COMMUNICATION

How to approach the difficult topic of death

Many nursing staff report feeling ill-prepared to discuss death with patients. Here, expert nurses share advice on supporting individuals when they receive bad news.

Compassionate communication is fundamental to nursing. Yet when it comes to breaking bad news or talking through potentially life-changing results with patients and their families, it is common for nurses to feel ill-equipped.

Earlier this year, Nursing Standard and Marie Curie surveyed 5,300 UK nurses about end of life care, and many of them told us they lacked the skills or confidence to have difficult conversations with patients and their families.

But imparting information in a clear and sensitive way has the potential to make an enormous difference to how patients and their families feel about their care.

We’ve drawn on expert advice and guidance to help you prepare, structure and reflect on difficult conversations with patients and their loved ones.

When bad news is delivered in a way that appears clumsy or insensitive, the experience will stay with the recipient long after the initial shock has been processed, the RCN advises. But if possible, find out as much as possible about the patient. Look into their recent blood results, medical history, their social situation and the level of support available to them at home, expert nurses say.

The RCN, in its advice for breaking bad news to parents, suggests mentally rehearsing the disclosure, enabling you to anticipate the possible questions you will be asked, parents’ emotional reactions and potential responses to offer.

‘Do not just think them, actually practise saying them. This will give you the confidence you need to speak to the family,’ the guidance says.

It also advises turning off bleeps and mobile phones.

Privacy matters

Where possible – and this can be difficult – try to find a private, tidy and comfortable room where your conversation cannot be overheard. Put a ‘do not disturb’ sign on the door and have tissues and glasses of water on hand.

Imparting bad news has traditionally been the realm of the doctor, often with a specialist nurse on hand, and this is often still the case. But the RCN says that, increasingly, nurses are taking on this element of care.
Either way, nurses remain central to providing support to families at the point when they receive bad news, or to reinforcing or explaining information delivered during consultations, the RCN says.

Specialist nurses can provide follow-up to the patient after bad news has been delivered, provide continuity of care and offer emotional support.

Patient-led process
The most important thing, whether it is a more formal discussion, or a patient or relative asking for a quick update, is to be patient-centred.

‘Let the patient or the family take the lead,’ advises Debbie Ripley, Marie Curie regional nurse manager for London.

When delivering news, break the information into bite-sized pieces of information, regularly check understanding and try not to overload people.

For nurses involved in care of dying patients, talking about death and breaking bad news is more of a continuing process than a one-off meeting.

Guidance from the National Institute for Health and Care Excellence (NICE) is clear that good communication and information are essential to these conversations, and need to be reassessed at different stages.

The NICE end of life quality standard says people approaching the end of life, as well as families and carers, should be communicated with and offered information in way that is assessible and sensitive to their needs and preferences.

Reassess people’s needs
The RCN says that difficult and sensitive conversations need to be reassessed, particularly at the end of life.

The last days and hours of someone’s life bring changes, and regular review of the person’s needs is required.

Constant communication is vital to ensure everyone understands what is happening and why decisions have been made.

Some basic counselling skills can help when it comes to such discussions with families, says Siobhan Fairhurst, an inpatient ward nurse at Marie Curie Hospice, Glasgow.

A useful counselling technique here is active listening – where the focusing is on what is being said by the patient, and can include summarising and paraphrasing.

The close relationship that nurses can develop with patients and families means they will often be asked for an update, Ms Fairhurst says.

‘We notice subtle changes or how families are coping or not coping,’ she says. ‘Not everyone wants to have formal conversations and meet someone else and go through their story again. What nurses are good at is getting to know people very quickly and building a rapport.’

Ms Fairhurst adds that nurses have to make sure it is appropriate for them, rather than the doctor, to impart certain information if someone asks them a question.

When discussing bad news or death, be aware you may not be the first person to have broached the subject.

‘A lot of patients say they are having to tell their story over and over again,’ says Ms Ripley of Marie Curie.

‘A conversation may have happened in hospital – we, in the community, may go in to talk about resuscitation and find it has already been

How to talk about a terminal diagnosis

- Check what information the person already has
- Give small amounts of information at a time
- Avoid using jargon
- Avoid euphemisms – for example say ‘dying’ instead of ‘passing away’
- Avoid excessive detail when explaining something – unless the person asks to know more
- Check how much they have understood
- Ask how they feel, having had the conversation.
  For example, ask: ‘That was a lot of information, how are you feeling about it?’

Source: Marie Curie Palliative Care Knowledge Zone
tinyurl.com/palliative-knowledge-zone

Siobhan Fairhurst: ‘What nurses are good at is building a rapport’
Fast facts

5,300
UK nurses took part in the 2019 annual Nursing Standard/Marie Curie end of life care survey

32%
of nurses feel fairly or not at all confident in discussing end of life care needs and wishes with patients and their families

1 in 3
nurses say they are not sufficiently supported at work to manage the grief and emotional stress of caring for dying patients

Source: Nursing Standard/Marie Curie end of life care survey

Debbie Ripley: 'There is a chance at diagnosis to start a conversation'

Finding answers

Questions are a natural part of formal meetings between clinicians and patients, but can be sprung on nurses when they are not expecting it.

Marie Curie urges nurses not to feel they must have all the answers.

It’s better to admit you don’t know than try to make something up. You can try to find the answers to questions and let people know later, the charity advises.

Ms Ripley says she has found a good way to start is to find out what the person asking the question currently knows and understands.

‘It is about finding out what people know already, and what they want to know,’ she says.

‘A lot of people are scared of dying and they want to know how they will die,’ says Ms Ripley.

‘But that is hard, as, say for people with cancer, a lot of people will die of something else, such as an infection. It is about finding out what level of detail they want.’

Demystifying death

There is a lot of mystery about death, says Ms Fairhurst.

‘People don’t know about dying any more and what it is going to look like. People are worried we don’t do anything at end of life, but care is still very much active.’

Relatives and patients will often want to revisit aspects of a medical consultation that they didn’t understand, Ms

Fairhurst says. ‘People will often come and ask “what did this or that mean”, which can be daunting sometimes.’

Ms Fairhurst advises telling people what the next steps are in terms of their treatment plan, and ensuring they leave with a contact number so they can get through to a member of the team.

Providing written information to take away can be helpful too, as well as flagging up charities such as Marie Curie.

When to raise the subject of advance care planning

Advance care planning (ACP) should be broached swiftly after bad news is broken. It may not be easy, especially in hospital, but it is vital to find out what people want in order to empower them.

Ideally this may happen 24 hours or so after the news of diagnosis has been broken to a patient. Often though, this may not be possible when the individual is an inpatient at time of diagnosis, because they may have been discharged before a prompt advance care planning meeting can be held.

‘There is an opportunity at diagnosis to start guiding a conversation,’ says Debbie Ripley, Marie Curie regional nurse manager for London. ‘Some illnesses progress quickly. If there is a diagnosis of motor neurone disease, for example, waiting a few weeks may not be appropriate. We want to empower people to take ownership of their care planning.’

Managing expectations

Ms Ripley says this is where a good understanding of local services and the patient’s home situation and support is important. People’s expectations need to be managed to ensure they get the best care.

‘It is all very well having ACP conversations, but sending someone home for end of life care without anyone to facilitate it may not be a good experience,’ Ms Ripley says. ‘Some areas of London, for example, don’t have overnight district nurses. It is about being realistic from the get-go, and that partly comes with experience.’

Discreet discussion

Finding the opportunity for the chat can be difficult. ‘When we are having ACP conversations, it takes time,’ Ms Ripley says.

‘In a hospital particularly, finding time and privacy can be difficult, with just the flimsy curtains to pull round the bed. Making sure the right people are around for the conversation is also important as a lot of people don’t have full mental capacity, or are really poorly.’

Macmillan Cancer Support guidance on ACPs urges staff to be honest, not give false reassurance, and not to avoid ACP conversations for fear of upsetting patients. The charity says some patients give cues that they are ready to start while others may need a prompt such as: ‘Many people at times like this want to discuss the future,’

Other sources

Nursing Standard/Marie Curie end of life care survey
rcni.com/marie-curie-2019
RCN information on end of life care
tinyurl.com/end-of-life-RCN
Macmillan Cancer Support: Let’s talk about death
tinyurl.com/macmillan-death