

NHS Education for Scotland

Transcript of Discussing Dying Video Script

Discussing dying is something most of us shy away from. The potential discomfort is not just in the patient's mind - it's also in the minds of the doctors and nurses who are looking after them. When it comes to holding an honest conversation about dying, we need to recognise the things in us as professionals that hold us back or make it difficult. We can't skirt the issue or hide behind uncertainty if the eventual outcome, dying, is not in doubt. The truth about dying - and what they might experience on the way - is what matters to the person whose care is in our hands. It is our professional and ethical responsibility to be open and honest about it.

Prognosis

Discussing dying begins with prognosis. For most people, dying is a process - not just an event. It can usually be recognised days, weeks or months before it happens. There are signals. A prognosis doesn't mean being certain about timing. Rather it means being truthful that the trends are in a specific direction, the end of life is in sight. Truth telling doesn't mean being crudely explicit. *"Hello George, I'm sorry to say this but you're going to die."* Truth telling in relation to dying begins simply with the willingness to talk about the future. If death is clearly on the horizon, it will mean being open and honest: *"George, I am not sure that we are going to be able to pull you through this illness."*

The Conversation

The questions we ask should prompt the patient to reflect on recent trends. "So Mary, how do you think things have been going over the last few months?" Reflection on how things are changing leads the way to contemplating "What Now? What Next?" When it comes to our health and even more to the prospect of dying, most of us will have fears lurking in the background. *"Is there anything you are afraid of?"* is a simple question, but one that allows patients to acknowledge and confront their fears with our support. Some patients prefer not to discuss their future, especially if it's about not surviving. It's simple to ask *"Would you prefer not to be having a conversation like this?"* and accept the answer.

If possible, and with consent, family members should be included. They will often ask questions that the patient is too frightened to ask, yet the answer is what they often want to know. Sometimes patients surrender their autonomy in favour of a family member. Sometimes a family member will be more than happy to take control. We need to be aware that this can lead to a perception of collusion, and the doctor-patient relationship can be compromised.

In discussing death and dying, we can be tempted to use code words and euphemisms. For example, when referring to dying we could say *"you might not be with us anymore"*. While this approach may seem kinder at the time, what is meant and what is heard are not always the same thing. We need to check that the truth has been received and fully understood.

Future Planning

Discussing dying is not just about bringing an undesirable truth out into the open. It's about addressing the practical needs that are vital to good future care. When the focus of medical care shifts, it is no longer about curing: more pills or another operation, about clinging on to life. Care becomes more relevant. The emphasis is less on survival than fulfillment. It is about symptom relief and supportive care. It is about personal choices and the process of letting go. Discussing dying is the gateway to these things. The health professional is the person who holds - or withholds - the key.

Conclusion

Discussing dying is more than just a once off. Just as we revisit symptoms and review treatments for many conditions, so we need to revisit and review our patient's thoughts on their prognosis and their care choices. Medical as well as personal goals will need to be redefined as the clinical situation evolves. The freedom to talk about what is important to us is a human need, especially in times of distress. Discussing dying addresses this need. It is a key responsibility for health professionals. It may be hard, but we should not be the one who avoids it.

The film was produced in March 2016 and can be found at www.sad.scot.nhs.uk or <https://vimeo.com/167887527>

For more information visit www.sad.scot.nhs.uk or contact supportarounddeath@nes.scot.nhs.uk