

TOPIC 1: Breaking bad news

Facts may not be remembered but the way they were given will be.

Key points

Breaking bad news is important to maintain trust, reduce uncertainty, prevent inappropriate hope, allow adjustment and avoid a conspiracy of silence. Whatever your level of experience, these are difficult conversations. Learned skills can help.

Be sure to avoid ambiguity even if you decide to use euphemism.

A ten step approach – use silence, pauses, reflecting words back to the patient and checking understanding at intervals throughout this sequence.

- **1. Preparation** be sure of the facts, make sure the right people are present, avoid being interrupted, take a colleague.
- **2. Find out what the patient knows** "What do you understand about your tests so far?" or "What do you think has been happening to you recently?"
- **3. Establish if more information is wanted** "Are you the sort of person who likes to know what's going on?" or "I have your results here...shall I go through them?"
- **4. Give the news**. Start with a warning, e.g. repeating a word/phrase the patient has already used. Perhaps "You said you were worried about the results" or "Did you ever think this might be serious?".

Deliver the serious news itself gently but clearly. E.g. "I am afraid the tests show a serious condition in your heart." or "Unfortunately the scan has picked up a serious problem." or "I am sorry to have to tell you the results seen under the microscope indicate you have a cancer."

- **5. Respect denial**. It can be a coping mechanism but may need to be challenged if it prevents honest discussion of treatment options, care planning or decision making. A gentle challenge might begin: "You say you are going to get better. This is a difficult time for you and I wonder if there are any thoughts or fears in your mind that things might turn out differently?"
- **6. Give more information if the patient can cope.** Check first because many patients will now have gone blank. "Do you want me to go on?"
- **7. Seek and listen to the patient's concerns**. "What's your biggest worry right now?" Give permission to discuss fears and concerns. Avoid premature reassurance especially about conditions you don't treat. Do not be drawn into explicit prognosis. "It's difficult to be precise at this time. Even patients with the same condition respond differently."
- **8. Encourage feelings to be expressed**. "How does this leave you feeling?" (NEVER say "I know how you feel.")
- 9. Summarise and agree a plan.
- 10. Be clear about the next contact and offer follow-up.

"I'm sure you will have lots of questions after I've gone, but I'll come back. Here's a piece of paper in case you want to make a note of things to ask."

TOPIC 2: Starting a future care planning discussion

'To buoy up a man with groundless expectations of recovery is really cruel' (Samuel Bard, 1742-1821)

When your clinical judgment suggests that a patient might well die in the next few months, it may be helpful to provide an opportunity for discussion about future care, provided the patient wishes to have this discussion.

Key points

Not every patient will want or be able to have discussion about future care. Do not force it upon them.

The Mental Capacity Act provides the legal framework for these discussions. All clinicians need to be clear how to assess capacity.

A patient with capacity makes decisions at the time they are needed.

A patient who lacks capacity cannot prepare an advance statement or advance decision to refuse treatment.

You are not bound by an advance statement, but you are bound to take it into account.

A valid and applicable advance decision to refuse treatment is legally binding.

Determining prognosis is not an exact science, and harder in some conditions than others. The point is not to get it right every time, but to support better planned care for increasingly frail patients.

The basic framework is the same as for 'breaking bad news' using phrases like:

"I'm afraid your latest scan shows us that your cancer is getting worse in spite of your treatment."

"This is the third flare-up of your airways disease in the last three months and each attack is leaving you weaker than you were before."

"The fact that you are losing weight and not getting about as much means your disease is getting worse even though you are on maximum treatment."

Introducing the idea of making a plan might go like this:

"This means it is important to begin thinking more about your future care, with particular attention to your preferences and wishes.

If you would like to do this, it is best done by someone who knows you well, such as your (GP/district nurse/Macmillan nurse). Or I could refer you to a colleague who specialises in this sort of care.

In my letter today I'll suggest they see you and give you some time to think about this sort of care planning, and register you as a patient needing extra attention."

Communication from secondary to primary care in clinic or discharge letter might include a paragraph such as:

"(name)'s condition is unfortunately worsening despite maximum treatment. I recommend this patient should be on your palliative care register, and offered discussion about future care planning including preferred priorities of care."

TOPIC 3: Completing a DNACPR form www.resus.org.uk/pages/DecisionsRelatingToCPR.pdf

Key points

DNACPR forms are '**single decision**' forms indicating that cardiopulmonary resuscitation is not to be started in the event of a cardio-respiratory arrest. '*DNACPR*' does not mean '*do not treat*': **many** interventions are **entirely** appropriate in patients with a DNACPR form completed.

If the clinical team makes a decision that CPR will not be offered because it will not be effective, your duty is to seek to advise the patient of this decision, not to ask if the patient wants CPR. Be prepared to offer a second opinion.

Document all reasons for the decision and the information/explanation given to the patient and/or those close to the patient.

If you decide <u>not</u> to advise the patient and/or others, the reason must be documented. Finding the conversation difficult, or fearing causing distress, is not sufficient justification to avoid this discussion (*Tracey judgment*, 2014).

Step 1: Review the patient's understanding of their current ill-health and its severity.

"How do you feel your health has been over the last few weeks?"
"Do you understand what we have been trying to do in terms of treatment recently?"

Step 2: Ask if they have any particular views on their own future treatment.

It is important to give a patient the chance to express their thoughts as this will give you a clue about their current expectations.

Be careful not to be drawn in to a discussion about theoretical but not intended options.

"Have you been having any thoughts about your treatment from now on?"

Step 3: Explain the purpose of treatment from this point onwards.

Emphasise the positive and useful options.

"Even though your illness is getting worse there are still good treatments that will help you. For example antibiotics, fluids through a vein, oxygen, blood transfusions, and medication to control the disease and symptoms." Stress the importance of quality of life.

"Above all we want to maintain your dignity and comfort, and help you get home again so you aren't spending so much time away from your family."

Step 4: Explain the interventions that will no longer be appropriate.

"In your situation there are some treatments that are no longer the right thing to do. These are treatments with no chance of success and that we feel will cause more distress than benefit. I am talking here of electric shock treatment to restart your heart, or using a life support machine to manage your breathing."

Follow this with reassurance.

"If you have a sudden problem with your heart or breathing we will make sure you have immediate oxygen and medication to relieve any pain or breathlessness."

TOPIC 4: Introducing plans when caring for a dying person

Key points

Before starting, make sure the patient is in a fit state to take part.

Treat pain, breathlessness, nausea etc. before starting the conversation.

If the patient has reduced consciousness or lacks capacity, you will have to adapt your message.

If you are speaking to a relative/carer because the patient is unable to participate, be absolutely clear that you are speaking to the **nominated person important to the patient**.

Use straightforward language and speak clearly

Step 1: Review the background to the present situation.

Check what they understand about their current medical problems

"Do you know what has been happening to you over the last few days?" Summarise what treatments have been given so far

"Shall I remind you what treatment we have been giving you?"

Summarise to what extent those treatments have and have not been successful "Some of these treatments have made a difference but despite this you are continuing to become more unwell."

Step 2: Explain that you think they may have reached the last days of life.

You will need to do this carefully in gentle stages if the patient is not expecting it. Use good communication skills techniques: go slowly, check understanding.

"Unfortunately the cancer has become more active again."

"Despite our treatments your condition is deteriorating."

"We are expecting that you will become weaker as the days go by."

"Unfortunately it is becoming apparent that you are reaching the last stage of your life."

Step 3: Explain the management plan.

Be explicit about emphasis on monitoring symptoms.

Be positive about symptom management. You must not leave the patient with any sense that 'there is nothing more we can do'.

"All your treatment now is to help you feel better even though you are not going to get better."

"The focus is now on your comfort and dignity, supporting you and your family."

"We will plan your care giving consideration to your priorities and wishes and taking into account how helpful certain treatments and investigations will be at this stage in your life."

"The emphasis is now on recording how you feel rather than on measuring blood tests or taking your pulse and temperature. This means we check frequently for any symptoms like pain, breathlessness, and feelings of sickliness or restlessness."

"There are several treatments we can give you to relieve these symptoms any time of day or night if you are uncomfortable. These include medications given under the skin for pain, breathlessness, nausea, chest secretions, and anxiety or fear."