Legal issues in end-of-life care 3: difficult decisions

Many nurses will have cared for patients for whom death represents a welcome end to intolerable pain and suffering. If a patient is terminally ill, the view of the patient, family and health professionals may be that life-sustaining treatment is no longer in that patient’s best interests. However, for nurses whose training and practice centre on the preservation of life, the idea of discontinuing active, life-sustaining treatment may be an uncomfortable one. Some elements of end-of-life care may be counterintuitive, and nurses may find it difficult to put to one side their instinctive desire to do all they can to preserve life.

Nurses caring for patients at the end of life may be confronted with ethical and legal concerns. However, for nurses whose training and practice centre on the preservation of life, the idea of discontinuing active, life-sustaining treatment may be an uncomfortable one. Some elements of end-of-life care may be counterintuitive, and nurses may find it difficult to put to one side their instinctive desire to do all they can to preserve life.

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The Court of Protection is the arbiter when there is doubt or disagreement about the discontinuation of treatment. However, for nurses whose training and practice centre on the preservation of life, the idea of discontinuing active, life-sustaining treatment may be an uncomfortable one. Some elements of end-of-life care may be counterintuitive, and nurses may find it difficult to put to one side their instinctive desire to do all they can to preserve life.

In the current legal environment, assisted suicide is unlawful. However, for nurses whose training and practice centre on the preservation of life, the idea of discontinuing active, life-sustaining treatment may be an uncomfortable one. Some elements of end-of-life care may be counterintuitive, and nurses may find it difficult to put to one side their instinctive desire to do all they can to preserve life.

Key points

- Nurses caring for patients at the end of life may be confronted with ethical and legal concerns.
- The courts uphold a patient’s right to refuse potentially life-saving treatment.
- The Court of Protection is the arbiter when there is doubt or disagreement about the discontinuation of treatment.
- In the current legal environment, assisted suicide is unlawful.

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Abstract Nurses caring for patients at the end of life will often be faced with ethical and legal challenges. They may feel uncomfortable, for example, with a decision to discontinue life-sustaining treatment such as clinically assisted nutrition and hydration. They may be reluctant to prescribe opioids for pain relief because they fear it might hasten the patient’s death. They may not know what to do when a patient asks for their help to end their own life. What does the law say on these particularly thorny issues? This third article concludes our series on legal issues in end-of-life care with an exploration of the law and case law relating to the discontinuation of treatment, the principle of double effect, and assisted suicide.

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who has decided that they do not want it, as long as they have the mental capacity to make that decision. Relatives and health professionals must abide by the patient’s decision, even if they disagree with it and even if the outcome is likely to be the patient’s death (Taylor, 2017).

The historic basis for a patient’s right to refuse treatment comes from cases such as Ms T’s (Re T [An Adult: Refusal of Medical Treatment] [1992] 4 All ER 649), in which the court upheld the patient’s right to refuse potentially life-saving treatment. Since then, the principle has been applied in a range of legal cases, either because those around the patient did not agree with the patient’s decision or because health professionals were not certain that the patient had the mental capacity to make that decision.

When a patient does not have capacity

Things become more complicated when the patient does not have the capacity to make decisions; for example, if they are in a persistent vegetative or minimally conscious state. How do you reach decisions regarding the discontinuation or withholding of life-sustaining treatment in such cases?

When parties agree

At present there is some uncertainty over the circumstances in which an application to the Court of Protection would be necessary if there is agreement between health professionals and others (such as a lasting power of attorney [LPA], a court-appointed deputy, family and friends) about withdrawing or withholding CANH from a person who is in a persistent vegetative or minimally conscious state.

In one recent case brought to the Court of Protection (M v A Hospital [2017] EWCOP 19), Mr Justice Jackson explored the evolving law in this area and concluded that, until more definitive guidance is available, a decision to withdraw CANH will generally be lawful as long as doctors follow current professional guidelines, such as those of the General Medical Council (2010) and Royal College of Physicians (2015). In these circumstances, clinicians will be able to rely on the legal immunity provided by Section 5 of the 2005 Mental Capacity Act; this is discussed in more detail in part 1 of this series.

When parties disagree

When parties disagree on the course of action, or when there is uncertainty, an application should be made to the Court of Protection, which will declare whether or not the proposed course of action is in the patient’s best interests.

Establishing best interests involves consideration of the patient’s known wishes and preferences, alongside a balanced evaluation of the risks and benefits of the proposed treatment (Taylor, 2014)—not just the medical, but also the “social and psychological” risks and benefits (Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67). The court will go as far as is reasonable and practicable to take into account what is known of the patient’s wishes.

Court of Protection Declarations

Court of Protection declarations may take a number of forms. They may say, for example:

- The proposed treatment or course of action may go ahead;
- The proposed treatment or course of action may go ahead if certain circumstances arise (for example, health professionals may administer antibiotics should the patient develop a chest infection);
- Clinicians may lawfully discontinue or withhold treatment either at that point in time or at some specified point in the future (for example, doctors may lawfully withhold antibiotic treatment should the patient subsequently develop a chest infection).

When questions relating to the withdrawal of life-sustaining treatment arise, it is the responsibility of the party proposing that treatment is withdrawn to ascertain that this would be in the patient’s best interests (W v M and others [2011] EWHC 2443 Fam). When there is any question of doubt, the matter will “be resolved in favour of the preservation of life”, as ruled in Burke, R (on the application of) v The General Medical Council Rev 1 [2004] EWHC 1879 Admin.

Box 1 outlines a case in which the Court of Protection had to determine whether a patient had capacity in order to decide whether or not treatment should continue or could be withheld.

Withdrawing treatment: the case of Anthony Bland

The House of Lords case Airedale NHS Trust v Bland [1993] AC 789 remains an important source of law relating to discontinuing or withholding life-sustaining treatment. On 15 April 1989, Anthony Bland, who was 17 years old, experienced severe brain injury as a result of oxygen deprivation following serious crush injuries to his chest sustained in what has come to be known as the Hillsborough disaster. More than three years later, he remained in a persistent vegetative state. While he could breathe without assistance, he had no higher-level brain function such as cognitive and sensory awareness. He was dependent on CANH and needed assistance with all bodily functions except breathing.

At that point, both Mr Bland’s family and the health professionals caring for him believed that it was no longer appropriate to continue CANH and that it should be withdrawn to allow Mr Bland to die peacefully and with dignity. The trust asked the Family Division of the High Court to declare that it would be lawful to withdraw CANH, and the court did so.

Box 1. Determining capacity: the case of Ms C

In a recent case, the Court of Protection was asked to determine whether Ms C, who had tried to commit suicide, had mental capacity to make a decision regarding life-preserving renal dialysis. If she was found to have decision-making capacity, her decision to refuse dialysis would have to be respected and she would die as a result.

The court decided that Ms C had the mental capacity to make that decision, given that she had no wish to live with “the prospect of growing old, the fear of living with fewer material possessions and the fear that she has lost, and will not regain, her sparkle”. The court made clear that, although Ms C’s decision could be considered “unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society”, Ms C was “a capacious individual [and], in respect of her own body and mind, sovereign” and that her wishes must therefore be respected (Kings College Hospital NHS Foundation Trust v C & Anor [2015] EWCOP 80).

A patient’s wishes may be communicated by the patient in person; by means of a valid advance decision to refuse treatment (ADRT); or through an LPA (see part 1 of this series). It would be unlawful if the patient’s wishes were not respected, which is illustrated in the case described by Lay (2017).
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Decisions about withdrawing life support may have to be decided by a court of law

However, the official solicitor successfully appealed against the court’s decision, arguing that withdrawing CANH would not only be a criminal act but also breach the trust’s duty of care to Mr Bland. In December 1992, the trust appealed to the House of Lords which, among other issues, considered two key questions:

- Is there a legal requirement to take all possible measures to preserve a patient’s life no matter what the patient’s individual circumstances might be?
- Is there a difference between the withdrawal or withholding of life-sustaining treatment and a deliberate act intended to hasten the patient’s death?

The court of the House of Lords held that, while the general rule must be to act to preserve life, this is not an absolute obligation and, in some circumstances, it would not be in the patient’s best interests to continue “treatment which has the effect of artificially prolonging his life” (Airedale v Bland [1993]). This removed the obligation to use medical means to prolong a patient’s life regardless of the circumstances.

Although the court of the House of Lords established that the law did not differentiate between withholding and withdrawing treatment, it made clear that there was a distinction between withholding or withdrawing life-sustaining treatment and taking active steps to hasten, or bring about, a patient’s death. Lord Goff explained that, while “the former may be lawful, either because the doctor is giving effect to his patient’s wishes by withholding the treatment or care, or even in certain circumstances in which [...] the patient is incapacitated from stating whether or not he gives his consent [...] it is not lawful for a doctor to administer a drug to his patient to bring about his death, even though that course is prompted by a humanitarian desire to end his suffering, however great that suffering may be” (Airedale v Bland [1993]).

Lord Goff went on to dismiss an argument made on behalf of the official solicitor that withdrawing CANH would represent a deliberate act to bring about death in the same way as “cutting a mountaineer’s rope, or severing the air pipe of a deep sea diver” (Airedale v Bland [1993]). Rather than deciding whether deliberate steps could be taken to end the patient’s life, the decision related to whether or not to “continue to provide his patient with medical treatment or care which, if continued, will prolong his life”. The former was, and would continue to be, murder (Airedale v Bland [1993]). This point was subsequently reiterated in cases such as Pretty v UK [2002] ECHR 427 and Nicklinson and Anor R (on the application of) [Rev 1] [2014] UKSC 38.

“Although nurses generally have a duty of care towards their patients, the law recognises that health professionals need to be able to exercise their professional judgement”

**Doctrine of double effect**

In addition to the discontinuation (or withholding) of CANH, there are other treatment decisions that may lawfully have the incidental effect of shortening a patient’s life. A typical example is the administration of medication with the intention of providing palliative relief of pain and other distressing symptoms at the end of life.

There are several reasons why effective symptom control may not be achieved, which may result in the professionals’ duty of care to the patient being compromised (Taylor, 2015). These include the following:

- Sedatives and opioid analgesics, such as morphine, can be effective in the management of pain and other symptoms, such as dyspnoea (Creedon and O’Regan, 2010), but there is evidence to suggest that some health professionals are reluctant to administer such medication because of a fear that patients may become addicted to it (Bass, 2011);
- Patients may be unwilling to take such medication for the same reason (Cowan, 2002);
- Patients may worry that taking these drugs may negatively affect their ability to share meaningful time with their loved ones (Taylor, 2015);
- Health professionals may have concerns about the legal and ethical implications of administering opioids, fearing that they may act as a respiratory depressant and have the incidental effect of hastening the patient’s death (National Institute for Health and Care Excellence, 2012).

Despite these fears, other than in anecdotal reports, there is no conclusive evidence that the administration of sedatives and opioids hastens death (Gallagher, 2010). Even if such evidence did exist, the doctrine of double effect has historically been used to justify this aspect of palliative care (Taylor, 2015).

The double effect legal principle has its basis in ethical theory and has the effect of removing liability in law for an act that is undertaken with good intentions but has an unintended and incidental adverse effect (Williams, 2001). So, for example, it would be ethically and legally justified to administer a drug with the intention of alleviating symptoms even if that drug had the unintended consequence of hastening death. It must be stressed here that the adverse effect must be unintended. If not, the act would likely amount to murder, as outlined by Lord Goff in Airedale v Bland [1993].

**Requests for treatment**

Although nurses generally have a duty of care towards their patients (Cassidy v Ministry of Health [1951] 2 KB 343), the law recognises that health professionals need to be able to exercise their professional judgement. There will be situations when patients ask for a particular treatment or intervention that is not clinically indicated, where there are more appropriate options, or where the intervention requested is one that the health professional “could not conscientiously administer” (Re J (A Minor) (Wardship: Medical Treatment) [1993] Fam 15).

In these circumstances, there is no requirement to comply with the patient’s request. As Lord Phillips MR argued in the case of Burke v General Medical Council (2004), “autonomy and the right of
self-determination do not entitle the patient to insist on receiving a particular medical treatment regardless of the nature of the treatment. Insofar as a doctor has a legal obligation to provide treatment this cannot be founded simply upon the fact that the patient demands it. This means that, even if a patient asks for it, nurses are under no obligation to provide a treatment that they do not believe to be clinically indicated. This has particular relevance in end-of-life care, when patients’ requests may pose significant challenges; for example, if they ask a nurse to help them bring about, or hasten, their death.

**Assisted suicide**

When the Suicide Act (1961) came into force, it was no longer unlawful for people to either take, or attempt to take, their own life. However, helping someone to end their life remains a crime. This is made clear by Section 2 of the Suicide Act, which states that: “[a] person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be liable on conviction on indictment to imprisonment for a term not exceeding fourteen years”.

The legislation on assisted suicide (or euthanasia as it is widely known) is regularly challenged, often on the basis that the prohibition of assistance set out in the Suicide Act (1961) is incompatible with an individual’s rights set out in the European Convention on Human Rights (ECHR) (1950) and enshrined in the Human Rights Act (1998). As an example, in the case of Pretty v UK [2002] ECHR 427, it was argued that the Suicide Act (1961) breached a person’s right to protection from state-inflicted degradation and torture under Article 3 of the ECHR; another argument put forward was that the right to life set out in Article 2 of the ECHR meant that as well as having the right to choose to live, a person also has the right to choose to die. Neither of these arguments were successful.

**Case of Noel Conway**

Noel Conway’s case (R (Conway) v Secretary of State for Justice [2017] EWHC 2447 (Admin)) is more recent. At the time of the judicial review, Mr Conway was a 67-year-old man who had motor neurone disease, together with a survival prognosis of less than six months. Mr Conway wanted help to end his life and argued that Section 2 of the Suicide Act (1961) was incompatible with his right to a “private and family life” conferred by Article 8 of the ECHR.

It had been suggested that Mr Conway might choose to end his life by asking to have his non-invasive ventilation removed and, in turn, receive only palliative care. This would have been lawful, as Mr Conway had the mental capacity to refuse the ongoing administration of this medical intervention. However, Mr Conway did not consider this option to be acceptable, as he wanted to be able to end his life at a time of his choosing by self-ingesting a medication prescribed by a health professional. He did not consider that ending his life by any other means would be “humane or acceptable” and thought it would add to the distress experienced by his “loved ones”.

However, the outcome of the judicial review was that Section 2 of the Suicide Act is compatible with Article 8 of the ECHR, and that any third-party assistance to end Mr Conway’s life would be unlawful – a point also made in Nicklinson and Anor v Secretary of State for Health and Social Care (2014) UKSC 38.

Given the substantive case law – including R (Conway) v Secretary of State for Justice [2017] EWHC 2447 Admin – along with the fact that Parliament continues to reject attempts – such as Lord Falconer’s Assisted Dying Bill – to make statutory changes to the current law, assisted suicide remains unlawful, regardless of how compelling the motivating factors may be (Taylor, 2017).

**Conclusion**

There is no legal obligation to either start or continue life-sustaining treatment if it is no longer in the patient’s best interests or if the patient does not want to receive it. However, the law draws a clear distinction between discontinuing treatment that is no longer of benefit to the patient and taking active and deliberate steps to end the patient’s life. Although it is lawful to administer palliative medication such as opioids and sedatives, even if they may have the secondary unintended effect of hastening the patient’s death, the administration of medication or any other action intended to end a patient’s life is illegal, even if it is at the patient’s request.

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**References**


General Medical Council (2010) Treatment and Care towards the End of Life: Good Practice in Decision Making. B.ly/GMCEoLC2010

Lay K (2017) NHS pays out £45,000 after woman kept alive against her wishes. The Times; 7 December 2017.

National Institute for Health and Care Excellence (2012) Palliative Care for Adults: Strong Opioids for Pain Relief. nice.org.uk/cg140


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