Legal issues in end-of-life care 1: the adult patient

End-of-life care is intrinsic to the work of many nurses, and although their first experiences of death and dying may have been difficult, they will have developed strategies for managing some of the issues associated with the care of dying patients. However, although they may have developed practical expertise, end-of-life care may still raise challenges around difficult decisions, such as withdrawing or withholding active treatment. When faced with such challenges, it is imperative for nurses to practise not only in accordance with the Nursing and Midwifery Council code (NMC, 2015) but also within “agreed professional, ethical and legal frameworks” (NMC, 2014). This article discusses the legal requirements relating to consent and decision-making in adults at the end of life.

Challenges at the end of life
No two patient deaths are the same. Patients may die in circumstances that are unexpected, shocking and tragic, while for others, death brings with it relief from a time of great suffering. However, regardless of the context, end-of-life care may raise legal, ethical and moral concerns. For example, nurses may question the appropriateness of administering opioid analgesics or sedation if they think that, in addition to having the desired palliative effect, these may also act as respiratory depressants and hasten the patient’s death; or they may question the appropriateness of withdrawing or withholding active treatment, such as antibiotics or clinically assisted nutrition and hydration.

A focus on individualised care
In 2012–13, the Liverpool Pathway for the Dying Patient (LCP), an end-of-life care protocol widely used at the time in UK hospitals, received negative media attention and was heavily criticised by professionals and the public alike – see for example Stanford (2012) and Boseley (2013). The storm around the LCP was useful in that it raised awareness of, and stimulated debate on, issues such as the withdrawal of clinically assisted nutrition and hydration. It culminated in an independent review, following which, the LCP was phased out.
Clinical Practice

Review


Since then, there has been a move away from generalised care protocols towards more individualised care planning that “reflect[s] the needs and preferences of the dying person and those who are important to them” (Leadership Alliance for the Care of Dying People, 2014).

In 2014, the LCP was replaced by One Chance to Get It Right, which focuses on individualised care planning informed by the wishes and preferences of the patient (Taylor, 2017; LACDP, 2014). Clinical guidance is provided by a revised National Institute for Health and Care Excellence quality standard on end-of-life care for adults (NICE, 2017).

Recent initiatives such as the AMBER care bundle (Guy’s and St Thomas’ Foundation Trust, 2017) and the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) (ReSPECT Working Group, 2017) exemplify the importance placed on forward planning (also called advance care planning) as the basis for gold standard end-of-life care.

Talking about death

Individualised, person-centred end-of-life care can only be achieved with knowledge and understanding of the patient’s wishes and preferences. This means talking about death, a subject that, even in the 21st century, some people still regard as taboo and are unwilling to discuss. Even when patients are willing to discuss their impending death, their condition may have already deteriorated to such a point that they are no longer able to engage in decision-making.

Historically, people tended to die in their own home, cared for by their families, and death was an accepted and normal part of life. This is no longer the case in contemporary British society, where death is often shrouded in mystery, misapprehension and fear (Taylor, 2015).

Most people (around 80%) die in a hospital, hospice or other care settings (Gomes et al, 2012) – although increasing numbers of people are achieving their wish to die in their own home. People may be reluctant to accept their approaching death, and to make plans for it (Department of Health, 2008).

Although nurses know that discussing death may cause distress, they also know that it is both good practice and generally a legal requirement to obtain the patient’s consent before proceeding with any treatment. However, as the patient’s condition deteriorates, they may no longer have mental capacity to consent to treatment, maybe because they are unconscious or otherwise cognitively impaired, or because they are no longer able to communicate their wishes (Taylor, 2014a). It is important that nurses understand how this might affect decisions about the patient’s care.

Mental Capacity Act

Historically, there was no clear legal framework for administering care to patients unable to consent to treatment, and no definitive criteria for taking their wishes and preferences into account.

The 2005 Mental Capacity Act (MCA, 2005), which came into force in England and Wales in 2007, provides a statutory framework for decision-making when there is reason to question an individual’s capacity to make decisions. In addition to providing a legal basis for patients who want to make an advance decision to refuse treatment (ADRT), it also sets out a framework for decision-making on behalf of patients who lack capacity, including lasting power of attorney (LPA) and court-appointed deputies.

According to DH guidance, consent will only be valid if all three of the following conditions are fulfilled:

- The patient has mental capacity to make decisions about their care? Although this will depend on the type of decision being made (Taylor, 2014b), it will generally be the responsibility of the person who will make the decision on the patient’s behalf if they are found to lack capacity.
- The patient has been informed of, and given the opportunity to weigh up, the risks and benefits associated with a particular intervention;
- Consent has been given voluntarily (DH, 2009).

The MCA specifies that “a person must be assumed to have capacity unless it is established that he lacks capacity”. It also sets out how to manage situations where the patient has permanently or temporarily lost capacity to make a decision. It has introduced a number of ways of authorising treatment for patients lacking decision-making capacity and has established a statutory obligation to take patients’ preferences into account when making decisions on their behalf. There are a number of options available if, after completing the two-stage test set out in sections 2 and 3 of the act, the patient is found to lack capacity.

Emergency situations

Even in emergency situations, the law requires the patient’s consent before the treatment can go ahead. However, there are exceptions:

- The patient lacks mental capacity to give consent;
- The patient has given authority to consent to the treatment through an LPA;
- The patient has given no previous indication – for example, verbally or in a valid ADRT – that they would refuse the treatment.

“In these circumstances, treatment may lawfully go ahead without the patient’s consent, providing that the treatment is in the patient’s best interests and is immediately necessary to save life or avoid significant deterioration in the patient’s health” (British Medical Association, 2016).

If a patient has appointed a welfare attorney, or if there is a court-appointed deputy or guardian, that person, where practicable, must be consulted about treatment decisions (BMA, 2016).

Who should assess mental capacity?

Who should assess the patient’s mental capacity to make decisions about their care? Although this will depend on the type of decision being made (Taylor, 2014b), it will generally be the responsibility of the person who will make the decision on the patient’s behalf if they are found to lack capacity.

For daily personal care and routine interventions, this would usually be the nurse planning to deliver the care (Ruck Keene et al, 2014; Taylor, 2014b; Department for Constitutional Affairs, 2007). However, when it comes to more complex end-of-life care decisions, such as withdrawing life-sustaining treatment, it may be necessary to apply to the Court of Protection, first to decide whether or not the person has capacity to make that decision and, if not, whether the care proposed by the clinical team would be in the person’s best interests (Ruck Keene et al, 2014).

It is important to be aware that, according to the MCA, the assessment of capacity is decision-specific. Simply because an individual lacks capacity to make one decision – perhaps whether to take antibiotic treatment for a chest...
Clinical Practice

Review

infection – it cannot be assumed that they will lack capacity to make other decisions – such as whether or not to take a bath. Also, capacity may fluctuate: even if a patient lacks capacity to make a decision at a particular time, it does not follow that they will never again have that capacity.

Advance decisions

The AMBER care bundle and ReSPECT emphasise the importance of clinicians working collaboratively with patients to determine patients’ wishes and preferences in advance of a care crisis or before the point where patients are no longer able to actively participate in decision-making.

However, these discussions may not take place for a number of reasons: the patient may be reluctant to discuss and make plans for their forthcoming death; the health professional may be unwilling to pursue the matter; there may be no time to consult the patient if, for example, they have sustained a traumatic brain injury or a catastrophic stroke.

In these circumstances, there are a number of ways in which decisions can be made on behalf of patients. Patients may have already set out their wishes and preferences when they still had capacity to do so, either in an informal advance statement of wishes (House of Commons Health Committee, 2015) or in a more formal, written ADRT (see sections 24–26 of the MCA).

As explained by the DCA (2007) and in Taylor (2017), an ADRT will only be valid if it meets the following conditions:

● It must have been made by a person over the age of 18 who had mental capacity to make the decision at the time it was made;
● It must set out and clearly specify the treatments or interventions the person refuses, and the circumstances in which they refuse them;
● If it refers to any form of life-sustaining treatment, it must be made in writing; be signed and witnessed; and clearly state that the decision stands even if the person’s life is at risk.

Providing that practitioners “reasonably believe” the ADRT is valid (MCA, 2005), they should respect the patient’s wishes by not administering the specified treatment or intervention. They would be acting unlawfully if they failed to comply with the directive (Lay, 2017). An ADRT is exactly that: a mechanism for patients to specify treatments they do not wish to receive in defined circumstances at some point in the future – as opposed to making an advance request for treatment (Bit.ly/BurkeCase).

Although some recent cases (such as Bit.ly/SalfordRoyalCase) have shown that the courts take a range of evidence into account when making decisions about withdrawal of life-sustaining treatment, the absence of a valid ADRT may present difficulties in practice – particularly where there is disagreement between clinicians and other parties. In these situations, an application to the court may be necessary. Legal advice should be sought before taking any further action (General Medical Council, 2010).

Lasting power of attorney

The MCA allows an adult – the ‘donor’ – to give to one or more people – the ‘attorney(s)’ – authority to make decisions on their behalf should they lack mental capacity to make decisions themselves. This is called an LPA.

There are two types of LPA: one for health and welfare, and one for property and financial affairs. It is possible to set up only one type of LPA, but only a health and welfare LPA will enable the attorney(s) to make health and care decisions on behalf of the person. Ideally, patients will have discussed their wishes and preferences with their attorney(s) beforehand (Taylor, 2017).

The attorney will have the same right to refuse or consent to treatment that the donor would have if they had capacity to make that decision, but this right will only come into force once the donor has lost capacity (DCA, 2007). Generally, a health and welfare LPA enables the attorney to refuse or accept treatment unless it specifically states that the donor does not want those decisions to be made by their attorney (DCA, 2007).

If the patient has made a relevant and valid ADRT after appointing an LPA, the attorney will not have authority to refuse or consent to the treatment mentioned in that ADRT. However, if an LPA gives the attorney authority to make decisions regarding life-sustaining treatment included in an ADRT that pre-exists the LPA, the attorney may choose not to adhere to the ADRT if it is no longer in the patient’s best interests.

Unless the LPA specifically gives the attorney the right to make decisions about life-sustaining treatment, the attorney will not have authority to refuse or consent to this type of treatment (DCA, 2007).

Care needs to be taken to ascertain whether a relevant and valid ADRT exists. Nurses will need to have access to the LPA documentation. They will also need to seek advice if there is any uncertainty about the scope and validity of the LPA. Any concerns they may have about a decision made under an LPA that they do not think is in the patient’s best interests should be reported to the Office of the Public Guardian (Bit.ly/OPGReportConcern).

Court-appointed deputy

If a person loses decision-making capacity before they are able to make an LPA, the MCA authorises the Court of Protection to appoint a family member, a local authority or a professional (such as an accountant or solicitor) as a deputy, with authority to make decisions on behalf of the person. The deputy will have a defined role in relation to personal welfare and/or property and financial affairs, and the scope of their decision-making will otherwise be the same as that of an attorney (Taylor, 2014a).

In the absence of LPA, ADRT or court-appointed deputy

If the patient has not made an ADRT or set up an LPA, and the Court of Protection has not appointed a deputy, health professionals may still make decisions about the patient’s care, either to administer or abstain from administering particular interventions, providing these are in the patient’s best interests (MCA, 2005).

Section 5 of the MCA gives legal
authority to carers – both formal and informal – to administer “care” or “treatment” if the patient lacks capacity to give consent. The MCA does not define “care” or “treatment”, but the MCA Code of Practice (DCA, 2007) specifies that these “should be given their normal meaning ... [and] that treatment includes diagnostic or other procedures”. Assisting with personal hygiene, inserting a urinary catheter, administering intravenous fluids, applying dressings and conducting minor surgical procedures are examples of interventions that might fall within the remit of section 5 (Taylor, 2014a; DCA, 2007).

Although there is evidence that immunity from section 5 of the MCA may apply to major decisions – such as withholding or withdrawing clinically assisted nutrition and hydration (the third article in this series will explore this in more detail) – it is important that practitioners obtain further guidance when considering such interventions. Obtaining further guidance is especially important if they are unsure whether the planned care fits in with the criteria.

For carers to be protected from any liability that would arise from treating patients without their consent, they must first take “reasonable steps” to establish that the patient lacks capacity to consent to a particular intervention and that this remains the case while the intervention is being delivered (MCA, 2005). They must also “reasonably believe” that the care or treatment is in the patient’s best interests and complies with any ADRT (MCA, 2005).

Even if an LPA or deputy has been appointed, section 5 of the MCA enables nurses to go ahead with some day-to-day care interventions without first getting their consent, provided that the interventions do not conflict, or are otherwise non-compliant, with “the decision of someone who has been authorised to make decisions for a person who lacks capacity to make such decision for themselves” (DCA, 2007). For example, it is unlikely that a nurse would need to obtain consent from an LPA before providing an unconscious patient with oral care, unless the LPA has specifically stated that this would be necessary.

Conclusion

Involving the patient in decision-making about their care is fundamental to the provision of good-quality, person-centred end-of-life care. Ideally, the patient will have been involved in discussions from an early stage to enable them to explore and set out their wishes and preferences. They may choose to make an ADRT or a less formal statement of wishes. They may appoint an LPA to make decisions on their behalf in the event that they are no longer able to make them themselves. However, if a patient has not been able, or did not want, to do any of this, nurses may continue to give them care and treatment providing these are in the person’s best interests and, as far as practiceable, reflects what is known of their wishes and preferences. NT

Box 2. Key legal information for end-of-life care in adults

- An adult patient is presumed to have mental capacity to consent to treatment and health professionals must not proceed with treatment if the patient has not consented to it
- An adult who has decision-making capacity can make a legally enforceable advance decision to refuse treatment (ADRT), even life-sustaining treatment
- An adult with decision-making capacity can appoint a lasting power of attorney (LPA) to make health and welfare decisions on their behalf in the event that they lose capacity
- The nominated attorney of a health and welfare LPA may refuse life-sustaining treatment on the patient’s behalf
- If the patient has made a relevant and valid ADRT after having appointed a health and welfare LPA, the attorney cannot give consent for any treatment included in the ADRT

References


General Medical Council (2010) Treatment and Care Towards the End of Life: Good Practice in Decision Making. Bit.ly/GMCEndLCP


Lay K (2017) NHS pays out £45,000 after woman kept alive against her wishes. The Times. Bit.ly/TimesADRT

Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right. Bit.ly/LACDPOneChance


NCCPC-Guideline-End-of-Life-and-Palliative-Care


For more on this topic online

- Informed consent 1: legal basis and implications for practice Bit.ly/NTConsent1

CLINICAL SERIES

legal issues in end-of-life care series

Part 1: The adult patient Nov 2018

Part 2: The child patient Dec 2018

Part 3: Withdrawing/withholding treatment and assisted suicide Jan 2019

For more articles on end-of-life care, go to nursingtimes.net/clinical-archive/end-of-life-and-palliative-care