

Seeking consent:

**Working with
older people**

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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 Social Services and Public Safety guidance, Reference Guide to Consent for Examination, Treatment or Care, sets out in detail the current law on consent and gives references to legal cases and good practice guidance from regulatory bodies. This booklet focuses on the particular issues which may arise when seeking consent from older people. There are separate booklets for those working with children and people with learning disabilities.

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 final part looks at the particular issues which arise when considering if life-prolonging treatment should be withheld or withdrawn from a person.

This guidance also sets out the current legal position on adults who are unable to consent for themselves.

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 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 or care being offered, even if this will clearly be detrimental to their health. Mental health legislation does provide the possibility of treatment for a person's mental disorder without their consent (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.

Consent is a process. Legally, it makes no difference if people give their consent verbally or non-verbally (for example by holding out an arm for blood pressure to be taken) or signing a consent form. 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 or care is complex, or involves significant risks or side effects. If the person has the capacity to consent to treatment or care for which written consent is usual but cannot write or is physically unable to sign a form, a record that the person has given verbal 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 their own health and social care decisions, unless the opposite has been demonstrated. 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 or case records.

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

- comprehend and retain information relevant to the decision, especially as to the consequences of receiving or not receiving the treatment or care 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 to the person (see page 5). Methods of assessing comprehension and ability to use information to make a choice include:

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

Some people may therefore have capacity to consent to some treatment or care provisions 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 treatment or care 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 person's capacity is fluctuating you should if possible delay treatment or care decisions until a point when the individual has the capacity to make their own decision. People close to the person may sometimes be able to assist you in choosing an appropriate time to discuss his or her health or social care wishes and options.

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, as long as they understand what is entailed in their decision, even if that decision is perceived by others to be irrational. For example, people might refuse an operation which you or your colleagues believe is in a patient's 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 or care 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. In some cases it may also be appropriate to make use of independent advocates. Where a language barrier exists an independent interpreter should be used as opposed to a family member. If a person is having difficulties communicating, people who know him or her 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 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 or care. In particular, they need information about:

- the benefits and the risks of the proposed treatment or care
- what the treatment or care will involve
- what the implications are of not receiving the treatment or care
- the alternatives that may be available
- the practical effects on their lives of receiving , or not receiving the treatment or care

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 regional 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 people obtain the information they need – for example where the person finds it difficult to ask questions of those perceived to be in authority, or where there are possible conflicts of interest between the person 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 great care that older people do not feel forced into making decisions they are not happy with because of pressure from others.

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 person'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 8 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 and social care professionals responsible for the person's care are responsible for deciding whether or not particular treatment or care 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

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 verbally or in writing as "advance directives" or "living wills". Advance directives may take two forms: they may explicitly refuse a 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 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 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 or care is genuinely in the person's best interests.

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

Ideally, decisions should be made which those close to the person and the health and social care 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 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 professional team and those close to the person should also be recorded.

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 burden of treatment imposed 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 8). 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. Great sensitivity must be used in seeking a patient's views on resuscitation unless they make clear that they do not wish to discuss resuscitation. They should be given as much time and support as they need to make a decision. The BMA, Resuscitation Council and RCN have published detailed guidance on what procedures should be followed when decisions about resuscitation need to be made¹. Health Personal Social Services (HPSS) Trusts will 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 health care 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.

Legally, artificial nutrition and hydration (ANH) is considered to be medical treatment or care, and so the same rules should apply as for any other kind of treatment or care. However, the British Medical Association (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' (PVS) 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.

¹ Decisions relating to cardiopulmonary resuscitation: a joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, 2002 available at www.bma.org.uk/cpr

Examples

A number of examples are given to illustrate the general principles of consent. They are not intended to provide guidance on specific cases but to enable you to assess how the issue of consent may affect your work with older people. Consent **MUST** be assessed on an individual basis.

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 realize this, they are able to offer the medication in an oral solution instead, which Mrs A willingly accepts.

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 or care, 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.

Example 3

Mr. J has a severe physical impairment. His wife cares for him, undertaking all his intimate personal care. He has always refused any form of help from the local Trust.

Mrs. J is desperate for some time to herself to see friends. She has received a carer's assessment from the Trust. She agrees with the care manager that the best way for her to get a break is for a home-care worker to provide a non-intimate sitting service, for three hours per week. Her husband won't like it (even though the home-care worker will leave him to his own devices) but he will agree to have the home-care worker in the house and she will enjoy her break knowing her husband is relatively safe.

One day the home-care worker hears Mr. J cursing and swearing. The care worker realizes that, while using the toilet, Mr. J has had an accident and is now dirty. The care worker calls to him: 'Are you all right?' Mr. J tells him to mind his own business. The care worker has no choice but to do just that, since Mr. J does not want help and he is at no imminent risk. Although his wife will be upset to find her husband dirty when she gets home, the care worker cannot intrude on Mr. J's privacy without his consent.

A few months later, while Mrs. J is out, Mr. J falls from his chair. The care worker hears the noise and calls to him: 'Are you all right?' Mr. J tells him to mind his own business, but this time it sounds like he is in real discomfort. The care worker investigates. Mr. J is lying very near the electric fire. He again insists on being left alone. The care worker turns off the electric fire so that Mr. J is safe until his wife returns.

Again, during one of the care worker's visits, Mr. J falls out of his chair, this time on his back. Again, he rejects help, but the care worker has been told that in his current condition, lying on his back could cause Mr. J to choke and he might therefore die if left. The care worker goes into his room and lays him on his side so he is no longer in any danger. Mr. J is furious, so the care worker provides no further assistance.

Further Sources Of Guidance And Information

Department of Health, Social Services and Public Safety, Reference Guide to Consent for Examination, Treatment or Care (available on www.dhsspsni.gov.uk)

General Medical Council, Seeking patients' consent: the ethical considerations (1998) GMC: London. (www.gmc-uk.org)

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