

End-of-life decisions

Views of the BMA

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Introduction

This note summarises the main points from some other BMA publications dealing in detail with aspects of end-of-life decisions. These include *Withdrawing and withholding life-prolonging medical treatment* (3rd edition 2007), *Advance decisions and proxy decision-making in medical treatment and research* (2007) and *The ethics of caring for older people* (2009). In addition, some of the BMA's general guidance on the law relating to incapacitated adults and the role of advocates may be relevant to end-of-life decisions and can be found on the BMA website.

This note covers three main issues:

- contemporaneous and advance refusal of treatment
- withholding and withdrawing life-prolonging medical treatment
- assisted dying: euthanasia and assisted suicide.

Background to BMA policies

The BMA is a professional association for doctors. Its policies are formulated at its annual representative meeting (ARM) where motions from the BMA membership are debated. A range of end-of-life issues are frequently discussed. BMA policy opposes euthanasia and does not believe that doctors should participate in actions deliberately intended to hasten death. Policy established in 2006, for example, rejects all forms of assisted dying and emphasises the importance of continuing to improve UK palliative care services. This policy was reinforced in 2009, when the BMA's ARM again voted against the idea of legislative change to allow assisted dying. BMA policy emphasises the right of all patients to good quality end-of-life care. The Association has repeatedly expressed concern that patients who could benefit from palliative care still lack access to it.

Contemporaneous requests for and refusal of treatment

People with a terminal or degenerative condition are often anxious about how their care will be managed and how choices will be made. Sensitive discussion of the options can be useful in clarifying their wishes. While competent, people generally decide their best interests for themselves. They may request or decline certain procedures. Requests for positive interventions should be taken into account, but ultimately clinicians have to decide which options are clinically appropriate to offer. Patients or their families cannot insist upon clinically inappropriate treatment. It should be borne in mind, however, that the Appeal Court has said that it is always appropriate for doctors to comply with a request for artificial nutrition and hydration (ANH) from patients with mental capacity who are unable to accept nourishment in other ways. The court made clear that this does not imply that patients can more generally insist upon receiving particular forms of treatment but that, as part of their duty of care, doctors must take reasonable steps to keep patients alive when this is the patients' known wish.

In terms of treatment refusal, the law and codes of ethical practice emphasise that adults with mental capacity can refuse medical treatment, including life-prolonging procedures. Where adults refuse treatment likely to benefit them, health professionals should ensure that there is no misunderstanding and provide information in a sensitive manner about the implications of refusal. Good communication is essential and may include exploration of alternative treatment options that might be acceptable to the individual. Ultimately, however, a refusal made by an adult with mental capacity must be respected.

Incapacitated patients

Decision-making in relation to adults who lack the capacity to consent on their own behalf is governed in England and Wales by the Mental Capacity Act 2005 (MCA). (Detailed guidance is available on the BMA website in *The Mental Capacity Act 2005: Guidance for health professionals* and the *Mental Capacity Act tool kit*.) In Scotland, the relevant legislation is the Adults with Incapacity (Scotland) Act

2000 (AWIA). (There is a separate BMA guidance note about this on the website.) In Northern Ireland, decisions are covered by the common law. Decisions with regard to incapacitated adults at the end of life must comply with the relevant legislation.

Both Acts incorporate previous good practice and common law in primary legislation. They also introduced some new responsibilities that health professionals need to be aware of. These are briefly summarised below in terms of their implications for end-of-life decisions. More detailed guidance on the treatment of adults who lack capacity can be obtained from the BMA's website. In brief, however, decisions for incapacitated adults must be made in the individual's best interests. (In Scotland, the law uses the term 'benefit' but this is generally interpreted in a similar way to 'best interests'.) Identifying best interests can be complex and depends upon the circumstances of each case. An assessment cannot be confined just to medical best interests but should encompass the person's known values and wishes. This requires consideration of any recorded statement, made when the person had capacity and discussion with those close to the patient.

Proxy decision-makers

In England, Wales and Scotland, competent people can nominate a proxy decision-maker, to be their welfare attorney. This proxy can then make health and welfare decisions on their behalf, once the individual has lost mental capacity. When nominating such a person, the patient can limit the proxy's powers in various ways. Welfare attorneys cannot refuse life-sustaining treatment on behalf of the incapacitated person unless this was explicitly stated by the person who nominated them. Any proxy decision-maker must make decisions based on the best interests of the incapacitated patient or what would benefit that person. If a serious dispute arises between a health professional and a proxy decision-maker, the case can be referred for adjudication to the Court of Protection, in England and Wales, and in Scotland the Court of Session.

Advocates/IMCAs

BMA guidance on *Statutory advocacy services* is available on the website. It details how in England and Wales, the Mental Capacity Act includes an advocacy scheme to support 'un-befriended' incapacitated adults. Where it is clear that a decision needs to be made on behalf of such an 'un-befriended' person regarding either serious medical treatment or place of residence, an independent mental capacity advocate (IMCA) needs to be involved. Consideration first needs to be given as to whether there is someone close to the adult (excluding paid carers) who can appropriately be consulted. In the absence of someone in that role whom it would be appropriate to involve the decision, an IMCA must be consulted. Although IMCAs cannot give consent on behalf of incapacitated adults, their views must be taken into account when assessing an incapacitated patient's best interests.

Advance refusals and requests

There is also separate BMA guidance on *Advance decisions and proxy decision-making in medical treatment and research*. Advance decisions allow competent adults to say what they would like to happen later if their mental capacity becomes impaired. These decisions become important once patients lose their mental capacity, are unconscious, or unable to communicate. Also known as a living will, advance decisions can request or refuse future treatment. Subject to certain criteria being met, refusals are legally binding. Even advance decisions that fail to meet the legal criteria can provide some insight into the patient's thinking and be helpful in indicating what is in the individual's best interests.

In England and Wales, advance decisions are covered by the Mental Capacity Act. To be valid and legally binding the advance decision must be specific about the treatment that is being refused and the circumstances in which the refusal will apply. Where the patient's advance decision relates to a

refusal of life-prolonging treatment this must be recorded in writing and witnessed. Patients must be explicit that they intend to refuse treatment even though this puts their life at risk.

In Scotland and Northern Ireland, advance decisions are not covered by statute but by common law. An advance refusal of treatment is likely to be binding in Scotland and Northern Ireland if the patient was an informed and competent adult at the time the decision was made (16 years old in Scotland and 18 in Northern Ireland).

The advance decision may be open to question if the circumstances that have arisen since the patient's loss of mental capacity are radically different to those that the individual had envisaged. Therefore, doctors need to consider whether the advance decision fits the current situation or if it differs significantly from the scenario the patient anticipated. Advance refusals made in the distant past and not updated are not necessarily invalid but if treatment options have substantially altered, its validity may be questioned. Doubts about validity can also arise if it appears that individuals already had impaired capacity at the time of making the decision. Or if evidence suggests that they lacked significant information or were subject to coercion when deciding. In case of doubt, legal opinion should be sought.

If an advance refusal of treatment appears valid and is applicable to the current circumstances, health professionals must abide by it. Patients cannot demand or refuse anything in advance that they cannot demand or refuse when conscious and competent. Therefore, patients cannot refuse in advance compulsory treatment provided under the mental health legislation or demand euthanasia or assisted dying. Also although advance requests or authorisation of specific treatment can be helpful, they lack legal weight if clinicians assess that treatment to be inappropriate.

Advance decisions have some advantages in terms of encouraging openness, dialogue and forward planning. They also have potential disadvantages as they cannot encompass unforeseen possibilities and options. Treatment decisions are often complex and treatment techniques evolve. Advance decisions made long before capacity is lost can fail to reflect how treatment options have changed. Patients' views can also change and the onus is on the individual, while competent, to ensure that their recorded views continue to match their current wishes.

Withholding and withdrawing life-prolonging medical treatment

Medical treatment can legally and ethically be withdrawn when it is unable to benefit the patient. It should be withdrawn when it is not in the patient's best interest or if the patient has refused it.

In practice, however, this is, a profoundly difficult decision. This was illustrated in 1993 by the House of Lords deliberations in the case of Tony Bland. In a persistent vegetative state (PVS) with no awareness of the world and no hope of recovery, Bland was not terminally ill but withdrawal of artificial nutrition would inevitably result in his death. Following judgments made in other jurisdictions and confirming that artificial nutrition constitutes a medical treatment, the House of Lords agreed that it could be withdrawn.

Medicine aims to restore or maintain patients' health by maximising benefit and minimising harm. When medical treatment ceases to provide a net benefit to the patient, this primary goal of medicine cannot be realised and the justification for intervening is gone. Unless some other justification can be demonstrated, most people would accept that treatment should not be prolonged. The BMA does not believe that it is appropriate to prolong life at all costs, with no regard to its quality or the burdens of the intervention.

Technological developments continually extend the range of treatment options available to prolong life when organ or system failure would naturally result in death. Patients with progressive, degenerative conditions can have their lives prolonged considerably but this will not necessarily reverse a patient's disease. Other patients, for example those with very severe brain damage, may remain stable for many years if life-prolonging treatment is provided, but this may be with no hope of recovering more than very minimal levels of awareness of their surroundings. They may lack the ability to interact with others or the capacity for self-directed action. In such severely damaged patients, treatment or intervention to prolong life by artificial means may fail to provide sufficient benefit to justify the intervention and the proper course of action may be to withhold or withdraw further treatment.

The guiding principles underlying any such decision must be to protect the dignity, comfort and rights of the patient; to take into account any known wishes of the patient and the views of people close to patients who lack capacity. Communication and consultation are essential. A thorough clinical evaluation, including the initiation of treatment for a trial period if appropriate, should take place, so that the decision is based on as accurate as possible an assessment of the benefits, risks and burdens of the treatment for that particular patient. Where the treatment to be withheld or withdrawn is artificial nutrition and hydration, a second clinical opinion should be sought before treatment is withdrawn or withheld from a patient who is not imminently dying. Furthermore, in England, Wales and Northern Ireland, the withdrawal or withholding of ANH from a patient in a persistent vegetative state needs to be subject to court review. In Scotland, this is not obligatory but it is advisable to seek legal advice.

The BMA's guidance, contained in *Withholding and withdrawing life-prolonging medical treatment*, gives advice on the ethical, legal and clinical issues, and sets out safeguards for decision-making. It indicates how the human rights legislation applies in this area. It also seeks to provide a coherent and comprehensive set of principles that apply to all decisions to withhold or withdraw life-prolonging treatment, which it is hoped will stimulate the development of local policies and guidelines. The General Medical Council has consulted on proposed revisions to its guidance on the same topic. For further information, see the GMC's website.

Doctors considering withholding or withdrawing life-prolonging treatment can find detailed guidance in the BMA book. In any cases of doubt, legal advice should be sought. In cases where the patient is an incapacitated adult, advice can be sought in England and Wales from the Official Solicitor. Northern Ireland has its own Official Solicitor to act on behalf of mentally incapacitated people. In Scotland, advice can be sought from the Mental Welfare Commission or NHS Central Legal Office.

Assisted dying

'Assisted dying' covers euthanasia (where someone other than the patient administers a fatal dose) and assisted suicide (where patients are assisted to end their own lives).

Traditionally, the BMA opposed any form of assisted dying, but in 2005 its ARM (its policy-making body) recognised that there were diverse opinions within society and the profession. It agreed that Parliament and society at large should decide the issue of possible legalisation. This meant that the BMA took a neutral stance on assisted dying. In 2006, however, BMA members voting at the ARM made clear that the majority opposed such legislation. Therefore the BMA dropped its neutral stance and again opposes all forms of assisted dying.

The current policy is that the BMA:

- (i) believes that the ongoing improvement in palliative care allows patients to die with dignity
- (ii) insists that physician-assisted suicide should not be made legal in the UK

- (iii) insists that voluntary euthanasia should not be made legal in the UK
- (iv) insists that non-voluntary euthanasia should not be made legal in the UK; and
- (v) insists that if euthanasia were legalised, there should be a clear demarcation between those doctors who would be involved in it and those who would not.

This was reiterated in 2009 when the BMA's ARM rejected a proposal to change the law and allow competent, terminally ill patients to choose assisted dying. It also voted against legal immunity for people who accompany patients to an assisted death abroad.

Euthanasia

Euthanasia which is the active and intentional termination of a person's life remains illegal in the UK. It is morally and legally different to the withholding or withdrawal of treatment. Arguments for legalisation of euthanasia are generally based on arguments about competent individuals' rights to choose the manner of their demise or about cases where medicine is unable to control distressing terminal symptoms. Although the BMA respects the concept of individual autonomy, it argues that there are limits to what patients can choose if their choice will impact on other people.

Arguments against legalisation often focus on practical points. If euthanasia were an option, there might be pressure for all seriously ill people to consider it even if they would not otherwise entertain such an idea. Health professionals explaining options for the management of terminal illness would have to include an explanation of assisted dying. Patients might feel obliged to choose it for the wrong reasons, if they were worried about being a burden, or concerned about the financial implications of a long terminal illness. Legalisation could generate anxiety for vulnerable, elderly, disabled or very ill patients.

Physician-assisted suicide

Aiding or abetting suicide is also illegal and carries a potential 14-year sentence. The arguments for and against assisted suicide and physician-assisted suicide are similar to those made in relation to euthanasia. Assisted suicide differs from euthanasia in that the individual retains control of the process, rather than the doctor or anyone else assisting. In its early policies, however, the BMA did not distinguish between euthanasia and physician-assisted suicide. In 1997, BMA policy mentioned both for the first time and while recognising that a diversity of opinion existed about them, opposed any changes in law to permit either.

In 1998 the BMA Medical Ethics Department published a discussion paper debating whether the moral arguments about physician-assisted suicide and euthanasia differ significantly. The BMA's ARM also called for a conference 'to promote the development of a consensus on physician-assisted suicide'. This took place in March 2000, resulting in a consensus statement opposing physician-assisted suicide.

Facilitating travel abroad for assisted dying

While suicide or traveling abroad to receive assisted suicide are not illegal, facilitating suicide is a criminal offence. The BMA receives some queries from doctors as to whether they can write medical reports for terminally ill patients to use abroad or whether doctors could accompany a patient going abroad for assisted dying. In such circumstances, doctors need to be aware of the possible legal implications of these, or any other actions, which might be seen as encouraging or facilitating suicide.

As yet, no doctor providing a report nor any accompanying person has been prosecuted for helping patients to travel abroad to end their lives. Nevertheless, some people feel that more detailed legal guidance should be available. In October 2008, in the Debbie Purdy case, the English High Court ruled that existing official guidance was sufficient regarding the liability of relatives who might be perceived

as assisting suicide. It said that no guarantees of immunity could be given. In February 2009, the Appeal Court reinforced this ruling saying that the Director of Public Prosecutions could not adopt a policy for a specific case and only Parliament could decide whether the law required amendment. Following her failed Appeal Court request, in June 2009 Debbie Purdy asked the House of Lords to rule that her husband would not face prosecution if he accompanied her to Switzerland.

In July 2009, the Lords also debated an amendment by Lord Falconer to the Coroners and Justice Bill which sought to exempt from prosecution people who accompany terminally ill patients abroad for assisted suicide. Lord Falconer argued that the existing law was unsatisfactory as it not only meant that some patients went to Switzerland to die prematurely or alone but also some had ended their lives mistakenly believing that they were terminally ill when they were not. He claimed that although the existing law had potential penalties for accompanying persons, it offered insufficient safeguards to vulnerable patients. The amendment failed. If passed, it would have required patients to make an informed, voluntary and independently witnessed declaration of their intention. Two independent doctors would have had to certify the patient's competence and terminal condition A week prior to the Lords' debate, the BMA's ARM had also discussed the liability of accompanying persons in a wider-ranging motion, which – had it been agreed – would have granted them immunity, without Lord Falconer's criteria being met. The BMA's ARM did not support the motion.

For further information about these guidelines, BMA members may contact:

askBMA on 0300 123 123 3 or
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Email: ethics@bma.org.uk

References

- 1 R (on the application of Burke) v General Medical Council [2005] 2 FLR 1223.
- 2 www.bma.org.uk/ethics
- 3 Airedale NHS Trust v Bland [1993] AC 789
- 4 R (on the applications of Purdy) v DPP & Another [2008] EWHC 2565 (Admin)
- 5 R (on the applications of Purdy) v DPP & Another [2009] EWCA Civ 92

