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Seeking consent:

working with people with
learning disabilities

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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 their 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 adults with learning disabilities. There is a separate booklet for those working with children.

The first part of this booklet concentrates on people who have the capacity to give or withhold consent to treatment, while the second part gives guidance on how you should act if the person is not able to make their own decisions. It should *never* be assumed that people are not able to make their own decisions, simply because they have a learning disability. 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part looks at the particular issues which arise when considering if life-prolonging treatment should be withheld or withdrawn from a person.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 support of families, friends, carers and others close to them will often be very important for people with learning disabilities. This guidance uses the phrase 'people close to the person' to refer to all these possible sources of support.

The Government has set out its intentions, in the policy statement *Making decisions*, to create a new legal framework for adults 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 people with learning disabilities, 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 they have the time and support they need to make their decision, unless the urgency of their condition prevents this. 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.

Where a patient objects and appears to withdraw consent during treatment, it is good practice to stop the procedure, if possible, and to establish the patient's concerns. Sometimes, an apparent objection may reflect pain or distress, rather than withdrawal of consent, and appropriate reassurance may enable you to continue with the procedure. If stopping the procedure at that point would genuinely put the patient's life at risk, you may be entitled to continue until the risk no longer applies.

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 people with learning disabilities as to any other adult. Where any doubt exists, 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 such as learning disability teams and speech and language therapists as necessary. This assessment and the conclusions drawn from it should be recorded in the person's notes or, where appropriate, in a form for adults who are unable to consent.

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 available for people with learning disabilities is appropriate and accessible (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.

People with learning disabilities will often have support from people close to them (family members, carers or friends) or from independent “supporters” or advocates, who can help them understand the issues and come to their own decisions. Where appropriate, colleagues from local learning disability community teams will also be able to act as ‘health facilitators’ on behalf of the patient.

Some people may have capacity to consent to some interventions but not to others. People with a mild to moderate learning disability, for example, would probably have capacity to make many straightforward decisions about their own care (such as deciding whether to have an operation to correct a hernia), but some 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. Occasionally an individual might temporarily lack capacity to take a particular decision because of an extreme phobia (for example, an overpowering fear of needles); again you should never assume that the individual lacks capacity to make any other decisions.

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, a person 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 where appropriate those supporting them, and find out the reasons for the refusal. In some cases, further information and discussion may mean the person would want 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 help communication between yourself and the person, using interpreters or communication aids as appropriate. If you and the person are having difficulties understanding each other, those close to the person may well be able to help, as may specialist colleagues such as speech and language therapists.

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 pictures, or explaining what is involved in simple terms and short sentences and being willing to repeat or reword explanations. Communication aids such as boards where people can indicate 'yes' or 'no' may also be helpful. You should also always check to make sure that the person has understood. Where a person's first language is not English, you may need to use an interpreter. If they use a sign language such as Makaton, then again an interpreter will be needed. St George's Hospital Medical School has published a booklet *Going into hospital* which uses pictures to explain many of the experiences which a person may have in hospital.¹

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.

¹ Sheila Hollins et al, *Going into hospital*, Gaskell/St. George's Hospital Medical School, London, 1998

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 person have a role to play in discussing the options, but you should take care that people do not feel forced into making decisions they are not happy with because of pressure from others, or are simply agreeing out of a desire to comply with authority.

Example 1

Ms Y is a 44 year old woman with a moderate learning disability who is going through the menopause. For several years she has had heavy periods, and medical treatment for them has been only partially successful. She is offered a hysterectomy which she refuses.

Ms Y is able to understand what is involved in the operation, and can weigh up the information provided to come to her decision. She therefore has the capacity to make the decision herself. However, she believes that once she has had a hysterectomy she will no longer be able to have sex with her longstanding partner. When she understands that this is not the case, she consents to the hysterectomy.

Example 2

Mrs. X is also a 44 year old woman with a moderate learning disability who is going through the menopause. She too has heavy periods which medical treatment has done little to alleviate. Like Ms Y she is able to understand what is involved in the operation, and is able to apply this information to her own condition. She therefore has the capacity to decide for herself.

Mrs. X does not want to have a major operation, and decides that she would rather cope with the effects of the heavy periods. She refuses the hysterectomy.

Example 3

Mr. B has a severe learning disability. He was found to have a brain tumour which would be fatal if left untreated. A high risk operation was possible. Over a period of weeks, Mr. B was talked through this very difficult decision with support from those who knew him well. Having understood the necessary information, he made a clear decision not to have the operation. He subsequently died – in control of his own body.

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 unconscious, for example. It may also apply to some people with severe learning disabilities. However, you must never make this judgement until all practicable steps have been taken to help the person make their own decision.

If a person is *not* capable of giving or refusing consent, it is still possible for you lawfully to provide treatment and care. However, this treatment or care *must* be in the person's "best interests".

No-one (not even the person's parents, or others close to them) 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 person makes clear that they don't want particular individuals to be involved. 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 (doctors, nurses, dentists etc) and the individual's family and friends.

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 people’s “best interests” are not limited to what would benefit them *medically*. Other factors, such as 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 to 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 person’s best interests. For example, if, despite all reassurance, a patient becomes very distressed by a particular investigatory procedure, this will be an important factor to bear in mind when deciding if the procedure is really essential.

The only interests which you should take into account when deciding if particular treatment is appropriate are the *person's* best interests. It is not lawful to balance these interests against the interests of their family, the interests of health professionals, or the interests of other people living with the individual. However, these interests will often be inter-linked: for example the effect of a treatment decision on family relations should be taken into account as part of the individual's "best interests", where family support is important to the person with learning disabilities.

Ideally, decisions should be made which both those close to the person and the healthcare team agree are in the 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. The courts have stated that certain procedures (including sterilisation for contraceptive purposes and donation of regenerative tissue such as bone marrow) should never be carried out without being first referred to a court. It is very unlikely that it would ever be in the best interests of a person lacking capacity to donate a solid organ, but were this to be considered it should also be referred to a court.

Family members cannot require clinicians to provide a particular treatment if the health professionals involved do not believe that it is clinically appropriate, but as part of a good relationship with those close to the person you should explain why you believe the treatment is inappropriate. Where possible, a second opinion should be offered. You must never make assumptions that particular treatments are inappropriate just because the patient has a learning disability. This is discriminatory and unlawful.

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 4

Mr. A is 40 and has severe learning disabilities. He lives with his parents and regularly attends a day centre, where he gets on very well with two particular care workers. He particularly enjoys hill-walking. He is currently suffering some discomfort from an inguinal hernia and an operation has been suggested to correct this.

Capacity

Although both clinicians and Mr. A's family have explained the proposed operation on several occasions in very simple terms, Mr. A is not able to understand what an operation might involve, or how it might help his current discomfort. He therefore lacks the capacity to make this particular decision for himself.

Best interests

The surgeon who suggested that Mr. A might benefit from the operation consults Mr. A's parents and other professionals involved with Mr A's care about Mr. A's best interests. The clinical benefits of the treatment are that it will reduce the discomfort which Mr. A is currently experiencing, and will also avoid the danger of possible emergency surgery in the future, should a section of gut become trapped in the hernia. More generally, Mr. A will be able to enjoy hill-walking again. The clinical disadvantages of the treatment are the risks inherent in any operation. There are, however, other disadvantages, as Mr. A is very frightened of needles – both Mr. A's care worker and his parents explain how distressed he has become in the past when he has had to have an injection.

Decision

The healthcare team and all those close to Mr. A agree that it would be in his best interests to have the operation, but to induce anaesthesia by mask instead of through injection. Mr. A's mother and one of his care workers go with him to the hospital for the operation and reassure him at each stage.

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 ventilation 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 last 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 person's best interests (see page 11). 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 do not have capacity, the decision to provide or withhold life-prolonging treatment must be based on an assessment of their best interests;
- if a person has refused the treatment in advance in a valid advance directive, this refusal must be honoured.

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 (UK) and RCN have published detailed guidance on what procedures should be followed when decisions about resuscitation need to be made.² 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 person should *always* be involved in coming to such a decision, unless the person has made very clear in the past that particular individuals should not be involved in their care. Other healthcare professionals caring for the person should also be involved in the decision-making process. When considering what will be in the person's best interests you should *never* make assumptions about the quality of life of someone with severe learning disabilities, or how that person values their life. In particular, you should use the person's ordinary life with their disability as the baseline from which to judge whether treatment will impose excessive burdens on them.

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

² *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 from web.bma.org.uk/cpr

followed if the person is unable to take a decision for himself or herself and it is believed that continuing to provide ANH is not in his or her 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.

Further sources of guidance and information

Appelbaum and Grisso, *Assessing competence to consent to treatment - a guide for physicians and other health professionals* (1998) OUP: Oxford

Department of Health, *Reference guide to consent for examination or treatment* (2001), Department of Health: London (available at www.doh.gov.uk/consent)

Joseph Rowntree Foundation, *Plain facts* magazine about research for people with learning disabilities and their supporters: includes an issue on healthcare decision-making (www.plain-facts.org)

Keywood, Fovargue and Flynn, *Best practice? Health care decision-making by, with and for adults with learning disabilities* (1999) National Development Team: Manchester (available from NDT, St Peter's Court, 8 Trumpet Street, Manchester M1 5LW)

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.





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