Royal College
of Physicians

Mythbusters

Palliative care

Many myths exist about care at the end of life that can add to the complexity of delivering care. Here we recount the main ones and provide responses that may be helpful for your own knowledge and in talking about dying with patients, carers, families and friends. These responses originally appeared in our 2018 report, *Talking about dying*.

‘Palliative care means that time is up’

Palliative care is about maximising quality of life when time is limited. It’s not just for when a person is close to death; it can be given earlier, even from diagnosis. It can be a change in focus, or exist in parallel with disease-targeted treatments. It can help with symptom control, psychological support and practical issues, and help patients to understand their illness better.

‘A ceiling of treatment has an implication on a patient’s individual worth’

Setting a ceiling of treatment is not a value judgement on a patient’s worth as a person. It is based on the likelihood that the intervention will achieve the intended outcome, that that outcome is acceptable to the patient and the patient feels the burden of treatment is worthwhile. This needs to be discussed sensitively with the patient and their loved ones to avoid misunderstandings. Less treatment at this point should go hand in hand with more care.

‘We should avoid mentioning death to acutely unwell patients’

Explaining to a patient and family that the patient is ‘sick enough to die’ won’t make them sicker, but it will enable everyone to understand the gravity of the situation and to respond appropriately.

‘People, patients and healthcare professionals do not want to talk about death’

Confronting one’s own mortality can be difficult. However, when supported, many people do want to talk about death. Disclosing a diagnosis of a terminal illness could help patients to feel more empowered about care and decision making, rather than diminish their hope.

‘Doctors can give precise prognoses when pushed’

If a patient is sick enough to die, you do not have to be sure of a timeframe to initiate the conversation.

Healthcare professionals can only give an indicative range of life expectancies. It is more helpful to give a timeframe of ‘many months’, ‘weeks to months’, ‘only a few weeks’, ‘could be as short as days or as long as a couple of weeks’, and to avoid numerical answers. A more precise prognosis is almost always wrong, and mistakes can be harmful.

‘Every patient who is dying should be made aware’

Everyone will have their own individual preferences. For many people, talking about death remains taboo. Healthcare professionals need to respect this while offering patients the opportunity to discuss their future.

‘Clinicians know what patients want without asking them’

Healthcare professionals sometimes assume that a patient will not want further aggressive intervention. However, while clinicians may be better placed than others to judge prognosis, illness trajectory or success rates of possible treatments, they cannot possibly know a patient’s individual priorities without asking.

‘Plans made in advance are binding’

People can and do change their minds about their priorities, including preferred place of death. Equally, a small but significant proportion of patients who are thought to be dying do improve.

Advance care planning is a process by which future care is negotiated and recorded in anticipation of future loss of mental capacity. As long as the patient has mental capacity, their contemporaneous wishes override any prior wishes they may have stated.

Advance decisions to refuse treatment (ADRTs) are legally binding if the patient has lost mental capacity and the ADRT is valid and applicable to the current situation.

Statements of wishes are not legally binding, but they do provide a useful guide to the patient's priorities and preferences if they are too acutely unwell to discuss or have lost mental capacity.

'Opioids are addictive and shorten life'

Correct opioid use at the end of life does not shorten life, but uncontrolled pain can. Opioid drugs are safe and effective for cancer pain management and to relieve other symptoms associated with cancer and non-malignant diseases. Opioid abuse and addiction are rare in people with advanced illness when prescribed under close medical supervision.

'Sedation shortens life'

Side effects of sedative drugs may include impairment of safe swallowing, reduced respiratory drive and reduced ability to eat and drink.

Rarely, dying patients may experience distress when symptoms cannot be controlled despite expert palliative care advice. In these circumstances, some patients may require sedating medication to diminish awareness of their suffering. If medication is sedating in its effect, the dose should be monitored to ensure that it is the minimum required to relieve distress. Medication used in this way does not shorten life.

'Hydration is inappropriate at the end of life'

The hydration status of all patients at the end of life should be assessed and reviewed regularly. Those who can take nutrition and hydration orally should be encouraged and assisted to do so. However, it is a natural part of dying and preterminal deterioration for people to lose interest in food and fluids.

For more information on clinically assisted nutrition and hydration, please see our 2021 guidance: *Supporting people who have eating and drinking difficulties*, available at www.rcplondon.ac.uk/projects/outputs/supporting-people-who-have-eating-and-drinking-difficulties

'Patients don't want to die in hospital'

Preferred place of death can be different for everyone. Many patients do want to be at home, but there are some who want to be in hospital when they die. Faced with the reality, people often only realise that death is close once they or a loved one is in hospital, and they often choose to stay when offered alternatives. Death at home can provide familiarity, dignity and comfort in some cases, but it can also create anxiety and challenges depending on what community resources are available.

'If healthcare professionals support patients to remain at home for end of life care, they put themselves at higher risk from the CQC, GMC or NMC'

If a healthcare professional can demonstrate that good end of life care, tailored to the patient's needs and requests, has been discussed and provided, there should not be a problem in the patient remaining at home for the end of their life. Recording and documenting preferences of plans made in advance is important, as conveyance to hospital is often emergency responders' default course of action.

More information

For more information about end of life care, please visit www.rcplondon.ac.uk/projects/outputs/talking-about-dying-2021-how-begin-honest-conversations-about-what-lies-ahead. There you can also find recommendations for physicians and our full *Talking about dying report* (2018), which includes case studies and references. If you have any questions or comments, please contact us via policy@rcp.ac.uk.