

Seeking consent:

working with older people

Contents

	Page
Introduction	1
Seeking consent: people with capacity	3
When adults lack capacity	9
Research	13
Withdrawing and withholding life-prolonging treatment	15

Introduction

If your work involves treating or caring for people (anything from helping people with dressing to carrying out major surgery), you need to make sure you have the person's consent to what you propose to do, if they are able to give it. This respect for people's rights to determine what happens to their own bodies is a fundamental part of good practice. It is also a legal requirement.

The Department of Health guidance, *Reference guide to consent for examination or treatment*, sets out in detail the current English law on consent and gives references to legal cases and good practice guidance from regulatory bodies for those who want to know more. This booklet focuses on the particular issues which may arise when seeking consent from older people.

The first part of this booklet concentrates on older people who have the capacity to accept or refuse treatment or care, while the second part gives guidance on how you should act if the person is not capable of making their own decisions. It should *never* be assumed that people are not able to make their own decisions, simply because of their age or frailty. The third part looks at research and the final part looks at the particular issues which arise when considering if life-prolonging treatment should be withheld or withdrawn from a person.

The Government has set out its intentions, in the policy statement *Making decisions*, to create a new legal framework for adults who are unable to consent for themselves. This guidance sets out the current position, pending the creation of that new framework.

Seeking consent: people with capacity

General points on consent

For a person's consent to be valid, the person must be:

- capable of taking that particular decision (“competent”)
- acting voluntarily (not under pressure or duress from anyone)
- provided with enough information to enable them to make the decision.

Seeking consent is part of a respectful relationship with an older person and should usually be seen as a *process*, not a one-off event. When you are seeking a person's consent to treatment or care, you should make sure that they have the time and support they need to make their decision. People who have given consent to a particular intervention are entitled to change their minds and withdraw their consent at any point if they have the capacity (are ‘competent’) to do so. Similarly, they can change their minds and consent to an intervention which they have earlier refused. It is important to let the person know this, so that they feel able to tell you if they change their mind.

Adults with the capacity to take a particular decision are entitled to refuse the treatment being offered, even if this will clearly be detrimental to their health. The only exception to this rule is where treatment is being provided for mental disorder, under the terms of mental health legislation (in which case more specialist guidance should be consulted). Detention under mental health legislation does not give a power to treat unrelated physical disorders without consent.

Legally, it makes no difference whether people sign a form to indicate their consent, or whether they give consent orally or even non-verbally (for example by holding out an arm for blood pressure to be taken). A consent form is only a record, not proof that genuine consent has been given. It is good practice to seek written consent if treatment is complex, or involves significant risks or side-effects. If the person has the capacity to consent to treatment for which written consent is usual but cannot write or is physically unable to sign a form, a record that the person has given oral or non-verbal consent should be made in their notes or on the consent form.

Does the person have capacity?

Adults are always presumed to be capable of taking healthcare decisions, unless the opposite has been demonstrated. This applies just as much to older people as to any other adult: age or frailty alone is not a reason for doubting a person's capacity. Where any doubt does exist, you or an appropriate colleague should assess the capacity of the person to take the decision in question, drawing on the assistance of specialist colleagues as necessary. This assessment and the conclusions drawn from it should be recorded in the person's notes.

For people to have the capacity to take a particular decision, they must be able to

- comprehend and retain information material to the decision, especially as to the consequences of having or not having the intervention in question, and
- use and weigh this information in the decision-making process.

It is very easy for an assessment of capacity to be affected by organisational factors such as pressure of time, or by the attitude of the person carrying out the assessment. It is your professional responsibility to ensure that you make as objective a judgement as you can, based on the principle that the person should be assisted to make their own decision if at all possible. It is essential

that the information you provide is appropriate and accessible for the particular patient (see page 7). Methods of assessing comprehension and ability to use information to make a choice include:

- exploring the patient's ability to paraphrase what has been said (repeating and rewording explanations as necessary);
- exploring whether the patient is able to compare alternatives, or to express any thoughts on possible consequences other than those which you have disclosed;
- exploring whether the patient applies the information to his or her own case.

Some people may therefore have capacity to consent to some interventions but not to others. People suffering from the early stages of dementia, for example, would probably still have capacity to make many straightforward decisions about their own care (for example washing or bathing, or whether or not to have an operation to correct a hernia) but might lack capacity to take very complex decisions. It should *never* be assumed that people can take no decisions for themselves, just because they have been unable to take a particular decision in the past. A person's capacity may also fluctuate: they may, for example, be able to take a particular decision one day even if they had not been able to take it the day before. Where a patient's capacity is fluctuating you should if possible delay treatment decisions until a point when the patient has the capacity to make their own decision. People close to the patient may sometimes be able to assist you in choosing an appropriate time to discuss the patient's healthcare wishes.

Capacity should *not* be confused with your assessment of the reasonableness of the person's decision. People are entitled to make a decision based on their own religious belief or value system, even if that decision is perceived by others to be irrational, as long as they understand what is entailed in their

decision. For example, people might refuse an operation which you and your colleagues believe is in their best interests because they do not want to take the risk, even if the risks in fact are very low. If a decision seems irrational, discuss it with the person, and find out the reasons for the refusal. In some cases, further information and discussion may mean the person would like the treatment to go ahead, perhaps in a slightly different form. However, you must never try to coerce the person into changing their decision. Seeking consent is about helping the person make their own, informed, choice, and different people will come to different decisions.

In practice, people also need to be able to communicate their decisions. You should take all steps which are reasonable in the circumstances to ensure that people can communicate their decisions, using interpreters or communication aids as appropriate. If a person is having difficulties communicating after a stroke, for example, people who know the patient well may be in the best position to understand what they are trying to say. Specialist colleagues such as speech and language therapists may also have an important part to play.

It is important that the person helping to 'translate' the older person's wishes realises that it is the older person's views and wishes which are important, not what they think is best for the older person. In some cases it may also be appropriate to make use of independent advocates.

What information do people need?

People clearly need enough information before they can decide whether to consent to, or refuse, treatment. In particular, they need information about:

- the benefits and the risks of the proposed treatment
- what the treatment will involve
- what the implications of not having the treatment are

- what alternatives may be available
- what the practical effects on their lives of having, or not having, the treatment will be.

It is essential that this information is provided in a form that the particular person can understand. This may involve using interpreters, where the person's first language is not English, and offering information in a variety of forms depending on the person's needs (for example if they have any sensory impairment) and preferences. Information about national and local support groups and advocacy schemes may also be very helpful both to the person and where relevant to those caring for him or her.

The manner in which information is presented is also important. You should ensure that information is provided in a respectful way, for example by finding an appropriate, private place to discuss confidential matters and by ensuring that you address the person in the way that they prefer. Independent advocates may often have a role to play in helping patients obtain the information they need – for example where the patient finds it difficult to ask questions of those perceived to be in authority, or where there are possible conflicts of interest between the patient and those close to him or her.

Is the person's decision made voluntarily?

It is very important to ensure that the person's decision is truly their own. Clearly, both you and your colleagues and people close to the older person have a role to play in discussing the options, but you should take care that older people do not feel forced into making decisions they are not happy with because of pressure from others.

Example 1

Mrs. A has suffered a stroke. She is now recovering but is experiencing some difficulties with speaking. Her blood pressure is high and it has been suggested that blood pressure medication would be appropriate to reduce the risk of further strokes. A nurse has explained to Mrs. A why blood pressure medication might help her, along with information about the main risk of such medication: that she might feel dizzy if she tried to stand up too quickly. Mrs. A appeared to understand the explanation and nodded her head when asked if she agreed to the medication. However, when the nurse attempted to help her to swallow the tablets, Mrs. A became very distressed and spat them out. The nurse was not able to establish whether Mrs. A had changed her mind about the medication, or whether there was any other problem.

Mrs. A's daughter has been visiting her daily and finds it easier to understand her mother's speech as she is able to spend much more time with her than any individual member of staff can. The nurse asks her for help in seeking her mother's views on blood pressure medication. The daughter knows that her mother has always had difficulties swallowing tablets, and is able to establish that this is the cause of her mother's distress. When the hospital staff realise this, they are able to offer the medication in an oral solution instead, which Mrs. A willingly accepts.

When adults lack capacity

General points

Even where information is presented as simply and clearly as possible, some people will not be capable of taking some decisions. This will obviously apply when a person is in a coma, for example. It may also apply to people with severe dementia, although you should never automatically assume that a person lacks capacity simply because they have dementia. A patient's capacity should always be assumed until proved otherwise.

If a person is *not* capable of giving or refusing consent, it is still possible for you lawfully to provide treatment and care, unless such care has been validly refused in advance (see below). However, this treatment or care *must* be in the person's "best interests". See page 10 for more information on how "best interests" should be determined.

No-one (not even a spouse, or others close to the person) can give consent on behalf of adults who are not capable of giving consent for themselves. However, those close to the incapacitated person should always be involved in decision-making, unless the older person has earlier made it clear that they don't want such involvement. Although, legally, the health professional responsible for the person's care is responsible for deciding whether or not particular treatment is in that person's best interests, ideally decisions will reflect an agreement between professional carers and those close to the older person.

Advance directives

Sometimes people may have expressed clear views in the past as to how they would like to be treated if in future they were to lose capacity. Such views may have been expressed orally or in writing as “advance directives” or “living wills”. Advance directives may take two forms: they may explicitly refuse particular treatment, or they may spell out the kind of care a person would wish to receive in certain circumstances.

If a person makes an advance *refusal* of certain kinds of treatment, then such a refusal is legally binding if at the time of making the decision the individual was competent, they understood in broad terms the implications of their decision, and the refusal is applicable to their current situation. Advance directives setting out the kind of care the person would like to receive are *not* legally binding, but should be influential when deciding what treatment is in the person’s best interests.

Best interests

The courts have made clear that a person’s “best interests” are not limited to what would benefit them *medically*. Other factors, such as the views and beliefs that they held before they lost capacity, their general well-being, their relationships with those close to them, and their spiritual and religious welfare, should all be taken into account. Moreover, people who lack capacity to consent or refuse a particular treatment option may still express willingness or unwillingness to co-operate with what is being offered. Such preferences should always be taken into account when deciding whether the proposed care or treatment is genuinely in the patient’s best interests.

The only interests which you should take into account when deciding if particular treatment is appropriate are the *older person's* best interests. It is not lawful to balance these interests against the interests of their family, or the interests of health professionals.

Ideally, decisions should be made which both those close to the older person and the healthcare team caring for the person agree are in that person's best interests. If it proves impossible to reach such agreement over significant decisions, the courts can be asked to determine what is in the older person's best interests. Family members cannot require clinicians to provide a particular treatment if the health professionals involved do not believe that it is clinically appropriate. However, as a matter of good practice you should explain to people close to the patient why you believe the treatment they have suggested is inappropriate. Where possible, a second opinion should be offered.

Where a decision to provide treatment is taken on the basis that this is in the person's best interests, the standard consent form should not be completed. Instead, you should make a written record (either in the person's notes or on a form for adults who are unable to consent) of the reasons for your decision and the involvement of those close to the person. Any disagreement between the clinical team and those close to the person should also be recorded.

Example 2

Mr. B has severe dementia. He lives with his wife, but spends one weekend a month in respite care so that his wife can take a break from caring for him. He has two sons, but only one is in regular contact, coming every few weeks to visit and take him out on trips. Mr. B is suffering from a cataract and his doctor has suggested that he should have an operation to remove it.

Mr. B is no longer able to remember facts for more than a few seconds, often asking the same question over and over again. His wife and his son, as well as his doctor, have tried to explain very simply to him what the operation will involve, but it is clear from his repetitive questions that he has not understood, and is not able to use the information to make a decision. He therefore lacks capacity to consent or refuse the offered treatment, and so a decision has to be made on the basis of his 'best interests'.

The doctor discusses the options with Mrs. B and her son and with a carer from the respite care home. In the past, Mr. B had had several operations and had had no hesitation about consenting to anaesthetic or sedation. He also still enjoys watching a lot of sport on television, and his cataract is significantly affecting his ability to do this. However he does get very distressed if he wakes up in an unfamiliar environment, and Mrs. B is concerned that he will find the whole experience deeply distressing, especially if it involves a hospital stay.

The family, doctor and care worker all agree that a cataract operation will significantly improve Mr. B's quality of life and that if possible it should go ahead. It is agreed that Mr. B should have the operation as day surgery, with Mrs. B able to be with him the whole time to provide reassurance.

Research

The same principles apply to seeking consent for research as for consent to treatment. Patients who have the capacity to give or withhold consent to research will decide for themselves whether or not they wish to participate.

The law relating to research where people are unable to give consent for themselves, is however currently unclear. In general, it is not appropriate to carry out research on adults who cannot give consent for themselves, if the research can instead be carried out on adults who are able to give or withhold consent. The only exception to this rule would be where clinicians believe that it is in the person's own best interests to be involved in research, as described below.

Therapeutic research

Treatment for many conditions is imperfect, and research is often carried out to develop new treatments, or compare the effectiveness of existing treatments. It may occasionally be in the best interests of a person who lacks capacity to consent to be entered into a clinical trial of a new treatment, for example if a standard treatment is non-existent, or of very limited effectiveness. You **must** be able to justify a decision to enter an incapacitated person into such a research trial on the basis of that individual's best interests.

Non-therapeutic research

Bodies such as the Medical Research Council and the Royal College of Physicians have suggested that it can be lawful to carry out research on incapacitated adults which will not benefit the individual, as long as this is

not against the interests of the individual. Such research might include, for example, taking extra blood samples, for the purposes of research into the condition from which the person is suffering. Such research should **never** be considered in incapacitated people if it is possible to carry it out instead on people with capacity. The principle that such research is lawful has never been tested in the courts, and this type of research should be considered with caution.

Withdrawing and withholding life-prolonging treatment

As medical science develops, it has increasingly become possible to prolong a person's life despite the failure of essential bodily functions: for example through artificial nutrition and hydration where a person is not able to absorb food in the usual way, or through artificial respiration where the person cannot breathe on their own.

Often, there will be no doubt that such treatment is benefiting the person and should be continued. However, in certain circumstances, for example where a person is suffering from the final stages of a terminal disease, or where the burdens the treatment imposes on the person outweigh the benefits to the person, it should not automatically be assumed that life should be prolonged at all costs, as this may not be in the patient's best interests (see page 10). Such a decision is distinct from a deliberate intervention with the intentional aim of ending life, which constitutes euthanasia and is unlawful.

The same broad principles apply to providing, or withholding, life-prolonging treatment as apply to any other kind of treatment:

- if people with capacity refuse treatment, the refusal must be accepted;
- if people no longer have capacity but have clearly indicated in the past that they would wish to refuse such treatment in the circumstances in which they now find themselves, the refusal must be accepted;

- if people no longer have capacity, and have not clearly indicated their wishes in the past, the decision to provide or withhold life-prolonging treatment must be based on an assessment of their best interests. The patient's age alone should never be a determining factor in assessing their best interests.


Cardiopulmonary resuscitation can in theory be carried out on any person in whom cardiac or respiratory function ceases. It will not, however, always be appropriate: for example where a person is in the final stages of a terminal illness. Ideally, decisions as to whether or not it will be appropriate to attempt resuscitation should be made in advance, when they can be properly considered. Competent people must be involved in these discussions, unless they make clear that they do not wish to discuss resuscitation. Great sensitivity must be used in seeking patients' views on resuscitation, and they should be given as much time and support as they need to make the decision. The BMA, Resuscitation Council and RCN have published detailed guidance on what procedures should be followed when decisions about resuscitation need to be made.¹ NHS Trusts are required to have local policies on resuscitation, along with information about them for patients.

Where a person lacks capacity, the responsibility for taking a decision to withhold or withdraw life-prolonging treatment rests with the doctor in charge of the person's care. However, those close to the older person should *always* be involved in coming to such a decision, unless the older person has made very clear in the past that such involvement would be unacceptable. Other healthcare professionals caring for the person should also be involved in the decision-making process. Any decision not to administer cardiopulmonary resuscitation must be reviewed regularly in the light of the person's progress. It should not be seen as a one-off decision.

¹ *Decisions relating to cardiopulmonary resuscitation: a joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing*, 2001, available at web.bma.org.uk/cpr

Legally, artificial nutrition and hydration (ANH) is considered to be medical treatment, and so the same rules should apply as for any other kind of treatment. However, the BMA has suggested that extra safeguards should be followed if it is believed that continuing to provide ANH is not in a person's best interests. A senior clinician, not involved in the person's day-to-day care, should review the case, details should be made available for clinical audit, and if the person is in 'permanent vegetative state' or a state very close to PVS, legal advice should be sought. The courts have stated that it is good practice for court approval to be sought before ANH is withdrawn from people in PVS.

This booklet has been produced with advice from the Department of Health's "Good practice in consent" Advisory Group. The text of this leaflet and other publications on consent can be found on the internet at www.doh.gov.uk/consent or ordered from the NHS Response Line on 08701 555 455.



If you require further FREE copies of this publication
please contact:

Department of Health Publications
PO Box 777
London SE1 6XH
Fax: 01623 724524
E-mail doh@prolog.uk.com

Please quote reference 25753 when ordering.

It is also available on our website at:
www.doh.gov.uk/consent

This publication can also be made available in braille, by email, or in large print,
on request.

The text of this document may be reproduced without formal permission or
charge for personal or in-house use.



First Published: November 2001

© Crown Copyright
Produced by the Department of Health
25753 1p 20k Nov 01 (BEL)
CHLORINE FREE PAPER