

End-of-life care

Providing high quality care to patients reaching the end of their life is an important part of the role of healthcare professionals. It is important to have the skills, knowledge and confidence to support patients and those close to them at this difficult time. General Medical Council (GMC) guidance ***Treatment and care towards the end of life: good practice in decision making*** provides valuable advice.

<https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life>

Basic considerations

Identifying patients

It is important to ensure that patients approaching the end of life are identified promptly to allow time for crucial discussions around treatment planning. The GMC guidance treats a patient as approaching the end of their life if “they are likely to die within the next 12 months”. This includes patients whose death is imminent (expected within a few hours or days) and patients with advanced, progressive incurable conditions, those who have existing conditions which may cause an acute deterioration and those with general frailty. It also includes patients with life-threatening acute conditions caused by sudden catastrophic events. Multi-disciplinary team meeting discussions can be beneficial in identifying patients who should be treated as approaching the end of life. There are also a number of helpful resources available, such as the Gold Standards Framework prognostic indicator guidance and the Supportive and Palliative Care Indicators Tool.

Difficult conversations

Talking about death can be distressing, but it is important that patients are given the opportunity to make their wishes known and that they have the necessary information to make decisions about their current and future care.

Discussions should be open and honest but sensitive to the needs and preferences of the patient and those close to them. Provide information at a pace and time that is appropriate for each person.

Support patients in understanding as much as they want to know about their diagnosis and prognosis. This includes exploring all appropriate available options, including the likely benefits, burdens and risks.

Consider also other aspects of a patient’s care, such as cultural issues, and support for mental health, social and spiritual matters. Take time to understand the patient’s wishes and concerns, as well as any beliefs or values that might influence their wishes.

When patients and those close to them are distressed, they may find it more difficult to take information in. Take steps to address this, for example by repeating information as necessary, checking how much has been understood and allowing time for what has been discussed to sink in. Those close to a patient can play a key role in making decisions about care, where the patient consents or where a proxy decision maker has been appointed in advance, and they should be supported to do so.

Clinicians should also respect the wishes of patients who do not want to have a difficult conversation straight away. In such cases it may be appropriate to delay the discussion until a more appropriate time. If a patient consistently declines to discuss their treatment, the clinician should make it clear that basic information must be provided in order for the patient to consent to any proposed intervention.

Patients need only be provided with information about options which the clinician considers to be clinically appropriate for their circumstances. Where a patient requests an intervention that is not considered clinically appropriate, explore it further with them and, where appropriate, the wider team. If it is subsequently decided not to provide this intervention, the patient should be advised of their right to seek a second opinion. This process should be clearly documented

Planning ahead

Anticipating and planning for future care needs can prevent delays and help ensure the patient receives care that is in line with their wishes. At the appropriate time, it is important to discuss interventions which may be considered in the event of an acute deterioration. This might include CPR, ventilation, clinically assisted nutrition or hydration and antibiotics for life-threatening infections. It is beneficial to know a patient's wishes before these interventions are required, whilst acknowledging that a patient cannot demand interventions which the clinical team deem to be inappropriate.

Preparing for the final stages of a patient's illness includes considering a potential loss of mental capacity. If this is a possibility, patients should be encouraged to think about how they would wish to proceed in such circumstances. They may wish to consider appointing a proxy decision maker (such as a lasting power of attorney or welfare power of attorney), or making legally binding advance decisions to refuse particular interventions. Confirm whether the patient wishes such information to be shared with those close to them, both now and in the event that they lose capacity in the future.

CPR

Discussing and making decisions regarding CPR can be particularly challenging. The GMC states that, whenever a cardiac or respiratory arrest is expected as part of the dying process and CPR will not be successful, making a decision in advance not to attempt CPR will help ensure a patient dies in a dignified and peaceful way.

In considering whether CPR will be successful, the benefits of prolonging life must be weighed against the potential risks and burdens. The GMC emphasises that this is not solely a clinical decision. Be sure to bear in mind that recent case law underlined the need for doctors to discuss resuscitation decisions with the patient (or with those who have an interest in the patient's welfare where the patient lacks capacity), unless they do not want such a discussion / it would cause serious harm. Clinicians need to explain the burdens and risks of CPR interventions, including the likely outcomes if CPR is successful, and take account of the patient's wishes and preferences.

When it is clinically judged that CPR will not be successful and should not be attempted, the GMC advises clinicians to consider carefully whether it is necessary or appropriate to tell the patient that a DNACPR decision has been made.

All discussions around CPR decisions should be clearly documented, including the reasons for any decision made. Any decision NOT to have such a discussion with the patient (because they indicated a wish to avoid it or you deemed it inappropriate) should also be noted in the records.

The GMC guidance contains further advice on these complex issues, including how to address disagreements, particularly where the benefits, burdens and risks are finely balanced. There is also helpful joint guidance available from the Resuscitation Council, British Medical Association and Royal College of Nursing.

Recording and sharing plans

The GMC states that all advance planning discussions and decisions should be recorded in a patient's notes. There are national and local templates for recording advance care planning and CPR decisions, such as the ReSPECT form.

It is recommended that patients keep a copy of their advance care plan and it is shared, with the patient's consent, with other healthcare professionals involved in their care, including emergency services such as out-of-hours and ambulance services. Keeping a record of who this information has been shared with will help ensure it is appropriately updated in the event of any changes.

Although an advance care plan is not legally binding in itself, it is an important reference document for those involved in the patient's care and improves continuity. Any advance decision or directive to refuse treatment made by the patient may be legally binding, once a patient loses capacity, if it is valid and applicable to the patient's current circumstances.

Common pitfalls

Complaints regarding end-of-life care provided are common. A 2015 report from the Parliamentary and Health Service Ombudsman in England found some recurring concerns:

- not recognising that a patient is dying. This inevitably means their care cannot be adequately planned or co-ordinated
- poor symptom control
- poor communication – in particular with regard to being open and honest with patients and their families
- inadequate services outside normal working hours
- poor care planning
- delays in diagnosis and referrals for treatment.

PHSO's report - *Dying without dignity* 2015

https://www.ombudsman.org.uk/sites/default/files/Dying_without_dignity.pdf

Key points

- timely identification of people who are reaching the end of their life is central to providing effective care and support
- achieving high quality care at the end of life depends on good communication with the patient, those close to them and other healthcare professionals
- anticipating and planning for future events is key to ensuring a patient's wishes are given appropriate consideration.

MDDUS often provides advice and assistance to healthcare professionals in relation to end-of-life care issues. You can contact a medical adviser via our website.

www.mddus.com, by email at advice@mddus.com or by phoning the advice line on 0333 043 4444

MDDUS resource hyperlinks:

<https://www.mddus.com/training-and-cpd/training-for-members/video-presentations>

Other useful guidance:

[GMC guidance: Decision making and consent](#)

[Gold standards prognostic indicators](#)

[Supportive and palliative care indicators tool from NHS Scotland](#)

[Joint Resuscitation Council/BMA/RCN guidance on CPR](#)

[ReSPECT](#)