



Moving into Adulthood & Getting a Life

Becoming an Adult: A guide to the Mental Capacity Act for families of young people with learning disabilities

About these guides

The 'Moving into Adulthood and Getting a Life' guides are a series of guides, written *by* and *for* families of young people with learning disabilities. However, some of the information contained in it may also be helpful for families of other disabled young people or those who have additional or special educational needs.

Each guide covers the many issues that families have to think and know about during the stage when their child is preparing for adulthood. This stage is often referred to by services as 'Transition'.

- **Getting Started:** Where to start. Things to think about. 'Jargon buster'.
An introduction to person centred thinking, planning and approaches. The start of the preparing for adulthood stage. The Year 9 review. Person centred thinking tools
- **Finding the right support:** What support are you looking for? Finding support providers.
Checking out support providers. Employing your own staff. Keeping safe
- **Education Matters:** Further education - Staying on at school or going to college. Residential colleges. Adult education and lifelong learning
- **Money Matters:** Benefit changes at 16. Managing money. Court of Protection
- **Social care matters:** Personalisation and choice and control. Personal budgets
- **Health Matters:** Staying healthy and safe. Health action plans. Personal Health Budgets
- **Social Life, Having Fun, Friends & Relationships:** Social life and having fun. Staying safe online. Growing up – sex and relationships. Circles of Support.
- **Becoming an adult:** The Mental Capacity Act. Supported decision making
- **Finding a job:** Work experience. Volunteering. Supported Employment.
- **Finding a somewhere to live:** Independent living. Supported living.

Introduction

For many of us, up until our child reaches the age of 18 we will have become used to making all the major decisions for them and some of the minor one's too. It can come as a bit of a shock to some of us (*especially if our child has more severe learning disabilities*) that once they turn 18 we're told they have choices, can make decisions ...and that the law supports this.

Families sometimes struggle with this for a number of reasons.

- Throughout our child's life we have been constantly made to focus on everything they can't do in order to get the support they, and we, as families need - Benefits forms, statements of special educational needs and health or social care support
- Some of us will have been informed at the time of diagnosis that our child would never be capable of living an independent life or that they have a mental age of 18 months, 5 years, 11 years etc. i.e they will always be a child
- Some families will have experienced situations where the Mental Capacity Act has been used to keep families at a distance. Sometimes this is because the Act has been misinterpreted and sometimes it has been because of a lack of understanding.

Consequently for lots of families, the Mental Capacity Act is a bit scary!

So, what is the Mental Capacity Act?

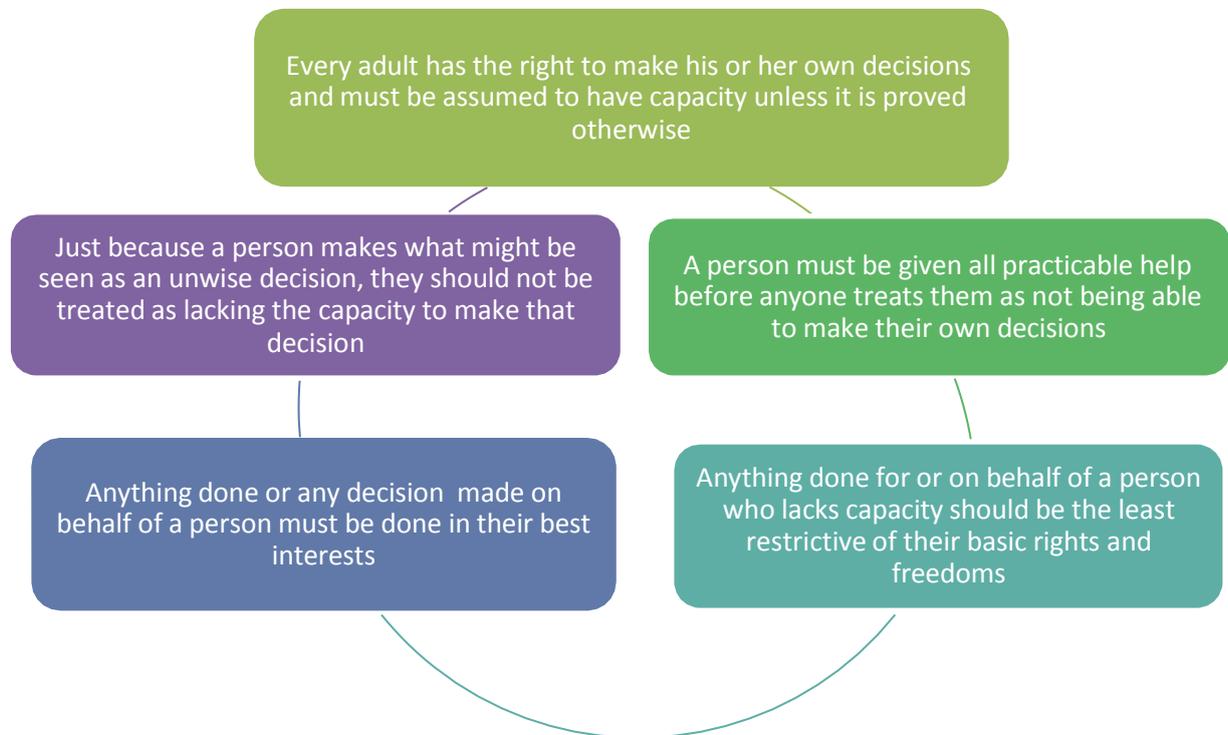
The Mental Capacity Act 2005 came into force in 2007. It provides a legal framework for the care, treatment and support of people who are unable to manage their own affairs and/or who lack the capacity to make some, or all, decisions for themselves. **The law applies to everyone over the age of 16 in England and Wales.**

The Mental Capacity Act is an important piece of legislation that families need to be aware of. It aims to protect both the individual who lacks mental capacity as well as those people who support them, including family members, friends and/or paid workers. The focus of the legislation is that the individual should be at the centre of the decision making process, whilst fully supporting the involvement of the people who know and love them best. It's the first piece of legislation to state that lack of capacity should not be assumed automatically and that people can no longer make decisions on behalf of others without following a clear process.

The Act is clear that all adults have the right to make their own decisions wherever possible. If they are unable to make their own decisions then others are able to act for them. However, any decision must ensure that the person remains at the centre of any decision made on their behalf and must always be in their best interests.

The Act also ensures that independent support is available, in the form of Independent Mental Capacity Advocates (IMCA), for those people without family and friends and facing decisions about change of accommodation and/or serious medical treatment.

There are five key principles of the Act:



The Mental Capacity Act covers major issues about property, financial affairs, healthcare treatment and where a person lives, as well as everyday decisions about what the person eats and their personal care.

How mental capacity is assessed

The Mental Capacity Act states that any judgement about a person's ability to make decisions must be on a decision-by-decision basis. It recognises that people should be encouraged to make whatever decisions they have the capacity to make rather than assuming that they can't make any decisions at all.

The test for capacity introduced by the act is called **the two stage test**. This test is usually carried out when a person's capacity is in doubt.

Stage 1: Is there an impairment in the functioning in the adults mind or brain? *If the answer is yes move to the second stage.*

Stage 2: Does the impairment or disturbance result in the adult lacking the capacity to make a particular decision? *You can answer this by asking four further questions.*

- Can they understand the information given to them about the decision?
- Can they retain that information long enough to be able to make the decision?
- Can they weigh up the information available to make the decision?
- Can they communicate their decision - by any method of communication?

**How information is presented is really important. All information must be presented in a way that is most accessible to the individual. This could be using easy words and pictures, DVD, sign language or any other method that the person uses to communicate.*

Best interest decision making

Once an individual has been assessed as being unable to make a particular decision at that time, the decision will then be explored on their behalf. This is called "Best Interest Decision Making"

The Mental Capacity Act is very clear that family, friends and the people who know the individual best should be involved in any best interest decision making and any Best Interest meeting should include them.

With the right support many people can make decisions but where people lack the capacity to make a particular decision the Best Interest Checklist is used to ensure that the best possible decision is being made on their behalf.

The Best Interest Checklist provides the framework for ensuring that the individual remains at the centre of the process.

- ✓ Cannot be based simply on the person's condition, appearance or behaviour
- ✓ All relevant circumstances should be considered
- ✓ Every effort should be made to encourage the person to take part in the decision
- ✓ Consider if the person is likely to regain capacity
- ✓ Special considerations apply about life sustaining treatment
- ✓ The person's past and present wishes, feelings, values and beliefs are taken into account
- ✓ Views of the people close to the person are considered and taken into account

[Mental Capacity Act 2005]

How people should be supported to make decisions and how families should be involved

Everyone should have choice and control about how they live their lives but young people with learning disabilities will need varying degrees of support to be enabled to do this. They should be supported to make their own decisions as much as possible. This includes involving them in the big decisions like where they live and who they live with as well as the smaller ones, like what they wear and what they eat.

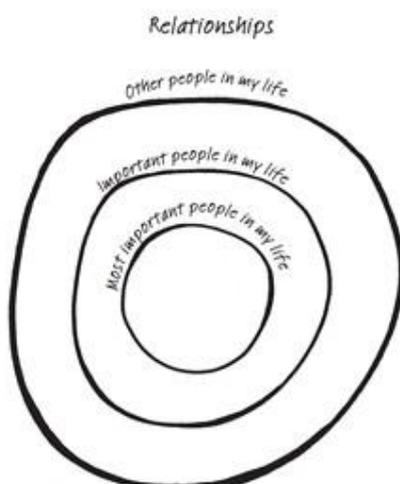
Good support is all about understanding people, what makes them “tick”, what’s important to them and how they communicate. As the people who know them best and have known them the longest, families have an important role to play in helping others (who support them or may be supporting them in the future) to understand all the detail in their lives



Person centred thinking approaches and tools to use.

- **Relationship Circle** – who are the important people in the person’s life?
- **Communication Chart** – what is the best way to communicate with them and how do they communicate with others?
- **Decision Making Agreement** – what decisions does the person need help with, how must they be involved and who makes the final decision?

Relationship Circle



A Relationship Circle is a tool to help map who are the important people in a person’s life. Who is the closest to them, family and friends. Who are the people who know them best? For further information about relationship circles see our [Getting Started](#) guide or visit the [Helen Sanderson Associates website](#)

Example of Communication chart

Matthew's Communication Chart

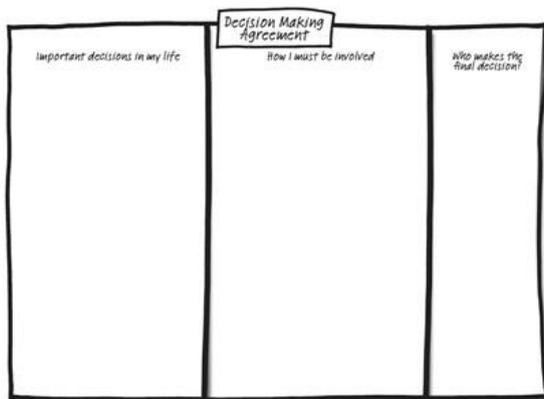
What is happening	Matthew does this	We think it means	And we should
Anytime	clapping	Matthew wants something, could be a drink, food or the channel on the TV changed.	Ask him what he wants and take his hand and ask him to show you
Anytime	Hits out	He doesn't want to do something. He could be feeling unwell.	Tell him not to hit you but think about what it is you're asking him to do. If it's something he's usually happy to do then arrange a visit to the GP. He could be unwell
Anytime	Blows "raspberries"	Matthew is playing a game, he thinks this is funny. He's not being rude	Blow a raspberry back. This makes him laugh
Anytime	Strokes his head	He's upset about something and comforting himself	Offer him reassurance or comfort by chatting to him or looking at a magazine, book or his Ipad

Decision Making Agreements

Decision making agreements are used to ensure that the people are supported to be involved in decisions and to agree who has the final say.

When supporting someone in their decision-making, here are some important questions to ask:

- Do I fully understand what is important to the person and their communication?
- Am I the best person to support this decision-making?
- Is the information that I have and am giving the person relevant to the decision?
- Am I presenting it in a way that the person can understand?
- I am giving the information in the right place and time?
- Have I given the person the best chance to make the decision themselves?



This tool helps:

- To think about how much power and control people have in their lives.
- To clarify how decisions are made.
- To increase choice and control people have in their lives.

It works by helping us to think about decision making and increasing the number and significance of the decisions people make.

Alice's Decision Making Agreement (*lives in her own home with full time support - (i.e. supported living)*)

Important decisions in my life	How I must be involved	Who makes the final decision?
Recruiting my Support staff	I have the opportunity to meet staff during the recruitment process. Candidates will complete an assessment/activity that I have devised with support from my management team and my mum, so that I can see if they have the right skills match/interests to support me	I am supported by the management team (and my Mum) to get the right, consistent staff team utilising the recruitment matching tool which identifies key areas where we seem compatible.
Health Matters	Changes in my physical wellbeing or mental health indicate an issue. I want to be involved in any discussions regarding my health. I would like to be told about any medication changes and the reasons why medication has either been introduced or discontinued	Health agencies (GP, Clinical Psychiatrist and other specialists) and my Mum We make the decision together, but the final decision must be agreed by me.
Money matters	My needs and preferences must be well recorded and my deputy (under Court of Protection) who manages my finances consulted.	My deputy (Mum)

My Family contact.	I like to see my family regularly. Both my brother and sister live away from my family home and I don't see them as often as I'd like to but I like to SKYPE them or use FaceTime. I like to send email messages with pictures and video's about what I'm doing	Me with support from the staff team and my mum
Where I live	I love where I live now and who I live with is very important to me. I do not want to move again. I want to make sure that I am involved in any decisions about where I live if my needs were to change or the place where I live was seen as not being able to meet my needs. I would like to discuss this with the Area Manager, my key staff, my social worker and my mum.	My Social Work team, my mum and my brother and sister

Further information about decision making agreements can be found here -

<http://www.helensandersonassociates.co.uk/reading-room/how/person-centred-thinking/person-centred-thinking-tools/decision-making-agreement.aspx>

Some young people will have the capacity to make most or all of the decisions in their lives and it's right that they are supported to do this. However, it's also quite natural for many of us to discuss and seek advice, talk through ideas with our families when there are big decisions we have to make. So, whilst promoting independence any provider organisation who is supporting the young person should encourage and offer the opportunity for the people to stay involved with their families. Staff supporting your child should be aware of the importance of family and friends and that they are there to support people, not to replace family and friends. (see '[Finding the Right Support' guide](#))

Further (more detailed) information, help and advice

The following guides have been developed by other organisations and are available on their websites.



Using the Mental Capacity Act

A resource for families and friends of people with learning disabilities

www.hft.org.uk/Family_Carer_Support/MCA_Resource_Guide

‘Using the Mental Capacity Act: a resource for family and friends of people with learning disabilities’ is the outcome of a joint project between Hft’s Family Carer Support Service, the Foundation for People with Learning Disabilities and the National Family Carer Network, and was funded by the Social Care Institute for Excellence. This can be found on the [HFT website](#) (in the family carers section, under resources)



The Mental Capacity Act Resource Pack: the Social Care Institute for Excellence gave Mencap the funds to produce a resource about the Mental Capacity Act (2005) and practical decision making for young people and adults with Profound and Multiple Learning Disabilities (PLMD). This can be found on [Mencap’s website](#). Or by contacting Mencap Direct Telephone: 0808 808 1111 Email: help@mencap.org.uk



Supported Decision Making: a guide for supporters. Written by [Paradigm](#) and [Helen Sanderson Associates](#) this guide is available on their websites.