

End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

A leaflet for healthcare staff



Making conversations easier

End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

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End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Initiating the conversation

Preparation

Communication skills

- Prepare yourself
- Prepare the environment
- Prepare your information

Prepare yourself

- Be aware of your appearance, as you will know, a professional demeanor is important.
- Take a few moments to ensure that you are in the right frame of mind for this conversation.
- Remind yourself that no matter how skilled your communication, the people you are speaking with are likely to experience considerable distress.

Prepare the environment

- Avoid interruptions – move to a quiet, private area.



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WHEN A PERSON IS DYING IMMINENTLY

Initiating the conversation

Prepare your information

- Clarify in your own mind the purpose of the conversation you are about to have (giving information and building shared understanding in a sensitive and supportive manner).
- Familiarise yourself with the person's background, family situation and healthcare history.
- Read carefully information from colleagues, relevant notes or letters.

TIME

Set aside adequate, protected time for a face-to-face meeting.



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Initiating the conversation

Establishing initial rapport

Communication skills

- Warm greeting
- Introduce yourself
- Check the person's name
- Check how the person likes to be addressed
- Use the person's name, particularly when demonstrating empathy
- Check who is with the person (name/relationship)
- Tell the person what you have done to prepare for the conversation

Greeting

- Explain who you are, your role, the team – even if you have already met the person and family, re-introduce yourself.
- Ask their names and relationship to the person.
- Acknowledge this is a difficult time.



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WHEN A PERSON IS DYING IMMINENTLY

Initiating the conversation

Hello, I'm _____ one of the specialist respiratory (or palliative care) nurses. I am part of the team looking after your wife.



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WHEN A PERSON IS DYING IMMINENTLY

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.



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WHEN A PERSON IS DYING IMMINENTLY

Initiating the conversation

Eye contact

Make and maintain appropriate eye contact with the patient.



Our eyes convey how we feel and what we are thinking.

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 person 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.



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WHEN A PERSON IS DYING IMMINENTLY

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.



A hand on the arm or shoulder if the person becomes upset.

Space

Give them space while staying connected with them.



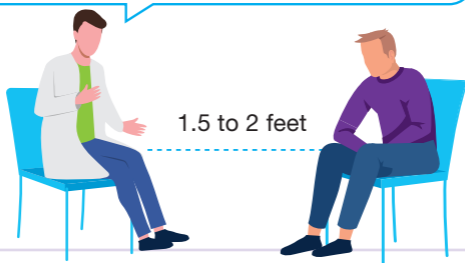
End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Initiating the conversation

Maintain focus on the person

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



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

TIP

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



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Gathering information

Assessing the person's understanding

Communication skills

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

- Finding out what the person already knows can help you to work out if they already know that death is likely and it helps you to fit what you are saying to what they already know and feel. Once you have established what the person and/or loved ones know and want to know more about, merge this with the information you want to provide.



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WHEN A PERSON IS DYING IMMINENTLY

Gathering information

Establish the person's understanding

We wanted to meet to update you on your father's condition. I've read through the notes and seen your father this morning. Before I start, can you tell me what you know already about your father's illness?

What is your sense of how things are going?

I reviewed the healthcare record and spoke with the doctors who were caring for your wife. Just so I know where to begin, can you tell me your understanding of her condition? (pause)

Demonstrate empathy

You look a lot more frail than you did last time I saw you, how are you feeling?



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WHEN A PERSON IS DYING IMMINENTLY

Gathering information

Explain the purpose of the conversation

So you have noticed that your father is getting weaker and struggling to breathe (pause). That is also our main concern and I'd like us to talk about what the next steps are.

I'll do my best to explain things clearly. But I might not always manage that, so if I don't, then please feel you can stop me and ask me to be more clear.



Provide structure

- Signpost your goal(s) for the meeting.
- Restate their concerns and summarise a shared agenda.
- Ask person/family to stop you if you use language they don't understand.



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WHEN A PERSON IS DYING IMMINENTLY

Gathering information

TIP

Speaking aloud about what is happening can help the person recognise for themselves that the patient is likely to die soon.



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Providing the right amount and type of information

Communication skills

- Chunk and check
- Ask what other information would be useful
- Avoid giving advice or reassurance prematurely

Chunk and check

- Provide small chunks of information and allow this to sink in. If the person/loved one understands it they are more likely to respond, either by acknowledging what you have said or asking a question.

*Your brother is very sick (Pause).
His lungs are not working (Pause).
And I am afraid that we won't be
able to get them working again.*

*I would like to share my thinking with you
about the way your illness is progressing.*



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WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

It's difficult to make predictions but it does seem as if you are you are coming towards the end stages of your illness.

Your father has COVID-19 (pause) and he is sick enough to die (long pause).

Ask what other information would be useful

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

Avoid giving advice or reassurance prematurely

- Avoid giving advice too early because doing so can come over as unsympathetic, as shifting from emotional troubles to solutions.
- Giving reassurance and turning to the positives too early can curtail talk about difficult things. It can move the conversation towards some positives, and then towards conversation closure. So, delay moving to reassurance and positives until difficult matters and difficult emotions have been addressed.



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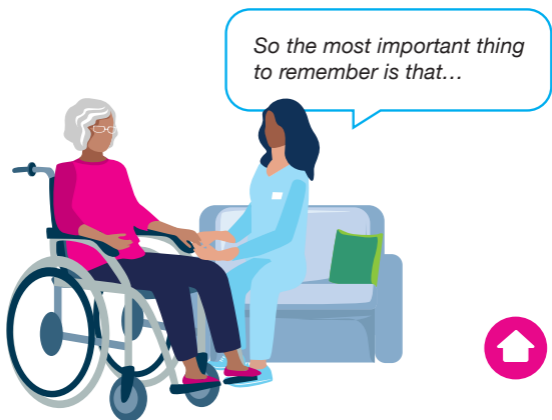
WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Aiding recall and understanding

Communication skills

- Use easy to understand language and avoid specialist terms (unless the person is already familiar with them)
- Organise the explanation
- Keep a steady, slow pace
- Pause often
- Check understanding
- Demonstrate empathy
- When the time feels right, suggest moving on to next stage of the conversation



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Language

- Avoid vagueness and ambiguity that could result in the person not understanding that the patient's death is imminent.
- By this stage in the conversation, you should be able to judge whether the direct terms '*die, dying, death*' are going to be helpful for this person, or whether they are likely to be too brutal. If the latter is the case, use less direct, but nevertheless unambiguous terms such as '*coming to the end of her life*', '*very unlikely to survive the night/for many more hours/days*' '*going to pass away soon*' '*so sick that you will not get better*'.

Organise and keep a slow, steady pace

- Structure the conversation.

First I want to talk about about how you have been during your hospital stay and then we can talk about what care from us would suit you best.



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WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Pause often

- Continue to pause and to leave plenty of space for those you are talking with to process, think, and talk.

Check understanding

- Watch their non-verbals – do they look like they are understanding and participating in the conversation or are they at a point where they might be overwhelmed and needing time and support before further conversation?

I have shared a lot of information with you. I am going to stop now and hear what questions you have...

How are you feeling about what we have discussed?

Demonstrate empathy

- Continue to provide empathic support.

This must be really tough.



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WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

When the time feels right, suggest a move on to the next topic or stage of the conversation

So in this situation, people often want to know what the next few days/hours are going to involve/look like. Would that be helpful for us to talk about?



TIP

During the conversation, the person you are speaking to may start to show distress, which you might hear or see in different ways – more pauses, they may increasingly reduce their eye contact with you, you may hear changes in voice or sobbing. If the person is crying, give them time – repeated phrases such as ‘it’s ok’ and ‘take your time’ are fine. The person crying may well apologise – just reassure them: ‘it’s perfectly ok to be upset’. Avoid ‘jollyng them along’, give them time.



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Providing information and planning

Incorporate their perspective

I.C.E. (Ideas, Concerns, Expectations)

- Ask what is important to the person now.

Let's talk about what is most important to you at this stage in your life.

Could we talk through what your Mum would want as she comes towards the end of her life? For instance, who she would want to have with her.

What would your father say is most important to him?



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Providing information and planning

- Use non-verbal responses to show your care – pause, make eye contact, perhaps offer tissues, if appropriate.

G.I.V.E. to connect, understand, and support

G

Get

that it's emotion

I

Identify

the emotion

V

Validate

by acknowledging feelings

E

Explore

to better understand the emotion



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Identify the emotion

It looks like you were not expecting this news.

I hear you're upset.

*Can I check in with you?
How are you feeling?*

*You seem a bit quiet.
Would you like to
take a break?*

*Do you sometimes find it difficult to talk
about how you are feeling?*



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Providing information and planning

Validate

- Acknowledge and validate how people feel, this builds connection and trust and makes emotion less overwhelming so they can participate.

It's overwhelming – everything you have been through.

This is a lot to hear. Yes, it is scary.

Those are difficult emotions to deal with, I am glad you mentioned them.



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WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Explore

- Explore emotions to better understand values and concerns.

Tell me more – what are you most worried about?

Time

- Allow person/family to speak without interruption.

Reflective listening

- Reflect what you observe or hear with a statement. To explore their thoughts further, use...

Tell me more.

- Invite questions.

I gave you a lot of information. What questions do you have for me now?



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Shared decision-making and planning

Communication skills

- Share your thinking
- Explore options
- Negotiate the plan
- Check with the person

Share your thinking and explore options

- Using 'we' can help the healthcare practitioner feel less responsible for the WHOLE of what is happening, and function to remind us that we are not solely responsible for what is happening and what happens next.

From what you have told me, you would like to be at home when you come to the end of your life. To try to make that possible, we would need to...



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Providing information and planning

So, what we are going to do now is to make sure your _____ is comfortable, we are going to give him medicine through what is called a syringe driver. This will help reduce his pain and his agitation (pause).

We are not going to disturb him by checking his temperature and his blood sugars, and we are going to avoid disturbing all of you whilst you spend this precious time with him. How does that sound?

Tell me what's important to your Dad. For instance, for some of our patients being shaved every single day is really important to them, but for some patients, they would rather not be disturbed in this way.



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WHEN A PERSON IS DYING IMMINENTLY

Providing information and planning

Negotiate the plan and check with the person

- Explain clearly what is and is not possible. If there are family/patient preferences, for instance regarding preferred place of death, then be clear about whether their preference is feasible, and what it would entail.

I'm sorry to say, if he was at home, we couldn't give your brother the amount of oxygen he needs in order to be relatively comfortable.

I wish it was possible to get your Dad home at this point.



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Closing the conversation

Ensuring appropriate point of closure

Communication skills

- Summarise the conversation (briefly)
- Check with the person

Summarise the conversation (briefly)

- Briefly summarise what was discussed.

So, your wife is moving towards the end of her life (pause) and although there aren't any treatments that will stop that, we are going to manage her symptoms, and keep her as comfortable as we possibly can. We've agreed she is going to stay here at the hospice, and I've told you that you and any other loved ones are most welcome to be here with her whatever the time of day or night. We will try to avoid disturbing you, but we will be on hand.



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Closing the conversation

Check with the person

- Allow family to correct or add information.
- Moving towards the end of the conversation with 'screening'...

Are there things you would like to ask, that I have not said, or explained enough?



End-of-Life Conversations

WHEN A PERSON IS DYING IMMINENTLY

Closing the conversation

Forward planning

Communication skills

- Outline next steps

Outline next steps

- Explain what will happen next, including when the next conversation(s) with staff will be.
- Encourage family to use available resources (clergy, social work and their own support network of friends, family and neighbours) and to attend to their own well-being.
- Emphasise support – that they are not alone.

I think we have had a very useful conversation. I am going to talk to the other members of the team and if you agree, I will document our decisions in your notes.



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WHEN A PERSON IS DYING IMMINENTLY

Closing the conversation

This is very hard on you. You may not be thinking about yourself but you need to take care of yourself as well.

So our priority now is to get you back home as soon as possible, even if that means you may die a little earlier than if we kept you in hospital.



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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.

