



Supporting people to make decisions...
A guide to the Mental Capacity Act for family carers

Contents

About this guide

This brief guide has been written for families with a relative who has learning disabilities and/or experiences autism. Our two family consultants are both carers themselves and have written the guide for family carers whose relative is supported by Dimensions.

This guide will explain....

- ➔ What the Mental Capacity Act is and what it means for families.
- ➔ How mental capacity is assessed.
- ➔ How we support people to make decisions and how we work with families
- ➔ Further information, help and advice.

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 lack capacity to make some, or all, decisions for themselves and/or are unable to manage their own affairs. 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 (including unwise decisions). 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). IMCA's are for those people who don't have family and friends able to support them and are facing decisions about change of accommodation and/or serious medical treatment. Sometimes IMCA's are used even when family and friends are around. This can happen if there is a conflict of interest or when there is an issue about the ability to provide competent support to the individual.

“...lack of capacity should not be assumed automatically”.

Five key principles of the act:

1 Every adult has the right to make his or her own decisions and must be assumed to have capacity unless it is proved otherwise.

2 A person must be given all practicable help before anyone treats them as not being able to make their own decisions.

3 Just because a person makes what might be seen as an unwise decision, they should not be treated as lacking the capacity to make that decision.

4 Anything done or any decision made on behalf of a person must be done in their best interests.

5 Anything done for, or on behalf of, a person who lacks capacity should be the option least restrictive of their basic rights and freedoms.

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

The Mental Capacity Act is relatively new and can seem confusing. 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 ones too. It can come as a bit of a shock to some of us (especially if our relative has more severe learning disabilities) that when our child becomes an adult or moves away from the family home 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 relative'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 wrongly 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 or 5 years (for example), i.e they will always be a child.

We also know that for many families the Mental Capacity Act is a bit scary because they are aware of situations where it has been abused and used to keep families at a distance. Sometimes it's because the Act has been misinterpreted and sometimes it has been because of a lack of understanding.

The Act is very clear that all decisions made about a person must be made in their best interests and any best interest decision must involve families and the people who know the individual best.

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
-  A DVD
-  Sign language
-  Any other method that the person uses to communicate.

Best interest and decision making

Once an individual has been assessed as lacking capacity 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 Best Interest Checklist is used to ensure that the best possible decision is being made on their behalf. It provides the framework for ensuring that the individual remains at the centre of the process.

Best Interest Decisions:

- ➔ Cannot be based simply on the person's condition, appearance or behaviour.
- ➔ All relevant circumstances must be considered.
- ➔ Every effort must be made to encourage the person to take part in the decision.
- ➔ Must consider if the person is likely to regain capacity.
- ➔ Take into account the person's past and present wishes, feelings, values and beliefs.
- ➔ Take into account the views of the people close to the person.
- ➔ Special considerations apply about life sustaining treatment.

[Mental Capacity Act 2005]

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.

How we support people to make decisions and how we work with families

At Dimensions we want the people we support to have choice and control in the way they live their lives. We also want to ensure that they are 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. Families have an important role to play in helping us with this; after all, you are the people who have known them the longest and know them best.

We use person centred approaches and tools to help us learn about people in a way that keeps them in control. This can help us build a rich picture of who a person is and how they choose to live their life. Everyone we support has a Support Plan which includes details of how to communicate well for those who have communication difficulties.

“Good support is all about understanding people...”

Alan's common communication chart

What's happening?	Alan does this	We think it means	And we should do
Anytime.	Banging, clapping, puffing and blowing.	Alan is fed up, bored, uncomfortable, thirsty or wants some company.	Sit with him, offer reassurance - chat with him, have a look at some magazines or a newspaper, offer him a drink or support him to have a walk around.
When offering assistance.	Hits out.	He could be frightened and might misunderstand your intentions. He does not want new people or small people to support him.	Reassure him of what you're doing. Small people or new people should not support Alan.
When being supported to walk.	Reaches his arms out.	He's lifting his arms up to hold on to you, not to hit you.	Be aware he's not going to hit you.
Anytime.	Strokes his head.	He's upset about something and comforting himself. Offer him reassurance or comfort by chatting	Offer him reassurance or comfort by chatting to him or looking at a magazine or newspaper.

Ruby's decision making agreement

Important decisions in my life	How I must be involved	Who makes the final decision?
Recruiting my support staff.	<p>I have the opportunity to meet staff during the recruitment process. Candidates will complete an assessment/activity, that I have devised with support from the management team, so that I can see if they have the right skills match and interests to support me.</p> <p>My needs are discussed as part of the Polymyalgia Rheumatica (PMR) process for staff.</p>	<p>I am supported by the management team to get the right, consistent staff team to utilise the recruitment matching tool. This identifies key areas where we seem compatible. We make the decision together, but the final decision must be agreed by me.</p>
Health matters.	<p>Changes to 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.</p>	<p>Health agencies (GP, Clinical Psychiatrist and other specialists).</p> <p style="text-align: right;">Cont...</p>

Important decisions in my life	How I must be involved	Who makes the final decision?
Money matters.	My needs and preferences must be well recorded and my deputy (under Court of Protection) who manages my finances consulted.	My deputy.
My family contact.	I have lost contact with my family (my brothers) since moving away from Norwich over 37 years ago. Now that I have moved back to the area I want to be supported to trace my family, if possible. I understand that they may not want to be in contact.	Me with support from the service management team and my named social worker.
Where I live.	I love where I live now and 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 service locality manager, my key staff and my social worker.	My social work team.

Some people we support will have the capacity to make most or all of the decisions in their lives and it is right that we support them to do this. However, it's also quite natural for many of us to discuss options and seek advice or, when there are big decisions we have to make, talk through ideas with our families. So, whilst promoting independence we also encourage and offer the opportunity for the people we support to involve their families. At the same time we remind our staff of the importance of family and friends and that they are there to support people, not to replace family and friends.

Dimensions has a strong commitment to working well with families. We value families as partners in the support of their loved ones and therefore encourage good communication and as much involvement as families wish.

Our Family Charter sets out our promises to families. All Family Charter agreements should be recorded in the family section of your relative's Support Plan, so, please make sure that the decisions you want to be involved in are recorded too. This can be reviewed at their annual review (or any other time you wish). Please speak to your relative's locality manager if you have any questions or concerns.

[Download a copy of the Family Charter here.](#)

“Dimensions value families as partners in the support of their loved ones...”

Further information, help and advice

There is a range of other publications to offer more support and advice. The blue text are links that, when clicked, will take you through to the website.

We have produced a number of Factsheets for Families, including one on seeking consent. If you do not have access to the internet or would prefer a paper copy please ask your relative's manager to print them off for you.

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

- [Supported Decision Making: a guide for supporters](#). This guide was written by **Paradigm and Helen Sanderson Associates** and is available on their websites.
- **'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. It was funded by the Social Care Institute for Excellence and can be found on the **HFT website** or by calling 0117 906 1751.
- **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 calling Mencap on 0808 808 1111.

If you have any concerns or questions regarding the Mental Capacity Act or how we support your relative to make decisions please contact your relative's locality manager or get in touch with our family consultant (family consultant details are on the next page).



Contact us

Family Helpline

- available 9.30am – 1.30pm Monday – Friday



0300 303 9161



family.helpline@dimensions-uk.org

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