



Transition Team

Supporting people who are unable to make decisions for themselves

Information for Parents and Carers

Introduction

Transition is the name given to the process of moving from children's services to adult services. Understanding how a person makes decisions about their healthcare is an important part of moving to adult services. Normally parents make decisions for their children and adults make decisions for themselves. But not all young people and adults with learning disabilities or complex needs can make decisions about their own care and treatment.

This leaflet explains the differences between decision-making, consent and information sharing for young people and adults who cannot make decisions for themselves. This information is important if you are a parent or carer of a young person with learning disabilities or complex needs. The information in the leaflet will help you support your child as they transition to adult services.

This leaflet explains

- How the law decides whether someone can make decisions for themselves (capacity)
- How a care or treatment decision is made when someone is unable to make the decision for themselves
- How the law protects the freedom of people who cannot make decisions about where they stay or live
- How the law protects the personal information of people who cannot make healthcare decisions.

The Transition Team will help you to understand this information and to use it when planning the transition. The Team will try to answer any questions you have.

If you would like this information in another language or format please contact the Transition team on: 0151 252 5823

How the law decides whether someone can make decisions for themselves

A person with **capacity** to make a particular decision has the ability to make that decision for themselves at the time the decision needs to be made. The **Mental Capacity Act** (MCA, 2005) is a law that supports decision making for anyone over the age of 16 who cannot make their own decisions about their care or treatment.

The Mental Capacity Act presumes that everyone aged 16 or over has the capacity to make decisions about their health and care. A capacity assessment is undertaken when there is concern that a person cannot make a particular decision. For example, someone may be able to decide whether they want fish and chips for tea but they may not be able to decide whether they should have an operation. **Capacity assessments** are usually undertaken by the person's health or care team as a routine part of the person's care.

Supporting people who are unable to make decisions for themselves

Professionals must make every reasonable effort to support the person to make a decision *before* they undertake a capacity assessment. This means

- Making sure that the person is not under the influence of medication that may make it difficult for them to understand
- Considering whether the person may have capacity in the future. And if the decision can wait until then
- Presenting the information in a way the person can understand

Professionals ask four questions to decide whether a person has capacity:

- Can the person understand the information needed to make the decision?
- Can the person retain the information for long enough to make a decision?
- Can the person weigh the information to make a decision?
- Can the person communicate the decision they have made?

The person has capacity to make the decision for themselves if the answer to all these questions is “yes”.

The important thing is that the person can make the decision. The decision doesn't have to be a wise decision. Other people don't have to agree with decision.

The person should still participate in decision making as much as possible, even if they do not have capacity to make the decision on their own. For example, a person may be able to make smaller decisions about a treatment, like what arm the nurse should take blood from. Any professional caring for the person must also listen to what the person wants or says, for example if a person is upset then this may mean stop.

How a healthcare decision is made when someone cannot make the decision for themselves

The Mental Capacity Act explains how decisions must be made for people who cannot make decisions for themselves.

Parents or those with parental responsibility will normally make decisions for children under 16 years who cannot make decisions for themselves. There is a different approach for making decisions for adults and young people of 16 or over without capacity. This is called **shared decision making**.

Shared decision making is where health and social care professionals work in partnership with the young person, their parents, carers and other people such as family members to make decision.

Shared decision making is based on establishing what is in the person's best interests. This means what is best for that person at that time.

A person's best interests are decided by:

- Listening to what the person says, or what we think they would want
- Listening to what their parents, and other people who have an interest in the person's welfare think
- Considering how all this might affect the person's health and well-being

Supporting people who are unable to make decisions for themselves

Making a decision for another person can be difficult. If there are several options that are in the person's best interests, the decision that is chosen should be the one that is the least restrictive. This promotes the freedoms and rights of that person. It might be that there is no need to do anything, or make a decision at all.

Parents and carers are especially important in shared decision making they know what their child's life is like day to day. They will have a greater understanding of what is important to and for the young person. Sharing your experiences and thoughts about what is important to and for your child is an important part of supporting their transition to adult services.

What happens if we all don't agree?

The change from making decisions as parents, to contributing to shared decision making, can be very difficult and challenging. It is important to remember that everyone has a duty to act in the person's **best interests**. This means doing what is best for the person.

During transition preparation professionals will work together with you and your child to plan future care. Being honest and discussing your concerns with the team will help a great deal.

If you feel you are not being listened to, explain this to the team caring for your child. You could ask to meet with your child's consultant, the person in charge of their care, or the whole team to discuss your thoughts and feelings. You can do this by yourself or with support from family or friends.

If you still feel you have not been listened to, contact PALs (Patient Advice and Liaison Service) within the hospital.

Extended Responsibilities of parents

Most of the time the best interests of the person are agreed by everyone involved and decisions are made using the shared decision making approach. But parents or other relatives can also apply for the authority to make some decisions on behalf of an adult or young person who lacks capacity.

The **Court of Protection** is a special court that deals with the Mental Capacity Act. The Court of Protection can appoint a person's parent or relative as their **Personal Welfare Deputy**. The Personal Welfare Deputy can take decisions about the person's personal welfare if they don't have capacity to make that decision themselves.

The Court of Protection may appoint a Personal Welfare Deputy when there is family disagreement about a person's best interests. Sometimes the Court of Protection appoints a Personal Welfare Deputy because there are many extended health and social care decisions to make.

For further information please refer to: <https://www.gov.uk/become-deputy>

How the law protects the freedom of people who cannot make decisions about where they stay or live

Supporting people who are unable to make decisions for themselves

A person with capacity who is being cared for in a particular place such as a hospital, care home or respite provider can decide when to leave. The person's freedom to come and go as they please is called their **liberty**. A person's liberty is protected by law.

An adult or young person might be **deprived of their liberty** if they are cared in a particular place outside their normal home but don't have the capacity to decide to leave. Deprivation of liberty can be difficult for parents or carers to understand. Deprivation of liberty is not a reflection on care provided. The person may be very happy where they are being cared for and they may be receiving treatment to make them feel better.

The law uses **Liberty Protection Safeguards (LPS)** to protect the liberty of adults and young people who don't have capacity. Liberty Protection Safeguards protect the liberty of people who lack capacity to decide whether to stay in a particular place outside their normal home and would not be able to leave, whether they wanted to or not.

Liberty Protection Safeguards apply to an adult or young person of 16 or over when

- They do not have the capacity to make a decision about where they are being cared for
- They are subject to continuous supervision and control
- Their freedom to come and go is restricted because of this decision

Liberty Protection Safeguards ensure that a person is only deprived of their liberty when:

- It is absolutely necessary
- It is in the person's best interests.
- It is the least restrictive option

A specially trained **Best Interests Assessor** decides whether a deprivation of liberty is in the best interests of an adult or young person without capacity. Best Interests Assessors are specially trained nurses, social workers or mental health practitioners who are not involved in the care of the person. They ensure that the person has an advocate as part of the decision-making process. They ensure that the views of parents, carers and anyone interested in the welfare of the person, including healthcare professionals are taken into account.

The hospital, care home or respite care provider will make an application to the Court of Protection for a deprivation of liberty. The decision must be reviewed regularly to ensure that it is still the best option

For further information please refer to:

Social Care Institute for Excellence. Mental Capacity Act (MCA). www.scie.org.uk/mca/

How the law protects the personal information of people who cannot make healthcare decisions

Supporting people who are unable to make decisions for themselves

Confidentiality means keeping a person's personal information private. A child's personal information is normally discussed with the child's parents or those with parental responsibility to help them make decisions on their child's behalf. But adults and young people aged 16 and over have the right to confidentiality.

Professionals sometimes need to share personal information about a person who doesn't have capacity. This could mean sharing personal information with parents or carers. It could also mean sharing personal information with other professionals.

Professionals will only share relevant personal information if it is necessary and in the person's best interests to do so. This may be because the information is needed for a decision about the person's care or treatment. It may also be because professionals are concerned about harm or the welfare of the person who doesn't have capacity. Professionals must only share personal information with people who need to know. They must only share essential and relevant information.

Confidentiality also applies to information that parents or carers share with health and social care professionals about the person's health.

This leaflet was produced in collaboration with Edge Hill University.

This leaflet only gives general information. You must always discuss the individual treatment of your child with the appropriate member of staff. Do not rely on this leaflet alone for information about your child's treatment.

This information can be made available in other languages and formats if requested.

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