

Treatment and care towards the end of life: good practice in decision making

New guidance from the General Medical Council supports doctors in making challenging and complex decisions about care at the end of patients' lives.

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Patients who are approaching the end of their life need high-quality treatment and care that supports them to live as well as possible until they die and assures their dignity in the dying process.

In the last few years, there have been significant developments and improvements in care for patients nearing the end of life. These have been led and supported through government and professional strategies across the UK. Nonetheless, we know that end-of-life care continues to raise emotional, practical and ethical challenges for the healthcare team. These include difficult discussions with patients and their relatives, uncertainties about the benefits and burdens of treatments, and managing care provided across a range of settings.

The General Medical Council (GMC) has revised and updated earlier guidance and produced a new booklet of advice to help doctors and other healthcare professionals navigate the complex ethical principles that help them make decisions at the end of life and provide better care to patients.¹

This guidance complements the end-of-life care strategies, pathways and programmes that are being developed across the UK and the clinical advice provided by professional bodies, such as the medical Royal Colleges and the National Council for Palliative Care.² It is designed to provide a framework of principles on which good care can be founded and to be used as the basis of decision making when difficult choices have to be made. The guidance is based on five key principles.

1. Equalities and human rights: patients who are approaching the end of life are entitled to receive the same quality of care as all other patients. All patients, and those close to them, must be treated with dignity, respect and compassion. Their individual needs must be considered and, wherever possible, met.

2. Presumption in favour of prolonging life: clinicians making decisions about potentially life-prolonging

treatment must start from a presumption in favour of prolonging life; their decisions must not be motivated by a desire to bring about the patient's death. However, there is no absolute obligation to prolong life irrespective of the consequences for the patient and irrespective of the patient's views.

3. Presumption of capacity: clinicians must work on the presumption that every adult patient has the capacity to make decisions about their care and treatment. Where a patient's capacity is clearly impaired, clinicians must make an assessment of whether the patient is able to make the particular decision in question.

4. Maximising capacity: if a patient's capacity to make a decision may be impaired, clinicians must provide the patient with all appropriate help and support to maximise their ability to understand, retain, use or weigh up the information needed to make that decision or communicate their wishes.

5. Overall benefit: if an adult patient lacks capacity to decide, the decisions clinicians make on the patient's behalf must be of overall benefit to the patient.

The guidance provides two decision-making models: one for adult patients who have capacity to make decisions; and one for patients who lack capacity. These reflect both the ethical principles and the legal requirements across the UK. In particular, they emphasise the need for working in partnership – with the patient, where possible, with the patient's family and carers, and with the wider healthcare team.

Update

The 2002 guidance focused on withholding and withdrawing treatment. This guidance takes a broader approach to the care of patients in their last year of life.

This means that the GMC has included new or expanded guidance on:

- Assessing overall benefits
- Acting on advance refusals or requests for treatment
- Advance care planning with the patient
- Diagnosing dying and dealing with other clinical uncertainties
- Working with and supporting family and others close to a patient, both while the patient is ill and after their death
- Working effectively within multidisciplinary teams and across service boundaries
- Decisions to withdraw, or not to start, nutrition and hydration provided by tube or drip
- Making and discussing decisions about whether to attempt cardiopulmonary resuscitation
- Discussing the possibility of organ or tissue donation.

On its website, the GMC has published a flowchart that shows the decision-making path for patients who lack capacity. It illustrates some of the key points along the path with short vignettes describing the issues that are raised. There are also links back to the guidance. The GMC has also published two longer case studies – on deciding whether to provide nutrition or hydration by tube or drip; and on when and how to make a “Do not attempt cardiopulmonary resuscitation” (DNACPR) decision. These are published alongside the guidance on the GMC website.

The guidance cannot provide answers to specific questions or tell doctors what to do. Good care involves making judgments about the specific needs of the individual patient; it is not about following rigid rules. The guidance can help clinicians by providing a framework of ethical principles, some guidance on what the law requires, and advice about how the guidance applies in particularly difficult areas, such as CPR (box 3).

Patients’ views

Before the guidance was revised, the GMC conducted a wide consultation of patients’ views (box 1), with a particular focus on older people and people with disabilities. Not surprisingly, perhaps, the key issues that emerged for these groups were that they wanted to:

- End life without distressing symptoms (in particular, pain)
- Make decisions and stay in control of their lives
- Avoid discrimination – older people, or people with disabilities, were afraid that they would not be given

Box 1: Consultation facts¹

- We received 529 consultation responses — 215 for the long questionnaire and 314 for the short questionnaire
- 22% of the responses to the short questionnaire were from individual doctors
- 33% of the long questionnaire responses were from individual doctors
- We held 20 consultation events across the UK, including a major conference
- Over 600 people attended the consultation events, including members of the public from hard to reach groups, doctors, nurses, ambulance staff, and managers.

CPR or other life-prolonging treatment because of assumptions about their quality of life.

Addressing all these issues depends on good communication – a theme that emerged repeatedly in our work with doctors, nurses, paramedics, patients and their families and carers. Understanding how patients’ needs can be met relies not just on a good clinical assessment, but also an understanding of their wishes and preferences, as well as their fears and concerns. The guidance emphasises the importance of advance care planning – not as a one-off event, but as a process of decision making as the patient comes to terms with a diagnosis and the onset of symptoms.

Good communication is also key in dealing with problems relating to CPR. Some patients, including the elderly, may have misconceptions about the effectiveness of CPR in cases where a patient has a poor prognosis as a result of cancer or other disease or condition. They may, therefore, see decisions not to provide CPR, and in particular, an advance DNACPR decision, as discriminatory, based on their age or their perceived quality of life.

Discussions with the patient about the issues and the realities of what CPR involves, and its probable outcome, can provide a way of reaching a resolution. But not all patients will want to have such discussions. In cases where it is clear that CPR will not work, raising the possibility of providing CPR, only to say that it is not appropriate, may do more harm than good. The guidance addresses these problems and also considers the role of carers and family members, particular where the patient is at home.

Good communication with colleagues in the wider health and care teams can also significantly improve patient care. Patients’ and professionals’ experiences showed that when patients’ wishes are known and shared

Box 2: Case study: an example of good end-of-life care

Mr Wu, who is 73 years old, was diagnosed 18 months ago with pulmonary fibrosis, after developing a dry cough and breathlessness.

His symptoms worsened and tests showed his lung function had deteriorated. He started to need regular hospital admissions. He told his general practitioner (GP) that he was tired of "going back and forth" from hospital and preferred to be at home with his family, but knew that his wife found it very distressing when he could not breathe and that his care was taking its toll on her.

His GP helped to put a care package in place that helped with his washing and dressing. The GP, community matron, and the community palliative care team provided support to enable him to stay at home.

During a recent home visit from his GP, Mr Wu asked frankly how long he had left to live and Dr Reagan (his GP) explained it was probably a matter of days to weeks. With Mr Wu's agreement, the community team placed his name on their end-of-life care register, recording his strong wish to die at home surrounded by his family if that was at all possible.

Days later, at 8 pm on a Sunday evening, Mr Wu became quite distressed. He took large doses of medication for his breathlessness and pain, but continued to call for help and became quite confused. Mrs Wu called the out of hours (OOH) service who suggested calling an ambulance but, on Mrs Wu's insistence, agreed that Dr Singh (the OOH GP) would visit. Dr Singh found Mr Wu to be distressed by breathlessness and unable to communicate. He measured Mr Wu's oxygen saturation and concluded that he needed to be admitted to hospital. Mrs Wu explained that if her husband was going to die, she knew he would prefer to be at home with her. She was clearly upset and the OOH service advised Dr Singh that there was a note on Mr Wu's file saying he had a strong preference to die at home.

Dr Singh discussed the options with Mrs Wu. He explained that in hospital, they would be likely to be able control his symptoms more quickly and it might be possible to stabilise his condition and allow him to return home. However, he understood Mr Wu's preference to be at home and he could seek advice and support from the palliative care team about how to manage the pain and breathlessness and allow Mr Wu to die at home. He explained that since Mr Wu could not communicate his present wishes, he needed to make a decision and felt that, on balance, it would be best to try to care for Mr Wu at home. Mr Wu's daughter arrived to support her family, and Dr Singh phoned the OOH palliative care team for further advice and to arrange for the team to attend.

GMC guidance — what it recommends:

- Starting with the presumption that Mr Wu has capacity to make the decision in question, he should be helped to understand his prognosis and the options for treatment and care (Paragraphs 11, 14)
- Advance care planning should be in place to encourage and support Mr Wu to think about what he might want to happen as his condition progresses, including his preferred place of care (paragraphs 52-57)
- Mr Wu's wishes and preferences should be recorded and communicated to others involved in his care (paragraphs 61, 75-76)
- Mrs Wu should be involved and supported; this should include sharing relevant information (using local systems) and working in partnership with the health and social care teams to provide effective care at home for Mr Wu (paragraphs 17-21, 22-23, 75-77)
- When Mr Wu lacks capacity to communicate his current wishes, taking account of the views of his wife and other information about his wishes and preferences, the treating healthcare professional should make a decision about what treatment and care that would be of overall benefit to Mr Wu (paragraphs 12 13, 15-16, 24-26, 40-43).

This case study is a fictional account to illustrate the typical issues that occur with end-of-life care and how to deliver good end-of-life care.

Box 3: What the guidance does and does not provide

Does provide

- Advice on the ethical and legal principles that underpin good care
- Guidance on how to put these principles into practice in areas such as CPR, nutrition and hydration by tube or drip
- Advice on working in partnership with patients, involving families and carers, working in teams, and consulting colleagues
- Vignettes and case studies. Links to guidance from a wide range of advice from speciality organisations and government.

Does not provide

- Advice on euthanasia and assisted suicide. These activities are illegal
- Rules about how to deal with specific circumstances
- Legal advice — but the guidance is consistent with the law across the UK
- Clinical advice

with all those contributing to the patient's care, the patient's needs can be more readily met. In Box 2, a typical case study is presented.

Conclusion

This guidance is based on long-established ethical principles, which include doctors' obligations to show respect for human life; to protect the health of patients; to treat patients with respect and dignity, and to make the care of their patients their first concern. It is not, and cannot be, exhaustive. It should however help doctors to make complex decisions when treating patients who are nearing the end of life. The guidance highlights the vital importance of good communication between doctors, patients and their families as well as between members of the healthcare team. Good communication is central to understanding and meeting patients' needs, to respecting their values and beliefs, and to supporting their families and carers.

References

1. General Medical Council. Treatment and care towards the end of life: good practice in decision making. <http://bit.ly/d3gzt5> (accessed 1 November 2010)
2. General Medical Council. End-of-life care references. <http://bit.ly/bslM5l> (accessed 1 November 2010)