

End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

A leaflet for healthcare staff



Making conversations easier

Clickable contents

Initiating the conversation

Preparation

Establishing initial rapport

Non-verbal behaviour

Gathering information

Assessing the person's understanding of their illness

Providing information and planning

Providing the right amount and type of information

Aiding recall and understanding

Incorporating their perspective

Shared decision-making and planning

Closing the conversation

Ensuring appropriate point of closure

Forward planning



Brings you back to contents

End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

“

Patients know you can't fix everything and don't expect it. But they'll never forgive you for not acknowledging that they are having a tough time.

Dame Lesley Fallowfield, 2006



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

Preparation

Communication skills

- Prepare yourself
- Prepare the environment
- Prepare your information

Prepare yourself

- Reflect on your own thoughts and feelings before the conversation. Self-awareness will make your communication more effective.

Prepare the environment

- It is important to prepare for the conversation by choosing an appropriate environment (a comfortable private room where you will not be interrupted).
- Ensure that there are enough chairs for everyone to sit down and arrange the chairs if necessary (e.g. at approximately 45-degree angles to each other), avoiding physical barriers (e.g. a desk) between yourself and the patient.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

Prepare your information

- Review the healthcare record. Consult with other members of the team.
- Rehearse the beginning of the meeting, what words will you use?
- Find out what the patient and family members know and have been told already. Has the patient been encouraged to bring a loved one/family member with them?
- Consider cultural background and language skills. Will a professionally trained interpreter be required?

TIP

Prepare for the conversation ahead, asking yourself *'What do I know?'*. Might the patient and their family already be anticipating sad news?, *'What does the patient and their family know already?'*, *'Where shall I have this conversation to ensure privacy?'*.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

Establishing initial rapport

Communication skills

- Warm greeting
- Introduce yourself
- Check the patient's name
- Check how the patient likes to be addressed
- Use the patient's name, particularly when demonstrating empathy
- Check who is with the patient (name/relationship)

Warm greeting

- Greet the patient with a warm 'hello'
- Consider nonverbal approaches like shaking hands.

Hello, my name is Gerard Leamy and I am the consultant neurologist.

Introduce yourself (name and role)



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

Check the patient's name and how they like to be addressed

*It's **Noirin** Russell, is it? And what do you like to be called... is it **Noirin** or...?*

Use the patient's name, particularly when demonstrating empathy

*That sounds like it was very tough for you **Noirin**.*

Check who is with the patient (name/relationship)

And who is with you here today?



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

TIP

Sad or distressing news is never easy to hear but having someone deliver the news with empathy and understanding can make the person receiving it feel supported and understood.



Initiating the conversation

Non-verbal behaviour

Communication skills

- Facial expression
- Eye contact
- Open body language
- Pace, pitch and tone
- Touch
- Space
- Maintain focus on the patient

Facial expression



- Be aware of your facial expression.
- At times during this conversation it will be appropriate for the clinician to have a warm expression and at others, a serious and engaged one.

Eye contact



- Make and maintain appropriate eye contact with the patient.
- Our eyes convey how we feel and what we are thinking.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

Open body language

How we sit, stand or walk can convey strong messages.



TIP

Leaning forward at times can demonstrate interest. At other times, leaning back with a relaxed posture can help show that you are listening attentively to the patient without wanting to come in with your own thoughts and words. Find a way to check your body positioning during the conversation and adjust it if you need to.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

Pace, pitch and tone



- Use appropriate pitch, slow pace and a warm tone of voice.
- It is often through our pace, pitch and tone that we reveal our feelings and attitudes.

Touch

- Touch can be used to show support, care and empathy.
- Holding a hand, or putting a hand on their arm or shoulder if they become upset.



Space

- Give your patient space while staying connected with them.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Initiating the conversation

Maintain focus on the patient

- If you need to turn to your computer screen, for instance to look up information the patient asks for, then explain to the patient what you are doing.

That's a really important point, I am just going to make a note of it now in your record...



TIP

Demonstrating relaxed and open non-verbal behaviour helps build rapport and trust. Remember that non-verbals are 'two-way'. Observing and interpreting the patient's nonverbals helps us to understand how they are feeling or the extent to which they agree with or understand the information being shared with them.



Gathering information

Assessing the person's understanding of their illness

Communication skills

- Establish the person's understanding (starting point)
- Explain the purpose of the conversation
- Establish patient understands the purpose of the conversation
- Provide structure

Establish the patients' understanding

- It can be helpful to begin by discuss the sequence of events leading up to this point (scans, biopsies and so on). Doing so helps build in a step-by-step way towards difficult news delivery.

I can imagine that it has been a long 2 weeks for you...



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Gathering information

- Give the patient opportunities to tell you what they know or are expecting as the patient may or may not be aware of the possible 'sad news'.

You're worried... what have you been worrying about? What is your sense of how things are going..?

Demonstrate empathy

- Use verbal and nonverbal listening skills (nodding, leaning, summarising and so on) to show the patient that you are paying careful attention to what they are telling you.

I can see that you look worried Claire. Do you want to tell me more about that?



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Gathering information

Explain the purpose of the conversation

So you know that the plan for today is to discuss the results of your biopsy?

Establish patient understands the purpose of the conversation

- Check if the patient wants to receive their results at this time. Some may recognise that the news is not what they had hoped for and may want to wait until family members are present.

I have the results here. Would you like me to go through them with you now?

Provide structure (summarise a shared agenda)

So I am going to tell you what the results are, answer your questions and then move on to discussing next steps...



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Gathering information

TIP

We meet patients every day and we will be familiar with how to engage patients in difficult conversations. Nevertheless, for the patient the visit is likely to be a one-off, not routine, and worrying and distressing. If the patient appears stressed or worried, using good communication skills carefully at the start of the conversation helps to build trust and puts the patient at the centre of the conversation.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Providing information and planning

Communication skills

- Warning shot
- Use easy to understand language and avoid specialist terms
- Chunk and check
- Provide structure
- Check understanding
- Ask what other information would help the patient
- Demonstrate empathy
- Share your thinking
- Explore options
- Negotiate the plan
- Check with the patient



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Providing information and planning

- Delivering sad news is a complex communication task. It requires responding to the patient's emotional reactions, involving the patient in decision making, the involvement of other family members and managing patient expectations. Some of these conversations can also involve challenges for you in terms of managing your own emotions.

Providing the right amount and type of information

Warning shot

- Use a warning shot to indicate that you have to deliver sad news.

As you know we took a biopsy/did a scan, and I am sorry to say that the results were not as we hoped.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Providing information and planning

Aiding recall and understanding

Use easy to understand language and avoid specialist terms

- Avoid giving too much information too early as this may overwhelm the patient.

I'm sorry to tell you this Claire, but the results from the investigations show you have cancer.

Chunk and check

- Pause often to give the patient time to process the information.

Your father is very seriously ill (pause).

Provide structure (signposting)

- Move from one part of the conversation to the next using signposting.

Ok, now that I know what you are worried about, let's talk about what we can do to help with that.



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Providing information and planning

Check understanding

- This can be done by watching the patient's nonverbal responses (when they have had enough) or asking them to restate key messages in their own words.

I know this is a lot to take in Claire. To make sure that I have explained things clearly to you, can you tell me what you've heard me saying about the next steps for you?

Ask what other information would help the patient

Many people also want to know...? Would that be helpful for you?



Providing information and planning

Incorporating their perspective

Demonstrate empathy

I can see that this is a shock for you Claire. This is really tough...

Shared decision-making and planning

Share your thinking

- Use 'we' and make suggestions. Check with the patient.

So what we think would be best to do now is... How does that sound?

Explore options

- Use open questions to understand the patient's goals, views and wishes.

What do you think? Tell me about...? What is important to you...?



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Providing information and planning

Negotiate the plan

- Signpost your own preference and determine the patient's preference.

How do you feel about?

Check with the patient

*Can I check that you are ok with the plan?
What questions do you have for me now?*



TIP

After giving the diagnosis, wait for the patient to re-initiate the conversation. Clinicians often find it uncomfortable watching patients like this in silence, but it is important to give the patient space to react. If there are non-verbal cues, describe what you see. Use language that mirrors or reflects the patient's language... *'it looks like you have something on your mind'*.



Closing the conversation

Communication skills

- Summarise the conversation (briefly)
- Check with the patient
- Safety netting
- Outline next steps

- The aim when closing the conversation is to check the patient's understanding of the sad news you have delivered and to agree next steps.
- Raising next steps can help with emotion management as closings can entail moving from expression of very difficult emotions towards concrete next actions. Also, when people raise future arrangements in any conversation, we all recognise that this signals a proposal or bid to close the conversation (just think of your own phone calls at home, we usually bring them towards a close by talking about future arrangements).



End-of-Life Conversations

DIAGNOSIS OF A LIFE-LIMITING ILLNESS

Closing the conversation

Ensuring appropriate point of closure

Summarise the conversation

The team are recommending that removing the lump and a course of radiation is the best care plan for you.

Check with the patient

- Check that the patient agrees with and is comfortable with the plan.

Can I check that you are ok with the plan?...What questions do you have for me now?



Closing the conversation

Forward planning

Outline next steps

- Offer ongoing support (e.g. contact details) as the patient may think of questions after the conversation. You could also offer assistance to tell others (e.g. family members) the sad news.

I will make arrangements for your procedure... We will be in touch with your GP.



Closing the conversation

Safety netting

- Document fully what you told the patient and their relatives and their reactions to the news. This will help to facilitate co-ordination of care.

In the meantime, if your symptoms change, then please go to your GP or call my secretary...

TIP

Delivering sad news can be difficult. It may be helpful to debrief with a colleague or take a short break before seeing your next patient.

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This Skills Card is the work of Ruth Parry (Loughborough University), Paul Kinnersley (EACH & Cardiff University), Peter Gillen & Eva Doherty (RCSI) & Winifred Ryan (HSE) with the help and support of Jonathan Silverman and many others in EACH.

