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Note on using this video

We try to make each video as authentic as possible (although this is not of course real life). At the same time, we design videos so as to demonstrate plenty of communication skills. You might feel that some points over-emphasised or rather repetitive. Be assured that in real life situations, you will be able to improvise how and when you use these skills, and you will be able to personalise them to the individual patient or family member that you are meeting.

In this particular video, we wanted to include a lot of detail about what normal dying looks like, sounds like and so on. We wanted to emphasise some points, including ways to talk about and respond to family members' concerns about a dying person no longer being able to take in food and drink. So this video is approximately nineteen minutes long, and lots of pieces of information are given by the practitioner. In real life, these pieces of information might well be conveyed over the course of several, shorter, less intense conversations. Once again, when you are at work and having conversations about normal dying, you will be able to make your own judgements about how much to say and when.

Supporting materials

Visit our webpage at *https://bit.ly/NHCP_MODULE_3_WEBAGE* for supporting materials on communication skills for end-of-life conversations about normal dying.

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Background

Edel is a highly experienced Social Worker. She has been visiting John Lynch for six months. He is elderly, has COPD, and frailty. Over the past few weeks, he has become more frail, and less mobile. He is now speaking very little, not wanting food or drink, and is sleeping much of the time. His GP Dr Forster and the public health nurse team have let the social work team know that they think John is nearing the end of his life. He is in a bed in the small downstairs study.

Edel has arrived at Mr Lynch's house and finds Mr Lynch's son Tom in the kitchen. He looks worried. Edel has met Tom several times before during her visits to his father.

Clips

There are four clips in this scenario.

FIRST CLIP

INITIATING THE CONVERSATION 00:00 – 00:25

Edel asks Tom how he is doing and listens attentively to his answer.

SECOND CLIP

GATHERING INFORMATION 00:25 – 02:02

Edel attempts to find out more about how Tom is feeling, what he recognises with regards his Dad nearing the end of his life, and how Tom is feeling specifically about this.

THIRD CLIP SHARING INFORMATION 02:04 – 18:14

Edel provides information about what happens, what is normal, what to expect as someone is moving towards the end of their life. The topics covered include a person no longer taking in food and drink, becoming weaker, sleeping more and having times of unconsciousness, changes in breathing, moaning or sighing, noisy 'rattling' breathing, skin colour, and that the process is often gentle. Edel also talks about the fact that it is not unusual for the person to die when no-one else is in the room.

She talks with Tom about being with, and caring for, someone as they are dying, including mouthcare, the benefits of people being around and talking, talking to the person including saying important things, and the importance of touch.

Edel reminds Tom of what support is around for him, and encourages him to take care of himself, during this difficult time.

Tom says that his Dad had said very clearly that he wanted to die at home. Edel sensitively raises the possibility that inpatient unit care might be needed for his father's symptom management and dignity. Edel also explains that the dying process can take quite a while, and is variable. Throughout, she shows affiliation and empathy.

FOURTH CLIP CLOSING THE CONVERSATION 18:15 – 18:56

They agree on what will happen next – they will go into the next room to see Tom's Dad. Tom expresses his gratitude to Edel and the team, she accepts this gracefully.



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Communication Skills FIRST CLIP INITIATING THE CONVERSATION 00:00 – 00:25

- Edel has positioned herself so she is fairly close to Tom and can look directly at him. She has placed her phone and diary to one side. With this positioning of herself and her items, she shows she is open to an attentive conversation.
- She starts with a broad question "How are you doing?". Silence, verbal ("mm-mm", "Uh-huh") and non-verbal encouragers (eye contact, nodding) encourage Tom to share how he is feeling.
- Tom's replies "I'm not great, to be honest". The 'to be honest' phrasing, is hearable as hinting that Tom thinks he should be doing better than he is, that he would only admit this when being 'honest'. Even very early on in the conversation, a skilled listener can pick up important hints about the person they are talking with. Here Edel can pick up not only that Tom isn't feeling good, but also that he feels somewhat self-critical about that. Edel directly addresses this later on.

SECOND CLIP GATHERING INFORMATION 00:25 – 02:02

- As a form of structuring for the visit, Edel confirms that they will talk about Tom's Dad, but asks if it is alright with Tom for them to focus for a while on how he is, and what support he has.
- Tom soon moves to talking about his worries about his Dad, rapidly focusing in on his Dad not eating or drinking, saying "Surely, he needs to eat". [00.50]

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- Edel could, of course, move straight into explaining that his Dad is coming to the end of his life, and that people who are dying no longer wish nor need to take in food and drink. Instead, she moves in a step-by-step manner towards this evidently painful matter. Moving step-by-step towards a sensitive matter is an important skill. Edel's first step is to convey, with empathy, that she recognises how concerned Tom is.
- In her next step, she works to find out what Tom knows, whether – at least in part – Tom recognises that his Dad is dying. She does so by referring to conversations with his GP and nurses. This is another skill: referring to or asking about what others have said is often an effective way to help people to bring a sensitive topic onto the surface of the conversation. This works here: Edel asks Tom if he has been able to talk to the GP. Tom replies: "Dr Foster said he thinks my Dad is nearing the end of his life.". That is, in responding to Edel's relatively broad question about conversation with another professional, Tom himself raises this key, sensitive matter, rather than Edel directly imposing this topic on him.
- [1.40] As Tom lists his concerns about his Dad, Edel responds with empathy. Notice the empathic skill here: she does not claim to fully understand, but she shows she is making the effort to try to understand *"I can imagine it's very hard"*. She demonstrates compassion by telling Tom how well he has been caring for his Dad.

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THIRD CLIP SHARING INFORMATION 02:04 – 18:14

- Edel and Tom are now clearly 'on the same page'

 both now talking about the signs that John is dying. Edel now gives important information, at slow pace, in chunks.
- [02.13] The first item of information Edel turns to is about **eating and drinking**: how a dying person reaches a point where they are "*no longer able to take in the food and drink.*". In this, she has picked up on what appears to be Tom's greatest concern, and she addresses it first. She emphasises using moistening swabs and how that is "*what is helpful now*".
- They briefly return to conversations with others

 this time with the nurse in his response, Tom shows he recognises his Dad is dying.
- Edel confirms this, using nonverbal skills and tone of voice to indicate gentleness and empathy. She confirms that the things Tom is seeing in his Dad are the signs of end of life.
- Now that Tom has started to use the term dying, Edel uses this term, rather than euphemisms.
 Sometimes indirect references to dying and death are useful, because they can be gentler. But if a patient or family member has used the direct terms dying/death, it is usually best to mirror their terms. By doing so, you show you are on the same page and willing to talk directly.
- Edel emphasises support for Tom from others.
- [04.14] Returning towards Tom's concern that his Dad is not eating or drinking, Edel explains to Tom that by offering his Dad mouthcare, he is continuing to nurture, and doing the right thing.

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She mentions that Tom may need to explain this to other family members who might still feel that John should eat and drink.

- [04.50] In a signposting and permission-seeking move, Edel says "would it be helpful if we talked a little bit about what you might expect?" notice she words this as a question; Tom could in theory refuse this offer, but he confirms that it would be helpful. Sometimes when we word things as a question, they are taken by the other person as proposing, and they will just give you the go ahead. An alternative approach is to briefly give a reason, and then go ahead with information giving - something like "it can make things a lot less distressing to know a little about what to expect, so I'm going to talk you through that". Avoiding posing a direct question about this kind of thing can feel less burdensome to the person you are talking about. If you remain attentive to a person's verbal and nonverbal responses, you will still pick up if they are not comfortable with what you are covering.
- In chunks, at slow pace, Edel starts the next 'chunk' of information – this being about increasing sleepiness and loss of consciousness. She tells Tom that his Dad might be able to hear and gain comfort from other's voices, even when he is sleepy or seems unconscious. She emphasises that this can be the time to say important things, things that need to be said to John.
- As in several other places in this conversation, Edel encourages Tom to care for himself, including by taking a break when other family members are around.

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- [7.05] Edel checks on how Tom is feeling at this point "Can I just check with you, how you are, with all that?". This prompts Tom to mention that his Dad was very clear about wanting to die at home. This results in a chunk of information about dying at home or in the inpatient unit. Rather than bluntly tell Tom that dying at home is just not always possible, Edel uses a gradual step-wise approach. She first acknowledges Tom and his dad's clear plan, sharing laughter about the sound of the dog next door. Then she cautiously and gently moves towards explaining circumstances in which the 'inpatient unit' would be best for his Dad: "sometimes with the best will in the world, it may not be possible for him to stay at home". She closes the topic with reassurance that the services around him will do what they can to keep him at home.
- [9.40] Edel explains more about "what's normal" in terms of sleepiness, loss of consciousness, and breathing. She continues to express empathy, to reassure him, and to encourage him to 'give himself some credit' for how well he is doing (note how these connect back to the feelings Tom expressed right at the start of the conversation).
 [11.04] Edel explains changes in breathing, the possibility of the person moaning or sighing, and she mentions how secretions can 'rattle'. Edel explains this is caused by saliva in the throat. Your explanation could also include the fact that sometimes the rattle can be quite loud and alarming, and can be caused by secretions deep in the chest.
- Edel explains that this process can go on for some time, that the end is often very gentle.

- [12.58] Tom raises the subject of holding his Dad's hand, how he thinks he can feel his Dad responding. Following Tom's lead, Edel now talk about touch for a while, **encouraging touching**.
- [14.00] Edel acknowledges that she has said a lot and that "you may not have taken it all in", she assures him that there can be plenty of further conversations.
- [14.18] She raises that fact that sometimes a person dies when their loved ones are not in the room. We can see from Tom's response that this is something of a relief for him to hear. We know that people often feel considerable guilt and regret that they were not in the room (or on the ward) at the time of their loved one's death. Explaining to people that this is fairly common may help reduce these levels of guilt and regret.
- [15.52] Edel raises how sometimes a person "*might need permission to go*".
- [16.10] Tom asks "how long do you think it's gonna take?". With gentle tone, Edel explains how variable this can be, that "sometimes it's amazing how long a person can stay... unconscious and alive without eating and drinking." . She tells Tom that the nursing staff who visit daily will be able to advise and update on this (the closer someone is to the actual end of their life, the more accurate staff estimates become).
- Edel reminds Tom to take practical support from others, and reassures him of continuing from the teams involved. She raises the future option of (professional) post bereavement support whilst also conveying that this is not always needed.

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FOURTH CLIP CLOSING THE CONVERSATION 18:15 – 18:56

- A common way of suggesting that a conversation might be coming to its end is to talk about what happens next. Edel does so by suggesting they go in to see Tom's father.
- Tom is not quite ready to follow Edel's move towards closing this conversation. Instead, he takes some time to mention his gratefulness to Edel and the team for their support. Edel doesn't carry on pushing towards going next door to see his Dad. She leaves Tom space to say what he wishes to, and when he comes to an end of his talk, she accepts his gratitude gracefully.

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