of the loss of expected hopes for their future &amp; through sensitive support, develop new hopes important to them now. This may not necessarily be a one of conversation, but a process (often supported by others also).</p>	<p>“As your <i>condition</i> has worsened and you say you are feeling less well as time goes by, I’m wondering whether it is helpful to you for us to consider what you feel is important to you about what you hope for in the future...”</p>
<p>“This patient is in denial. We need to get him to accept what is happening”.</p>	<p>Labelling patients as being <i>in denial</i> sets them up as adversaries who must be convinced of imminent death. This erodes trust, making decision-making more complicated.</p> <p>Denial itself is a very adaptive coping mechanism. However, persistent denial may prevent the patient (or family) facing/dealing with important practical or emotional issues. This can lead to problems impacting on the closeness of the patient/family, implementing care packages in end stages of life &amp; bereavement problems. It is not our job to prevent patients coping in this way but to tentatively explore underlying fears &amp; concerns to see if they can be addressed or to help those for whom denial is no longer complete or working as a coping mechanism. Complete denial is a strong coping mechanism. Sensitive assessment, negotiated exploration &amp; gentle probing is unlikely to break it.</p>	<p>“What is your understanding of your <i>condition/disease</i>?”</p> <p>“Where do you see things going? Have you given thought to what might happen if things don’t go in that direction?”</p> <p>The health care professional approaches decision-making as a process of discovery that will evolve over time.</p> <p>Gently probing/challenging any inconsistencies in the strength of their denial</p> <p>“You say it couldn’t have been serious, yet you said you were worried that you might have died when you were admitted; what made you feel that?”</p> <p>“Is there ever a moment when you don’t think things are going to go in that direction?”</p> <p>“I can see you are finding this difficult; do you feel able to talk about it?”</p>