

Advance decisions and proxy decision-making in medical treatment and research

Guidance from the BMA's Medical Ethics Department

Assessing mental capacity

Advance decisions

Proxy decision-makers

In England & Wales, Scotland, Northern Ireland

Contents	
Introduction	1
What this guidance covers	1
Part 1 – Assessing mental capacity	1
The concept of mental capacity	1
Assessing mental capacity	1
The law relating to mental capacity	2
Understanding “best interests”	2
Part 2 – Advance decisions	2
Definitions	3
Who might make an advance decision?	3
Legal position	3
Legal position on capacity needed to make advance refusals of medical treatment	3
Criteria for legally valid advance refusal of treatment	4
Additional criteria for advance refusal of life-prolonging treatment	4
Common law criteria for validity of advance refusal of treatment	4
Advance refusal of “basic care”	4
Emergencies	5
Advance requests	5
Legal position on advance requests	5
Practicalities regarding any kind of formal advance decisions	5
Provision of information	5
Voluntariness	6
Verbal advance decisions and verbal amendments	6
Written advance decisions	6
Health professionals witnessing advance decisions	6
Reviewing advance decisions	6
Storage of advance decisions	7
Assessing validity of advance decisions	7
Implementation of advance decisions	7
Disputes and doubts about validity	7
Conscientious objection	8
Part 3 – Proxy decision-making	8
Legal position on proxy consent to treatment decisions in England & Wales	8
• <i>Lasting powers of attorney (LPAs)</i>	8
• <i>Appointing an attorney</i>	8
• <i>Duties of attorneys</i>	8
• <i>Role of health professionals regarding attorneys</i>	9
• <i>Independent mental capacity advocates (IMCAs)</i>	9
• <i>Disputes, Court of Protection, deputies</i>	9
Legal position on proxy consent to treatment decisions in Scotland	9
• <i>Welfare attorneys and welfare guardians</i>	9
• <i>Listening to relatives</i>	9
• <i>Disputes, the Sheriff & Mental Welfare Commission</i>	9
Legal position on proxy consent to treatment decisions in Northern Ireland	10
Proxy consent to research	10
Other relevant BMA guidance	10
References	10

Introduction

What this guidance covers

This guidance covers the law and ethical issues involved in competent individuals making advance decisions about their later medical treatment and proxy decisions about medical treatment made by other people on behalf of adults who lack mental capacity. When they are mentally competent, patients decide for themselves whether or not to accept the medical treatments recommended by health professionals. This guidance is about what happens when that mental ability to make a valid decision is lost.

Part 1

A key consideration for health professionals prior to focussing on whether there are valid advance or proxy decisions available is to assess whether the individual has indeed lost the mental capacity to decide for him or herself. Part 1 sets out the law on mental capacity and advice on how it should be assessed.

Part 2

When people can no longer make or communicate their decisions, medical choices have to be made which reflect their best interests. Some people may have previously indicated what they consider to be in their interests by making their own advance decision about the medical treatment they do or do not want in future. In ordinary practice, medical treatment decisions generally involve a series of steps as patients' views and clinical conditions change. New medical techniques may emerge and each stage of treatment normally involves discussion between patients and health professionals. Loss of mental capacity robs people of the opportunity to participate in a continuing dialogue or to re-assess their options. Advance decisions are an imperfect substitute, but for some they are the only means of expressing their wishes about what they want to happen. There are both benefits and potential dangers to making some treatment decisions in advance, not least due to the risk of error in evaluating possible future developments. Nevertheless, if the decisions made when they were competent comply with the legal criteria set out in Part 2, health professionals are legally bound to comply with them. Most of these binding decisions concern treatment refusal. As well as the law governing advance decisions, Part 2 also covers the practicalities of recording and implementing them and the safeguards if it appears that an advance decision is invalid or has been retracted.

Part 3

Some people prefer to nominate someone they trust to decide for them in future or the courts may appoint someone to do that when the patient is mentally incapacitated. Until relatively recently in the UK, nobody could consent to medical treatment on behalf of a mentally incapacitated adult and that remains the legal position in Northern Ireland. In Scotland, however, such decisions can be made by a welfare attorney. From October 2007, treatment decisions can also be made by a welfare attorney in England and Wales. In the absence of such an attorney, or close family members or other appropriate decision-maker, an independent mental capacity advocate (IMCA) needs to be involved in serious decisions in England

and Wales. Part 3 outlines the legal provisions governing such decision-makers and advisers and looks at the scope of the decisions that they can make - not only about medical treatment but also the patient's participation in research.

Part 1 – Assessing mental capacity

The concept of mental capacity

Mental capacity or competence is a key concept for advance decisions and proxy decision-making for adults and so it is important to be clear about what it means. Capacity and competence mean the same thing and the terms are used interchangeably. All adults are assumed to have capacity unless there is evidence to the contrary. Capacity is also "task specific". This means that the individual's ability to weigh up the issues and come to a decision is assessed in relation to the specific choice that has to be made. Unless they are unconscious, most people can make some valid decisions even if their mental faculties are impaired. When patients decide on a course of action which has risky or harmful health consequences, however, doctors need to be confident that the patient understands that. More evidence is needed that the person has the capacity to understand the implications if the choice has a potentially hazardous outcome than in situations where the consequences are relatively trivial or benign.

In this context, capacity or competence refers to people's ability to make a decision, which may have legal consequences for the decision maker or for other people. When they have this ability, patients decide for themselves, including deciding what they would like to happen to them in the future. When they lose their mental capacity, that is the trigger for their advance wishes to be considered or for the proxy decision-maker to take over. In the absence of an advance decision or a proxy to indicate where the patient's best interests lie, the health team treating the incapacitated individual assess what would be in the person's "best interests". (See below).

In order to make an advance decision or appoint their own proxy decision-makers, individuals must have sufficient mental capacity to understand what the process involves and what flows from it. In most cases, there is no doubt about the mental capacity of individuals wishing to record an advance decision as long as they appear to have the everyday ability to make reasoned decisions and understand the likely consequences.

Assessing mental capacity

Capacity must be assessed in relation to the decision in question at the time the decision needs to be made. For their advance decisions to be valid, people must be able to understand and weigh the implications and consequences of their choices, when they make them. When consulted by a patient intending to draft an advance decision, doctors should consider whether there are reasons to doubt the patient's ability to make the decisions in question.

Capacity is assumed unless evidence suggests the contrary. If asked to witness an advance decision, health professionals should be aware that it may later be assumed they verified that the individual had capacity at the time of making the decision. If they are satisfied that the individual

does have capacity at that stage, health professionals may wish to note that on the document. If there is doubt about the individual's capacity to make the decision in question, it is advisable for a formal psychological assessment to be carried out to avoid confusion later.¹ In general terms, in order to make a valid treatment decision, the individual should

- understand what the decision is
- be capable of choosing and understand why a choice is needed
- have information about risks, benefits and alternatives
- understand and retain enough basic information to make the choice
- be aware of how it is relevant to him/herself
- know there is a right to consent or refuse (except for compulsory treatment under mental health legislation)
- know how to refuse
- be capable of communicating a choice.

The law relating to mental capacity

As capacity is task or function-specific, assessing whether an individual has the capacity to make a certain decision depends on what that particular decision entails. It is irrelevant whether the incapacity is temporary, fluctuating or the person retains the capacity to make other decisions. Greater evidence of understanding must be demonstrated for decisions that have serious consequences. This is covered in detail in the BMA and Law Society's book *Assessment of Mental Capacity*.² UK statute law also provides some general pointers on how capacity, and the lack of it, is defined.

- **In England and Wales:** The Mental Capacity Act 2005 defines what is the absence of capacity. If, at the time the decision needs to be made, patients are unable to make or communicate the decision because of an 'impairment of, or a disturbance in the functioning of, the mind or brain', they are deemed incapable.
- **In Scotland:** The Adults with Incapacity Act 2000 defines people as incapacitated if they cannot make decisions or communicate them or remember their decisions. The impairment may be due to a mental disorder or a physical inability to communicate in any form.
- **In Northern Ireland,** there is no specific statute and so capacity is covered by the definition previously established in English case law. This says that to demonstrate capacity individuals should be able to:
 - understand in broad terms and simple language what the medical treatment is, its purpose and nature and why it is or will be proposed for them;
 - understand its principal benefits, risks and alternatives;
 - understand in broad terms what will be the consequences of not having it
 - make a free choice (i.e. free from undue pressure);
 - retain information long enough to make a decision.

Understanding "best interests"

The general legal and ethical rule is that mentally incapacitated people are treated in their "best interests". Part of what makes up their "best interests" are patients' own wishes and desires as well as consideration of what

seems most beneficial clinically. Where individuals lack mental capacity, an important step is identifying what they would have wanted. It can be complex because people vary in the value they place on concepts such as being kept alive at all costs, being free from invasive treatment or life being prolonged when there is no hope of regaining mental capacity. When competence is lost, a fundamental consideration is the known past wishes and values of the incapacitated person. These may be formally recorded as a documented advance decision (or advance statement) or, in settings such as hospices, there may be a note in the patient record of verbal discussions which have taken place. Patients' relatives can also often provide a view about what the individual would have wanted.

Factors to take into account when considering what is in a patient's best interests

- the patient's own wishes and values (where these can be ascertained), including any formally documented advance decision;
- the views of welfare attorneys, court-appointed deputies or proxy decision-makers as well as patients' close relatives, partners or carers about what the patient is likely to see as beneficial;
- in the absence of such a clear steer on what the patient would have wanted, a clinical judgement needs to be made about the effectiveness of the proposed treatment, particularly in relation to other options;
- where there is more than one option, which option is least restrictive of the patient's future choices;
- the likelihood and extent of any degree of improvement in the patient's condition if treatment is provided;
- any knowledge of the patient's religious, cultural and other non-medical views that might have an impact on the patient's wishes.

Where there is a dispute or uncertainty about what is in an incapacitated person's best interests, legal advice may need to be sought, as is discussed in Part 2.

Part 2 – Advance decisions

People who understand the implications of their choices can state in advance how they wish to be treated if they later suffer loss of mental capacity. Apart from mental health interventions covered by statute, adults when they are competent can *refuse* medical procedures contemporaneously or in advance. Advance refusals can be legally binding on health care providers. Individuals may also make some *requests* concerning future treatment they would like or say whether they are willing to participate in research after competence is lost. Such requests or authorisations can help health professionals later to assess what would be in the best interests of the patient. Any advance decision is superseded by a competent contemporaneous decision by the individual concerned, or by the decision of a proxy decision maker who was subsequently appointed to make that decision.

Definitions

Advance decision is a general term covering a range of options which in the past were known as "advance statements". An advance decision may describe a written

document, a clear oral statement, a signed printed card, a smart card or a note of a discussion recorded in the patient's file. Any of these may convey a sense of the individuals' wishes but to be legally binding an advance decision must fit certain criteria.

Advance directive/living will/advance refusal is a clear instruction **refusing** a medical procedure or interventions such as participation in research. Voluntarily made by a competent and informed adult, an unambiguous advance refusal is likely to have legal force. (See below.) Health professionals are generally bound to comply when the refusal specifically addresses the situation which has arisen.

As there are only very limited circumstances in which patients can insist that specific medical treatment be given, decisions purporting to "direct" health professionals are generally refusals. A refusal may be invalid if, for example, the treatment options have materially changed since the patient lost competence. It may also be unenforceable if the refusal would seriously affect other people adversely by exposing them to the risk of harm as people do not have a right to put others at risk.

An advance authorisation or request reflects individuals' preferences for certain positive interventions after competence is lost. Like advance refusals, advance requests and authorisations must be made when the individual is competent and aware of the implications. Requests help identify how patients would like to be treated but are not binding, if in conflict with professional judgement. Nevertheless, in some circumstances, the health team may be obliged to provide artificial nutrition and hydration at the end of life if it is clear that this is what the patient wanted. Since the legal situation regarding advance requests for artificial nutrition and hydration is complex, it is advisable to consult the separate BMA publication which covers it in detail.³

Who might make an advance decision?

Some people fear that once they become incapable of making decisions, they might be subject to medical interventions which are unable to deliver a level of recovery or quality of life, that they would find acceptable. The whole purpose of an advance decision is to make provision for decisions that will need to be taken in the future after the deterioration of the individual's mental faculties. Advance decisions can be useful for individuals who have strong views, a medical condition likely to involve a future period of mental impairment and predictable treatment options. People who choose to make advance decisions aim to extend into the future their present ability to control some events. Nobody should feel compelled to make them and, indeed, pressure to do so could invalidate the choices made. Advance decision-making is not necessarily right for everybody. Some people make clear that they do not want to know the implications of their diagnosis. They may prefer decisions to be made for them in the context of the situation as it arises by people they trust.

Legal position

In England and Wales, advance decisions are covered by the Mental Capacity Act 2005 scheduled to come into force in October 2007. In Scotland, the Adults with Incapacity (Scotland) Act 2000 came into force in 2002 and introduced a statutory framework for the medical

treatment of incapacitated people over the age of 16. While it does not specifically cover advance decisions, it obliges health professionals to take account of the patient's past and present wishes, however communicated.⁴ In England and Wales, the Mental Capacity Act not only covers medical treatment decisions but also makes provision for mentally incapacitated people to be involved in research. (Research is covered at the end of this guidance). In Scotland, the Adults with Incapacity (Scotland) Act 2000 also regulates the involvement of incapacitated adults in research. In addition the 2004 Medicines for Human Use (Clinical Trials) Regulations address proxy decision-making for participation in medical research as well as advance consent or refusal by the individual prior to the onset of incapacity. In Northern Ireland, there is no statute on this subject but English case law which sets out criteria for advance refusals is likely to be followed.

Legal position on capacity needed to make advance refusals of medical treatment

The level of capacity required to request or refuse treatment in advance is the same level that would be required for making the decision contemporaneously. It may be demonstrated by patients who lack insight into other aspects of their life as long as they understand the implications of the specific choice before them. In 1993, for example, the courts upheld the rights of a patient with a psychotic disorder to refuse validly in advance amputation of his gangrenous foot even though he held demonstrably erroneous views on some matters.

Re C

C was a 68-year-old patient suffering from paranoid schizophrenia. In 1993, during his confinement in a secure hospital, he developed gangrene in his foot. According to medical opinion there was an 85% chance that C would die if the leg was not amputated below the knee. Whilst content to follow medical advice and to co-operate with more conservative treatment, C refused to consent to the amputation.

C had grandiose and persecutory delusions, including that he had an international career in medicine. He expressed complete confidence in his ability to survive aided by God and the health care team but he acknowledged the possibility of death as a consequence of his refusal of amputation.

The High Court was asked to decide whether C was competent to make the decision. The court held that although C's schizophrenia impacted on his general capacity, he was able to make a valid decision about the treatment. Therefore the amputation could not proceed without his consent and nor could it be carried out in the future if his mental capacity deteriorated.

Re C (adult: refusal of treatment)⁵

Even clear and specific advance refusals cannot override other legislation. Thus an advance refusal of treatment cannot override the legal authority to give compulsory treatment under the mental health legislation. While they cannot refuse compulsory treatment, wherever possible patients should be involved in the advance planning of it. Treatment plans for both informal and detained patients

should wherever possible be discussed in advance with the patient. Patients' preferences regarding treatment options should also be included in the plan.

England and Wales: In order for an advance refusal of treatment to be legally valid and therefore binding on the healthcare team, certain criteria set out in the Mental Capacity Act 2005 must be met. If advance directives do not meet these criteria, they can still be useful in assessing the patient's best interests but are not legally binding.

Criteria for legally valid advance refusal of treatment

- the person making the directive must be aged 18 years or older when it is made
- the person must be mentally competent when the directive is made
- the directive must specify – in medical or lay terms – the treatment refused
- it can specify the circumstances in which the refusal is to apply
- the person making the directive has not withdrawn it nor subsequently appointed an attorney to make the specified decision
- the person making the directive has not done anything clearly inconsistent with the terms of the directive
- the individual lacks capacity to make decisions at the time the directive is invoked.

Additional criteria for advance refusal of life-prolonging treatment

A refusal of any recommended medical treatment can result in a deterioration in the patient's condition or even death but where they intend specifically to refuse life-sustaining procedures, individuals must:

- clearly indicates that it is to apply even if life is at risk and death will predictably result
- put the decision in writing
- ensure it is signed and witnessed.

In England and Wales, where there is doubt about the validity of an advance directive, an application may be made for a declaration from the Court of Protection.

Scotland and Northern Ireland: Advance directives are not covered by statute in Scotland and Northern Ireland and nor have there been any specific cases considered by the courts in those jurisdictions. It is likely that the courts in Scotland and Northern Ireland would take a similar approach to the English courts. Prior to the passing of the Mental Capacity Act in England and Wales, a number of English legal cases, such as those of "T" and "C" (mentioned above) had already established that a valid advance refusal of treatment has the same legal authority as a contemporaneous refusal.⁶ Respecting the advance refusal of competent adult patients is also a requirement of Articles 5 and 8 of the Human Rights Act.

Re T

T was 20 years old and 34 weeks pregnant when she was injured in a road traffic accident. T's mother was a Jehovah's Witness but T herself was not. On two occasions, after spending time alone with her mother, T told staff she did not want a blood transfusion. A

caesarean section was carried out but the baby was stillborn. T's condition deteriorated and, had it not been for her advance refusal, the anaesthetist would have given her a blood transfusion. T's father and boyfriend challenged the validity of the advance directive. The challenge was upheld and the blood transfusion was given.

The basis for the decision was that T had been acting under the influence of her mother and the refusal did not represent a legitimate expression of T's free will. It also appeared that T had not been informed that a blood transfusion might be necessary in order to save her life and so it could not be assumed that she intended her refusal to apply to a situation that was life-threatening.

In dismissing the appeal against the decision, the Appeal Court made clear that an anticipatory refusal, if clearly established and applicable in the circumstances would be binding on health professionals. In T's case, however, these criteria were not met.

Re T (adult: refusal of medical treatment)⁷

Common law criteria for validity of an advance refusal of treatment

- The patient must be an adult at the time the directive is made
- the patient has been offered sufficient, accurate information to make an informed decision
- the circumstances that have arisen are those that were envisaged by the patient and
- the patient is not subjected to undue influence in making the decision.

In Scotland, the Code of Practice issued under the Adults with Incapacity (Scotland) Act advises that a competently made advance decision should be seen as a strong indication of the patient's former wishes. Health professionals are obliged to take account of such known former wishes and therefore are likely to be bound by a valid advance refusal of treatment although this has not yet been tested in the Scottish courts. If there is doubt about whether an advance directive is valid or not, a declaration on the validity of advance directives can also be sought from the High Court in Northern Ireland or the Court of Session in Scotland

Advance refusal of "basic care"

The BMA uses the term "basic care" to cover the sorts of care primarily intended to keep patients comfortable rather than specifically to extend their lives. It includes offering them food, liquids, pain relief, hygiene measures and management of distressing symptoms, such as breathlessness and vomiting. In brief, any procedures designed to alleviate patients' pain, symptoms or distress are facets of basic care. Near the end of life, patients seldom want nutrition or hydration but basic care includes measures such as moistening a patient's mouth for comfort. While they are competent, individuals may prefer to tolerate some pain or discomfort in order to remain alert but they cannot decide in advance to refuse pain relief and basic care when their competence is lost. In the BMA's view, it would be unacceptable for health professionals to leave a person who is now mentally incompetent in pain. The courts have made clear that artificial feeding and hydration are not necessarily part of basic care but are

procedures that patients can refuse or which may not be offered if deemed futile.

Emergencies

As a general principle, the law expects doctors to act reasonably in the circumstances in which they find themselves. In an emergency situation, where it is unclear whether or not an unconscious or otherwise mentally impaired patient has refused treatment in advance, it is reasonable not to delay treatment if that would result in a serious risk to the person's life or health. If there is a valid and applicable advance refusal of treatment, it should be followed. If treatment has been initiated in good faith and, an advance decision is subsequently discovered which is clearly relevant to the current circumstances and fulfils the criteria for validity set out above, it should be followed.

One potential problem is that patients with a serious diagnosis may not have envisaged a more unpredictable event such as a traffic accident when making their advance refusal of treatment. If their intention is clearly spelled out, it should be evident that the advance decision is not applicable to the current situation. If, however, it is unclear whether the individual intended an advance decision to apply in all circumstances of impaired capacity, including an apparently unforeseen situation, the advice about "assessing validity" should be followed.

Advance requests

When they have a diagnosis likely to involve loss of mental capacity, it is good practice to talk to patients about foreseeable future treatment options if patients want to discuss them. If there has been no advance discussion prior to the patient losing mental capacity, doctors will provide treatment on the basis of their assessment of what would be in the patient's best interests. Advance discussion can be helpful if the patient has clear views which differ from what is predictable or what most other patients would choose. Although they can request a particular treatment now or in the future, that does not mean it will be automatically provided. Doctors cannot be obliged to provide clinically inappropriate treatment or treatment which has a very small chance of success. If the requested intervention cannot achieve its physiological aim or if the burdens of the treatment would outweigh the benefits for the particular individual, it will not be provided.

Legal position on advance requests

In terms of life-prolonging interventions, health professionals have a legal as well as an ethical duty to protect life, under Article 2 of the European Human Rights Convention, but its scope is limited. In some circumstances, however, advance requests for specific life-prolonging treatment such as artificial nutrition and hydration should be respected. The law in this area is complex and so it is advisable to consult the detailed BMA guidance for those situations.⁸ The Burke case (below) clarified that doctors have a duty to take reasonable steps to comply with a patient's request that artificial nutrition and hydration be provided in future when he or she could no longer communicate.

Burke v GMC

Mr Oliver Leslie Burke was a 45-year-old man who suffered

from cerebellar ataxia with peripheral neuropathy, a progressively degenerative condition that follows a similar course to multiple sclerosis. As his condition worsened he would lose the ability to swallow, requiring artificial nutrition and hydration (ANH). Medical evidence indicated that he would retain mental capacity until close to his death but Mr Burke was concerned that the GMC's guidance on withdrawing life-prolonging treatment gave doctors the discretion to withdraw ANH even if his death was not imminent. He claimed that it was incompatible with Articles 2, 3, 6, 8 and 14 of the European Convention on Human Rights. In July 2004, a judge agreed with him and upheld the challenge but this was overturned by the Court of Appeal which made clear that there was no question of ANH being withdrawn. This is because he had made it clear that he would want to receive this treatment when his health deteriorated and when he was no longer able to express his wishes. The Appeal Court held that the doctors' duty of care included the duty to take reasonable steps to prolong the patient's life where that was the patient's wish. To deliberately interrupt life-prolonging treatment, in the face of a competent patient's expressed wish to be kept alive, with the intention of thereby terminating the patient's life, would leave the doctor with no answer to a charge of murder.

R (on the application of Burke) v GMC⁹

The duty to provide life-prolonging treatment, where this is the patient's wish does not extend to treatment that is not clinically indicated and doctors are not obliged to provide such treatments. It is unclear how far the principles established in this case about ANH can be extrapolated to other treatments. What is reasonable in each situation needs to be judged in the context of the case, taking account of relevant factors such as the patient's ability to benefit from the treatment requested and the possible detriment to other patients awaiting treatment.

Practicalities in relation to drawing up advance decisions

There are some practical issues that need to be considered by individuals who want to draft advance decisions and for the health professionals caring for them or later implementing the patient's decisions. If they have strong views, patients need to consider how to make those clearly known. Various steps are open to them. Some draw up a clear statement of their intentions to be lodged with their medical record. Some carry copies with them or a card indicating that they refuse certain procedures. Jehovah's Witnesses, for example, often carry cards stating their refusal of blood products. There is also ongoing discussion about how patients' wishes may be recorded on the summary care record, developed as part of the NHS Connecting for Health Care Records Service project.

Provision of information

Ideally, advance decisions should be drafted with appropriate discussion with health professionals rather than by patients in isolation. Medical advice can lead to a better informed declaration but it is important for any adviser to help patients clarify their own wishes rather than influence them. Foreseeable options and uncertainties need to be explained and it is important to be sensitively frank. The professionals who may subsequently have to implement

patients' advance decisions will be relying on the fact that the individual was properly informed when formulating them.

A mundane question that sometimes arises is whether discussion specific to the drafting of an advance decision should be seen as a usual part of the patient-doctor dialogue or should it rather be seen as an extra service for which patients can be charged. In the BMA's view, it is part of normal good practice to discuss with patients the general implications of their known conditions and the treatments likely to be available for those in the foreseeable future. Conducting an assessment of mental capacity solely for the purpose of an advance decision, however, is not a "primary medical service". It can be seen as specific to the patient's choice to draft an advance decision and may attract a payment.

Voluntariness

A key criterion for advance refusals of treatment is that they must be voluntary. In most situations, this is clearly the case. A particular situation in which establishing voluntariness can be difficult is when people in custodial settings may be under peer pressure to make an advance refusal of artificial feeding or resuscitation. Prisoners may use hunger strikes as a method of protest and prohibit future medical interventions once they become unconscious. The World Medical Association has detailed guidance on the management of hunger strikes and treatment refusal in custodial settings.¹⁰ In such settings, it can also be difficult for detainees to withdraw their refusal of treatment without losing face. If not retracted, however, advance refusals by competent, informed individuals are as legally binding in a custodial setting as they are in the wider community.

Verbal advance decisions and verbal amendments

If suffering from a condition requiring long-term care, individuals have opportunities for discussion with the health-care team over a long period. They may feel their wishes are sufficiently well known or reflected in the notes so that there is no need to write them down. In hospice or specialist palliative care settings, this form of oral advance directive is common practice. A general expression of views cannot be accorded the same weight as a firm decision but can be helpful in illustrating the patient's past wishes, even if expressed in a verbal form that would not meet the legal criteria. Nevertheless, there are advantages to recording firm decisions in a written document or on the shared electronic record, when available. Many patients only lose capacity shortly before death. Until the point that capacity is lost, the individual's current views always outweigh anything they decided earlier. They can verbally amend or withdraw the advance decision as long as they have capacity.

Written advance decisions

Written decisions should use clear language and be signed by the individual and a witness. Although not legally binding, authorising decisions (advance consent) can assist health professionals to accommodate decisions which are so personal that only the individual concerned could make them. A key concern for many people is to be able to say where they would like to be cared for and where they wish

to die or who they want called to their bedside. Adults cannot authorise or refuse in advance, procedures which they could not authorise or refuse contemporaneously. They cannot authorise unlawful procedures or insist upon futile or inappropriate treatment. If individuals want to refuse life-sustaining treatment, they need to say clearly in the advance decision that they are aware that this refusal is likely to result in their death. In England and Wales, this is a legal requirement for validity under the Mental Capacity Act 2005 and such clarity of intention is also advisable in Scotland and Northern Ireland where there is no statute covering this point. Women of child-bearing age might want to consider the possibility of their advance decision being invoked at a time when they are pregnant. Although it is not a requirement, they may wish for the sake of clarity to state what they would want to happen in that event.

Health professionals witnessing advance decisions

As mentioned earlier, health professionals are often asked to witness an advance decision or note the patient's advance wishes in the health record. If they do so, it may be assumed that they verified the patient's capacity when the decision was made. In the BMA's view, this should not be automatically assumed, given that doctors do not normally assess patients' mental capacity unless there are reasons to question it. Adults are assumed to have mental capacity unless there is evidence to the contrary. Doctors who act as a witness and have no reason to believe that the patient suffers from impaired capacity may specifically add a note to that effect. If, however, there is any reason to doubt that the patient understands the implications of the decision, and especially if the consequences of the decision are likely to be serious or clearly pejorative for the individual, an assessment of capacity is advisable. The BMA and Law Society have jointly published guidance on assessing capacity.¹¹

Reviewing advance decisions

In England and Wales, the question sometimes arises as to whether an advance decision drafted long before the Mental Capacity Act was passed would still be valid. The Act sets out the criteria that must be met for an advance directive to be legally binding but this mainly echoes what was already the common law. Therefore an existing decision may continue to be valid but it is advisable for the drafter – if still competent – to check that it meets the criteria in the Act. If it does not conform to the criteria and the patient is already incompetent, much depends on the other available evidence of the individual's wishes and legal advice may be needed. Even if not legally binding, a clear statement of the individual's wishes can be helpful in establishing what would be in that person's best interests and it will be taken into account.

While competent, patients are recommended to review their advance decisions periodically. Lack of review does not necessarily invalidate an advance decision but may raise questions about it. Obviously, when there are multiple copies of a document lodged with various relatives or health professionals, it is vital to ensure they are all up to date and patients must take steps to make clear if the decision has been retracted. Dilemmas arise for health professionals if there is no indication of review and treatment options or the individual's medical condition

changed significantly prior to loss of competence. When they review their decision, patients should indicate that they have done so. An updated document is more likely to be applicable to the circumstances. Outdated or badly drafted decisions cause confusion and can result in patients being treated differently than they intended.

Storage of advance decisions

The main onus is on patients to make arrangements for any advance decision to be known about and people close to the patient should be aware of its existence. Many people who make advance decisions give a copy to their GP. For chronically ill patients, who are treated by a specialist team over a prolonged period, a copy of the advance decision should be in both relevant hospital files and the GP record.

Some people also carry a card, bracelet or other measure indicating the existence of an advance decision. As the National Programme for IT in the NHS develops, it may also be possible for patients to record the existence of their advance decision on the shared electronic record. Health professionals, once alerted to the existence of a relevant decision, should make reasonable efforts to find it. In an emergency, however, this may not be possible unless it is very promptly made available or registered on a system such as the electronic patient record.

Assessing validity

When time permits, efforts should be made to check the validity of any document presented. Basic verification includes checking that a written statement actually belongs to the patient who has been admitted, is dated, signed and witnessed. Emergency treatment should not be delayed in order to look for an advance decision if there is no clear indication that one exists. Nor should emergency measures be delayed if there are real doubts about the validity or applicability of an advance refusal.

In order to assess whether an advance refusal of treatment is valid, health professionals need to consider:

- Whether the current circumstances match those the patient envisaged;
- Whether the decision is relevant to the patient's current health care needs;
- Whether there is any evidence that the patient had a change of heart while still competent;
- Whether the decision, if old, has been reviewed;
- Whether, since the decision was last updated, new medical developments would have affected the patient's decision;
- Whether the patient subsequently acted in a manner inconsistent with the decision made in the advance decision or subsequently appointed a proxy decision-maker to make the decision in question.

The advance decision may be invalid if the current situation differs significantly from that which the patient anticipated. As mentioned previously, people who draft an advance refusal knowing that they have a diagnosis likely to result eventually in permanent loss of mental capacity may fail to envisage circumstances in the shorter term where an accident leaves them temporarily unconscious but capable of recovery. Anticipating the former, they may fail to make provision for the latter case, where they would want life-prolonging treatment provided. If a refusal is not

applicable to the circumstances, it is not legally binding although it may still give valuable indications of the general treatment options the patient would prefer. If a decision requests or consents to certain options, the health team will have to judge whether the treatment is medically appropriate or advisable for that patient at that time. If there is doubt about whether an advance directive is valid or not, a declaration should be sought from the Court of Protection in England and Wales, the High Court in Northern Ireland or the Court of Session in Scotland.

Implementation of an advance decision

If an incapacitated patient is known to have objections to all or some treatment, health professionals need to consider the available evidence about the patient's views. In England and Wales, the Mental Capacity Act requires that the advance decision be in a written form if it refuses life-prolonging treatment. It must also meet the other criteria set out in the Act. In other parts of the UK, the common law position which is set out earlier in this guidance prevails.

A valid written and witnessed treatment refusal is binding, unless retracted or unless a proxy was subsequently appointed to make the decision. Healthcare professionals are protected from liability if they:

- stop or do not initiate treatment that they reasonably believe has been refused by a valid and applicable advance decision;
- provide treatment if they have taken reasonable steps to find out if an advance decision exists but are unable to satisfy themselves that there is a valid and applicable advance decision.

Previous oral decisions about treatment can be helpful as part of decision-making but much depends on the reliability of the evidence and whether the individual was properly informed and envisaged the situation which has arisen. When individuals have been in-patients, they may have discussed their wishes with the health care team and made clear their expectations in terms of certain interventions. These verbal wishes should be noted in the medical record if the individual clearly wants them to be taken into account.

Disputes and doubts about validity

In any case of doubt or dispute, legal judgment will be based upon the strength of the evidence. Where there is genuine doubt about the validity of an advance refusal, there should be a presumption in favour of life and emergency treatment provided as it would be for other patients. As mentioned above, health professionals who follow what they reasonably believe to be a valid and applicable advance refusal of life-prolonging treatment are not liable for the consequences of withholding that treatment. But those who knowingly provide treatment in the face of a valid advance refusal may be liable to legal action.

Initially, the clinician in charge of the incompetent patient's care should consider the available evidence of the patient's former wishes and decide whether there is an advance decision which is valid and applicable to the circumstances. A clearly applicable advance refusal has legal force if the criteria are met and there is no reason to believe it was

either retracted or a proxy was appointed to make it. An advance request for positive interventions needs to be considered in the context of the individual's overall care and treatment options. There may be clinical reasons for not complying with a patient's requests but if it is for life-prolonging treatment, attention needs to be given to the legal issues discussed above in relation to the Burke case. In cases of serious doubt or disagreement about the scope or validity of an advance refusal, emergency treatment should normally be given while legal advice is sought.

In England and Wales, the Court of Protection can make a decision where there is genuine doubt or disagreement but it cannot overturn a valid advance refusal. In Scotland, if there is doubt about whether an advance decision is valid or not, a declaration can be sought from the Court of Session. In Northern Ireland, such a decision needs to be sought from the High Court.

Conscientious objection

Some health professionals disagree in principle with patients' rights to refuse life-prolonging treatment. They are entitled to have their personal beliefs respected but cannot impose them on patients who do not share them. They should make their conscientious objection clear when the matter of withholding or withdrawing treatment is first raised. If the patient still has capacity, he or she may wish to transfer to another health professional. For patients with an advance refusal of treatment who have already lost their mental capacity, arrangements need to be made for health professionals without a conscientious objection to handle the patients' care. In England and Wales, the Code of Practice on the Mental Capacity Act advises that if a transfer of care cannot be agreed voluntarily, the Court of Protection can direct those responsible for the care to make such arrangements. In an emergency, if no other health professional is available, health staff with a conscientious objection should not act contrary to a known and valid advance refusal. It is unacceptable and unlawful to force treatment upon a patient who has validly refused it in advance.

Part 3 – Proxy decision-making

If the decision to be taken concerns the withdrawal or withholding of life-prolonging treatment, the BMA's separate detailed guidance should be consulted.¹²

Legal situation on proxy consent to treatment decisions in England and Wales

Lasting powers of attorney (LPAs)

Although enduring powers of attorney relating to the management of property and affairs have existed since 1985, they were not applicable to medical decisions. Until the implementation of the Mental Capacity Act 2005 in October 2007, nobody was able legally to make medical decisions on behalf of another adult in England and Wales. Under the Act, powers of attorney extend to health and welfare decisions. As well as consenting to or refusing medical treatment, personal welfare decisions can include questions about where the incapacitated person lives, their daily care, their social activities, personal correspondence and arrangements for community care services. The BMA

has published separate detailed guidance on the Mental Capacity Act.

Appointing an attorney

Competent adults can nominate another person to make health care decisions on their behalf when they themselves lose capacity. If they do so, they are officially known as "donors" since they are giving decision-making power to someone else. To be valid, the LPA must be a written document on a statutory form and must describe the nature and effect of the LPA. The document must be signed by the donor and by the attorneys and include a decision by another independent person saying that the donor understands the LPA's purpose and makes it voluntarily. The decisions made by the attorney will then be as valid as if made by the donor. The legal transfer of health decision-making authority has to be specified and does not extend to refusing life-sustaining treatment *unless* this is explicitly stated. The individual creating the LPA can choose one or several people to make different kinds of decisions or to act jointly and can also set conditions on the exercise of the powers. The individual can also nominate replacement attorneys in case one dies or becomes unable to carry out the functions. Donors can have their LPA registered while they are still capable or attorneys can apply to register it.

Duties of attorneys

The Mental Capacity Act Code of Practice published by the Department for Constitutional Affairs provides detailed advice on Lasting Powers of Attorney and anyone acting as an attorney is advised to read it. Attorneys must abide by the principles of the Act and have to make decisions in the "best interests" of the incapacitated person, which includes considering the donor's known wishes. They must respect any restrictions or conditions posed by the donor. Where possible, donors should be assisted to make the decision in question for themselves and doctors may need to assess whether the donor has the mental capacity to make a particular decision. (See Part 1 on assessing capacity and also chapter 4 of the Mental Capacity Act Code of Practice). If the donor has sufficient capacity to make the health or welfare decision, a personal welfare LPA cannot be used (but a property and affairs LPA can be used if the donor still has capacity unless the donor specified otherwise). Before taking action under the LPA, attorneys must ensure that the LPA has been registered with the Public Guardian as an unregistered LPA does not confer any powers.

Role of health professionals regarding attorneys

When health professionals are preparing care plans for patients who have appointed a personal welfare attorney, they must first assess whether the patients themselves have capacity to agree the plan. If the patient lacks that capacity, agreement must be sought from the attorney, who should also be consulted about what is in the patient's best interests. The LPA allows attorneys to make decisions to accept or refuse medical treatment on the patient's behalf once the patient is incapable of making the decision, unless the LPA has specified that the attorney should not make those decisions. An attorney cannot consent to treatment if the patient made a valid advance refusal of it, unless the LPA was made *after* the advance decision and

transferred that decision to the attorney. Also if the patient wanted the attorney to have powers to accept or refuse life-prolonging treatment, the LPA must specifically state that. If the health team has a significant concern relating to medical treatment decisions taken under the authority of an LPA, the case can be referred for adjudication to the Court of Protection.

Independent mental capacity advocates

Another of the Mental Capacity Act's innovations in England and Wales is the development of an independent advocacy scheme for particularly vulnerable incapacitated adults who lack other forms of support. Where it is clear that a decision needs to be made on behalf of an incapacitated adult in relation to either serious medical treatment or place of residence and there is no one close to the adult to provide advice or guidance, including an attorney or deputy, an independent advocate should be involved. Serious medical treatment is defined as treatment which involves providing, withdrawing or withholding treatment in circumstances where:

- in the case of a single treatment being proposed, there is a fine balance between its benefits to the patient and the burdens and risks it is likely to entail for him or her,
- in a case where there is a choice of treatments, a decision as to which one to use is finely balanced, or
- what is proposed would be likely to involve serious consequences for the patient.

Disputes, Court of Protection and Court-appointed deputies

In England and Wales, the Mental Capacity Act also created a new Court of Protection, which is the final arbiter in relation to the legality of decisions made under the Act, including decisions in relation to an individual's capacity.

In addition to adjudicating in relation to specific decisions, the Court has the power to appoint deputies to assist with continued decision-making. (Chapter 8 of the Mental Capacity Act Code of Practice provides detailed guidance on the role and responsibilities of deputies). An appointment order sets out the specific powers and scope of the deputy's authority. There are some general limitations on their authority. Deputies cannot make decisions that they think the person concerned has the capacity to make him or herself. They cannot refuse life-sustaining treatment on the individual's behalf. Nor can they go against a decision made by an attorney acting under an LPA granted by the individual before losing capacity. Where concerns arise about whether an attorney acting under an LPA is making decisions in the best interests of the patient then the Court of Protection can adjudicate.

Legal position on proxy consent to treatment decisions in Scotland

The Adults with Incapacity (Scotland) Act 2000 gives health professionals the authority to do what is reasonable and necessary to safeguard the health of an incapacitated adult. It also makes provision for the appointment of health care proxies who should be consulted unless an emergency situation arises which would make such consultation impractical. The Office of the Public Guardian

holds a register of valid proxy decision-makers.¹³ The BMA has published separate detailed advice about the Adults with Incapacity (Scotland) Act.

Welfare attorneys and welfare guardians

Competent people over the age of 16 can appoint a welfare attorney to make medical decisions for them once their mental capacity is lost. Alternatively, the sheriff court can appoint a welfare guardian with similar powers. Once an attorney or guardian has been appointed, that person must be consulted about any proposed medical treatment where it is practical and reasonable to do so. Attorneys can consent to treatment on the patient's behalf or refuse it if they do so in accordance with the Act's principles which state that the chosen course of action

- must benefit the patient
- must provide benefit while being the least restrictive of the patient's liberty
- take account of the patient's former known wishes
- take account of the views of other relevant people insofar as it is reasonable and practical.

Listening to relatives

The Adults with Incapacity (Scotland) Act also obliges health professionals to take account of the views of the patient's nearest relative and primary carer.

Disputes, the Sheriff and the Mental Welfare Commission

If doctors propose a course of treatment for the incapacitated person which the welfare attorney refuses on the patient's behalf, the treatment cannot proceed until an opinion has been obtained from a doctor appointed by the Mental Welfare Commission for Scotland. If the appointed doctor agrees that treatment should be given, it can proceed even if the attorney continues to refuse but any of the parties – including the attorney or any other person with an interest in the patient's welfare – can apply to the Court of Session for a decision. If the welfare attorney asks on the patient's behalf for treatment which doctors consider inappropriate, an application can be made to the sheriff to declare whether or not the treatment would benefit the patient.

Legal position on proxy consent to treatment decisions in Northern Ireland

Currently in Northern Ireland, nobody can consent or refuse medical treatment on behalf of an adult who lacks mental capacity. Health professionals can, however, provide treatment without consent, if it is considered by the clinician in charge of the patient's care to be necessary and in the patient's best interests. The legal authority for this is based on common law. It dates back to a 1989 English case, *Re F*, in which the court made clear that necessary treatment can proceed where it would be in the best interests of an incapacitated adult, even though they cannot consent to it.

Re F

F was in her mid-30s and suffered from a severe mental disorder. She developed a sexual relationship with another patient in a residential facility. It was considered to be in her interests to allow her relationship to continue but

pregnancy was deemed to be something with which she could not cope. Minimally invasive methods of contraception were seen as unsuitable and so a legal declaration was sought that it would not be unlawful to sterilise F, even though she could not provide consent to the intervention. The House of Lords ruled that doctors could provide medical or surgical treatment to an incompetent adult where the treatment was necessary and in the patient's best interests.

F v West Berkshire HA [1989]¹⁴

Proxy consent to research

In England and Wales, the Mental Capacity Act permits the enrolling of incapacitated adults in some forms of medical research. It applies to research which is deemed "intrusive". That is to say, it covers research that would be unlawful if it involved a mentally competent adult who had not given consent. (Some research, such as that using anonymised data or anonymised tissue from living people does not require consent regardless of whether or not the donor has capacity.) The Act does not apply to clinical trials of new drugs which are covered by separate rules (see below). Researchers must ascertain whether the patient – although mentally impaired – can give a valid consent or refusal to being involved. If not, the general principles of the Act must be followed in terms of seeking the views of people close to the patient. The Mental Capacity Act Code of Practice (chapter 11) provides guidance on the sort of people who need to be consulted. Generally it would be a relative of the patient but could be a person involved in the patient's care or interested in his or her welfare. It cannot be a professional or paid care worker. A deputy appointed by the Court of Protection or an attorney acting under a registered LPA can be consulted about the patient's participation in research but not if the deputy or attorney are acting in a paid or professional capacity. In addition, research involving incapacitated adults can only proceed if:

- it has research ethics committee approval
- it cannot be carried out on competent adults
- it is linked to the diagnosis or treatment of the condition from which the patient suffers
- it fulfils the requirements of the Act and considers the individual's interests
- it is not contrary to the patient's interests and is likely either to benefit the patient or provide information to help others with similar conditions
- risks are negligible and the benefits are in proportion to any burdens
- any objections made by the incapacitated person are respected.

Regulations have also been drawn up under the Act to cater for the management and protection of an adult enrolled in a research project who loses capacity after the research has commenced.¹⁵

In Scotland, the Adults with Incapacity (Scotland) Act permits the involvement of incapacitated adults in research where the purpose is to gain knowledge about the causes, diagnosis, treatment or care of the patient's incapacity. The research may aim to provide direct benefit to the patient or

to improve knowledge of the patient's condition and so benefit other people suffering from it. In order for incapacitated adults to participate the following conditions must also be met:

- Consent from a proxy or the nearest relative is needed
- The patient must show no objection
- The research has ethics committee approval
- It involves no or only minimal risk for the patient
- It involves no or only minimal discomfort

In Northern Ireland, there is no statute covering this type of research and so participation of incapacitated adults is only clearly lawful if it is deemed to be in the interests of the individual.

Participation in clinical trials is regulated separately under the Medicines for Human Use (Clinical Trials) Regulations 2004 (SI 2004/1031) which permit the enrolment of incapacitated adults in clinical trials relating to pharmaceutical products. As with any other research project, proposals involving incapacitated adults must be approved by a Research Ethics Committee (REC), and it must not be possible to conduct the research involving individuals who retain the capacity to consent. Before an incapacitated individual can be enrolled in research, somebody close to the patient who is willing to be consulted should agree to it. This could be a close relative or a welfare attorney. Where such a person cannot be identified, a proxy decision-maker who is independent of the research can provide proxy consent. Additional safeguards are in place once the research is underway. Where the incapacitated individual shows signs of distress or resistance, these must be respected, and the individual withdrawn from the research. Likewise if he or she indicates by any means the wish not to continue to take part in the research, then he or she must be withdrawn.

Other relevant BMA guidance

This guidance note updates the BMA's 1995 Code of Practice on *Advance decisions about medical treatment* and summarises the legislation which impacts on medical decision-making for incapacitated adults. The Association has also issued separate guidance notes on the Scottish Adults with Incapacity Act (*Medical treatment for adults with incapacity: guidance on ethical and medico-legal issues in Scotland*) and detailed guidance on the implications of the Mental Capacity Act 2005 in England and Wales. Decisions about whether or not to intervene to prolong life after the loss of mental capacity is covered in detail in the BMA's book *Withholding and Withdrawing Life-prolonging Medical Treatment*. This guidance does not discuss euthanasia or physician assisted dying which are covered fully in other BMA publications, available on its website.

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

askBMA on 0870 60 60 828 or



British Medical Association
Department of Medical Ethics, BMA House
Tavistock Square, London WC1H 9JP
Tel: 020 7383 6286
Fax: 020 7383 6233
Email: ethics@bma.org.uk

Non-members may contact:

British Medical Association
Public Affairs Department, BMA House
Tavistock Square, London WC1H 9JP
Tel: 020 7387 4499
Fax: 020 7383 6400
Email: info.public@bma.org.uk

References

- 1 For England and Wales, the BMA and the Law Society have produced detailed guidance for doctors and lawyers on assessing capacity. Although the law differs in Scotland, clinical aspects of assessment of capacity are the same there and in Northern Ireland.
- 2 BMA, *Assessment of Mental Capacity*, 2nd edition, 2004 – undergoing revision for re-publication in autumn 2007.
- 3 BMA, *Withholding and Withdrawing Life-prolonging Medical Treatment*, 3rd edition, 2007.
- 4 The BMA has separate detailed guidance on the Act.
- 5 Re C (Adult: Refusal of Treatment) [1994] 1 WLR 290.
- 6 See, for example, *Airedale NHS Trust v Bland* [1993], *op cit*, Re T (Adult: Refusal of Treatment) [1993] Fam 95 and Re C (Adult: Refusal of Medical Treatment) [1994].
- 7 Re T (adult: refusal of medical treatment) [1992] 4 All ER 649.
- 8 BMA, *Withholding and withdrawing life-prolonging medical treatment: guidance for decision-making*, 3rd edition, 2007.
- 9 R (on the application of Burke) v General Medical Council [2005] 2 FLR 1223.
- 10 World Medical Association, *Declaration of Malta*, revised 2006.
- 11 BMA, *Assessment of Mental Capacity*, 2nd edition, 2004 – undergoing revision for re-publication in autumn 2007.
- 12 BMA, *Withholding and withdrawing life-prolonging medical treatment: guidance for decision-making*, 3rd edition, 2007.
- 13 www.guardianship.gov.uk or email custserv@guardianship.gsi.gov.uk.
- 14 Re F (mental patient sterilisation) sub nom F v W Berkshire HA [1989] 2 All ER 545.
- 15 Mental Capacity Act 2005 (Loss of Capacity During Research Project) (England) Regulations 2007. <http://www.opsi.gov.uk/si/si2007/draft/20075590.htm>. Mental Capacity Act 2005 (Loss of Capacity During Research Project) (Wales) Regulations 2007. http://newydd.cymru.gov.uk/docrepos/40382/dhss/4038226/Th_e_Mental_Capacity_Act_2002.pdf?lang=en.