

Consent to medical treatment for eye health

The Mental Capacity Act (2005) is designed to help people over the age of 16 to make their own decisions whenever possible. It also aims to enable people unable to make certain decisions to receive care or intervention which is in their best interests. The legislation sets out principles to guarantee any treatment or intervention benefits the person involved and that each person's rights are promoted, even when they are unable to make a decision. The Act aims to ensure the right treatment is provided for the person, taking into account their views and the views of their main carers, supporters, advocates and professionals. People in Scotland are covered by the Adults With Incapacity Act (2000).

Adults with learning disabilities are ten times more likely than others to have serious sight problems. If a sight test identifies an eye condition which can only be treated effectively with an invasive procedure, for example cataracts, this can be worrying for a person with learning disabilities and for their carers and supporters. Making a decision about consent for medical treatment may not be easy, but a learning disability should not stop anyone from benefiting from treatment which could improve their quality of life and which is readily available to others.

This factsheet explains issues around consent to treatment. By using case examples we'll illustrate how the Mental Capacity Act (2005) should be used. We'll also look at how people with learning disabilities should be supported to make decisions according to their capacity to consent and, when necessary, how to ensure that decisions taken by others are in the person's best interest i.e. providing the right treatment at the right time to maintain or improve health or wellbeing.

Further reading from SeeAbility:

Eye Surgery Support Plan to help coordinate eye surgery for someone with learning disabilities

Easy read factsheet about **Consent and Capacity**

The Mental Capacity Act (2005)

What does the Mental Capacity Act (2005) mean for access to eye care treatment?

Case examples

(Explanation of terms used can be found in the glossary towards the end of this factsheet).

George, aged 72, was told by his consultant at the hospital that he needed surgery to remove cataracts which were impairing his vision. The consultant felt George had a mild learning disability, which was confirmed by his supporter. George could fully understand the procedure recommended by the consultant and understood possible benefits and risks from the treatment. George could also appreciate there might be side effects. George consented to treatment and the cataracts were removed, resulting in improved vision and quality of life for George. The procedure was not only in George's best interests, but he could fully understand the issues involved in the treatment.

Learning points:

For consent to be valid, it must be given voluntarily by an appropriately informed person who has the capacity to consent to the intervention in question. If a person with a learning disability fully understands a treatment or intervention and it is in his or her best interests, then this person can consent to treatment.

Abdullah, aged 58, was told by his consultant at the hospital that he needed surgery to remove cataracts which were impairing his vision. Abdullah has a mild learning disability and could fully understand the procedure recommended by the consultant. After being given information about cataract surgery, he understood possible benefits and risks from the treatment, as well as any potential side effects. Abdullah refused the treatment. He said he had made his mind up because he felt that he was happy with his quality of life and felt, for him, the treatment wasn't needed. The community nurse disagreed and noted that in her opinion Abdullah would benefit from the treatment and so treatment should proceed.

Abdullah's opinion was respected: treatment should not proceed if the person has a full understanding of the intervention or treatment, and can appreciate both positive and negative potential effects from the procedure. The community nurse must respect the person's opinion even if she disagrees with it. It is important to recognise that Abdullah can, at any stage, change his mind. If he did change his mind, and agree to have surgery, this decision must also be respected.

Abdullah may benefit from ongoing monitoring and support which should continue to be offered to him.

Learning points:

Care should be taken not to underestimate the capacity of a patient with a learning disability to understand. Many people with a learning disability do have the capacity to consent if time is spent explaining issues in appropriate language, using visual aids and signs as necessary (DOH 2002).

Capacity should not be confused with a health professional's assessment of the reasonableness of the patient's decision. If any adult with the capacity to make a decision refuses treatment, then this decision must be accepted. People with a learning disability who understand a treatment or procedure can refuse that treatment or procedure.

Marcus, aged 24, was told by his consultant at the hospital that he needed surgery to remove cataracts which were impairing his vision. Marcus had previously been assessed as having a severe learning disability and Autistic Spectrum Disorder. Marcus could not fully understand the procedure recommended by the consultant and could not understand possible benefits and risks from the treatment, as well as any potential side effects. Pictures, photographs, gestures and the spoken word were used to communicate with Marcus to help him understand the proposed treatment.

A meeting was arranged to explore Marcus's best interests and referrals were made to the Independent Mental Capacity Advocate (IMCA) service, as well as involving the social worker, family carers and a local community nurse who knew Marcus well. Marcus could co-operate with the treatment even though he didn't understand. Treatment proceeded in Marcus's best interests, with everyone agreeing that cataract surgery would improve Marcus's quality of life.

Learning points:

It is important the individual is given enough information to make a decision, including all the facts known about the proposed treatment. The person needs to be given information in their chosen format and which is appropriate to their language and culture. Information can be made accessible by using speech, gesture, signs (Makaton, BSL, or hands-on signing), symbols, pictures, audio or photographs as appropriate. People with learning disabilities should not be expected to make important decisions without information that is accessible to them. The Accessible Information Standard (2016) places a requirement on NHS services to provide information in an individual's preferred format.

It is always important to act in the individual's best interests; this is defined as choosing actions or interventions that support a person to get the best outcome in the most humane and least restrictive way possible.

Patricia, aged 56, was told by her consultant at the hospital that she needed surgery to remove cataracts which were impairing her vision. Patricia had previously been assessed as having a severe learning disability and could not fully understand the procedure recommended by the consultant. She could not understand possible benefits and risks from the treatment, nor could she appreciate potential side effects of treatment. Pictures, photographs, gestures and the spoken word were used to communicate with her to help her to understand the proposed treatment.

Patricia had recently moved to a residential unit after her brother, who was her main carer died, and staff at the home were getting to know her. A meeting was arranged to explore Patricia's best interests. Referrals were made to the Independent Mental Capacity Advocate (IMCA) service, as well as involving the social worker, staff from the home and a local community nurse who knew Patricia well. The team noted Patricia would find it difficult to tolerate or cooperate with aspects of her treatment because she couldn't understand.

A referral was made to a psychologist, so they could help Patricia become more familiar with some aspects of the treatment such as wearing a patch over one eye and accepting eye drops. Plans were made to ensure staff would be available to support her throughout her time in hospital, with the hospital also providing additional nursing support while she was an in-patient.

Learning points:

If a person with a moderate or severe learning disability would have great difficulty complying with a treatment or intervention considered to be in their best interests, even with appropriate support, it is essential the IMCA service is consulted. If the person's human rights were to be infringed, it is important to seek legal advice.

The journey from initial discussion to final treatment and aftercare should be recorded, so a written 'trail' is available for future reference. These notes can explain and justify why certain decisions have been made.

The clinician (usually the doctor, nurse or therapist) providing the treatment or investigation is responsible for ensuring the patient has given valid consent before the treatment begins. Family carers and staff can support the process of gaining the person's consent. They can also contribute as part of the multi-disciplinary team when the person's best interests are discussed.

Glossary of Terms

Adults with Incapacity Act (2000)

Scotland's law sets out to not only protect people with learning disabilities, but also to promote as much independence as possible for each person. The Act covers many areas of life, including medical treatments.

Best interests

If an adult lacks the capacity to make a decision, then any decision made on their behalf must be based on their best interests, involving them as far as is possible. Best interests mean in the interests of the patient, i.e. the right treatment at the right time to maintain or improve health or wellbeing. This approach aims to help overcome inequalities in health care and to ensure any decision made for a person who lacks capacity is made without discrimination.

Capacity

Capacity is defined as an individual's own capability to make a decision. We cannot assume an individual cannot make a decision, either because that person has a disability or because of their age - whether he or she is 16 or 106. A general assumption about an individual's capacity to make a decision cannot be made. Each decision needs to be considered separately at the time.

Consent

A person can only give consent for a treatment or procedure if they fully understand both the possible benefits and risks of the intervention. The ability to consent to or to refuse treatment or intervention is each person's right and this right should be respected in line with the Human Rights Act (1998) and the Disability Discrimination Act (1995). People who cannot consent to treatment still have the right to expect the right treatment, given at the right time in the most humane and least restrictive way possible in line with their best interests.

Deprivation of Liberty Safeguards (DoLS)

The Deprivation of Liberty Safeguards are part of the Mental Capacity Act 2005. They apply when someone lacks capacity to make a decision themselves. The safeguards are designed to protect people from harm. The safeguards set out how this will happen and who should be involved in these decisions.

It is the responsibility of the person offering the treatment, such as a doctor, to ensure consent from the person has been sought. However, carers, IMCAs, advocates and those who know the individual can contribute to the process in support of best interests.

Independent Mental Capacity Advocate (IMCA)

An Independent Mental Capacity Advocate (IMCA) can represent and support a person who lacks capacity and give views to a decision maker, such as a hospital doctor, consultant, nurse or other professional who has recommended the treatment or intervention.

If you have any concerns, the IMCA may be able to offer general advice or support. IMCA services work slightly differently in different areas, but they all support the Mental Capacity Act (2005).

The Mental Capacity Act (2005)

The Mental Capacity Act (2005) came into effect in 2007 and is designed to help people make their own decisions whenever possible. It also aims to enable people who are unable to make certain decisions to receive care or intervention which takes their best interests into account.

An important principle of the Mental Capacity Act (2005) is the duty to make sure each individual receives support to make their own decisions, based on information that is accessible for that person. The Act also clarifies how best interests are applied to people who are unable to make a specific decision.

Further Reading (correct as of December 2016)

Mental Capacity Act – Making Decisions

www.gov.uk

Social Care institute for Excellence (SCIE) – MCA resource.

www.scie.org.uk

Deprivation of Liberty Safeguards

www.scie.org.uk/publications/ataglance/ataglance43.asp

Adults with Incapacity Act Scotland (2000) Act

www.legislation.gov.uk/asp/2000/4/contents

For more information and advice on eye health please look at our other factsheets on our website: seeability.org/looking-after-your-eyes