



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

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Foreword

The Mental Capacity Act 2005 was implemented in 2007. Guidance on how it should work in practice was provided by the Mental Capacity Act 2005 Code of Practice. In his foreword to the Code, the Lord Chancellor described the Act as a vitally important piece of legislation that would make a real difference to the lives of people who lack mental capacity.

“It will empower people to make decisions for themselves whenever possible, and protect people who lack capacity by providing a flexible framework that places individuals at the very heart of the decision-making process. It will ensure that they participate as much as possible in any decisions made on their behalf and that these are made in their best interests”.

He pointed out that, although many people are under a formal duty to have regard to the Code, “the most important relationships will often be with close family and friends who know the person best”.

This resource has been developed specifically for family and friends of people with learning disabilities, using knowledge gained through practical experience since 2007, so that they understand how the Act affects them and those they care about.

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 (FCSS), the Foundation for People with Learning Disabilities (FPLD) and the National Family Carer Network (NFCN), and was funded by the Social Care Institute for Excellence (SCIE).

The project team hope you will find the information it contains of interest and help.

Robina Mallett

Family Carer Support Officer, Hft
2011

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SECTION

1

Introduction

The ability to make decisions is sometimes called **mental capacity**. There is a law – the Mental Capacity Act 2005 – which sets out what should happen in England and Wales if someone is unable to make a decision for themselves.

This information pack is designed to help the family carers of people with learning disabilities understand how the Mental Capacity Act applies to them when:

- they want to support a member of their family to make a decision
- the family carer needs to make a decision or act on a relative's behalf
- someone else (a paid worker or organisation) makes a decision or acts on behalf of their relative.

The written material in the pack gives detailed information about what should happen in these situations and recommends sources of further information and advice on specific topics, e.g.

→ *Read more in Section 10: Managing finances*

The DVD of films shows how family carers, and people who have worked with family carers, have used the Mental Capacity Act in practice. We suggest that you use the two resources together to get the fullest understanding of how the Act might affect you and anyone with learning disabilities in your family.

The information contained in this pack and the films are also available on the Hft website www.hft.org.uk/family_carer_support/MCA_Resource_Guide

Where should you start?

From our work supporting family carers, we know that there are some decisions

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that concern families more than others. You might find it useful to go straight to the section that most closely describes your situation:

- I am helping my son or daughter to plan for adulthood (transition) **Section 7**
- I want to ensure that my relative's finances are looked after properly **Section 10**
- My relative needs to have health care..... **Section 14**
- My relative is moving home..... **Section 8**
- I am not happy with a decision that has been made by someone else on behalf of my relative..... **Section 15**

You may want to find out more about the most common features of the Mental Capacity Act:

- How to work out if someone lacks capacity to make a decision (how their capacity is assessed) **Section 5**
- What happens when a decision has to be made for a person who cannot make it themselves (this is called a 'best interests' decision)..... **Section 6**
- Getting authority to make decisions on behalf of a person who lacks capacity (becoming a welfare benefits appointee, a deputy or an attorney) **Sections 11, 12, 13**
- Words and phrases you may come across as you find out more about the Mental Capacity Act – words in **bold font** (other than headings) are explained in this section **Section 18**



Each section ends with '**You may be interested in...**'

There are details here of other resources – booklets, guides and films – that will give you more information.

You can order a free hard copy of this resource together with a DVD by contacting the Family Carers Support Service at Hft:
 Telephone: **0117 906 1751**
 Email: **familycarersupport@hft.org.uk**

SECTION

2

The five principles of the Mental Capacity Act

Whilst reading every section it is important to remember the five key principles underpinning the Mental Capacity Act.

- **We must begin by assuming that people have capacity**

“A person must be assumed to have capacity unless it is established that he/she lacks capacity.”

- **People must be helped to make decisions**

“A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.”

- **Unwise decisions do not necessarily mean lack of capacity**

“A person is not to be treated as unable to make a decision merely because he/she makes an **unwise decision**.”

- **Decisions must be taken in the person's best interests**

“An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his/her **best interests**.”

- **Consider whether the decision can be made in a way that is less restrictive of the person's freedom**

“Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.”

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SECTION



Code of Practice of the Mental Capacity Act

The Mental Capacity Act **Code of Practice** provides guidance and information about how the Act works in practice and describes the responsibilities of ‘assessors’ of capacity, ‘decision-makers’, independent supporters, care homes and hospitals. It has statutory force, which means that certain categories of people have a legal duty to be aware of what it says about their responsibilities when acting or making decisions on behalf of individuals who may lack the capacity to act or make these decisions for themselves.

This covers a wide range of people including:

- healthcare staff, such as doctors, dentists, nurses, therapists, radiologists, ambulance crew
- social care staff, such as social workers, care managers
- care home assistants, care workers providing domiciliary care services and others contracted to provide a service, others occasionally involved in the care of people who lack capacity to make the decision in question, such as housing workers, leisure staff or police officers.

There is no legal duty for these people to ‘comply’ with the Code – it should be viewed as guidance rather than instruction. However, if they have not followed relevant guidance contained in the Code, they will be expected to give good reasons why they have departed from it if a court or tribunal considers it to be relevant.

The Act also applies more generally to *everyone* who looks after, or cares for, someone who lacks capacity to make particular decisions for themselves, including family carers. Although family carers are not legally required to have regard to the Code of Practice, the guidance given in the Code will help them to understand the Act and apply it.

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You may be interested in...



You can download a copy of the MCA Code of Practice from:

www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm

Hard copies can be bought (£15.00 + £3.75 post and packaging) from TSO (The Stationery Office) or major bookshops (ISBN 9780117037465) .

You can contact TSO by phone: **0870 600 5522**

Email: **customer.services@tso.co.uk**

or visit their website: **www.tsoshop.co.uk**

If you are a Deputy or have Lasting Power of Attorney you can be sent a copy of the Code of Practice free of charge.



‘What every carer needs to know: a guide to mental capacity’: published by Carers UK, with funding from the Social Care Institute for Excellence. Written in plain English this provides an overview of what mental capacity law is all about and looks at how carers should be involved in making important decisions alongside the professionals and the people they look after. The guide is free to carers and can be ordered on:

Telephone: **0845 241 0963**

Or downloaded from: **<http://bit.ly/mc56oS>**

SECTION

4

Involving family carers

The Mental Capacity Act provides for family carers to be involved in a decision that affects a relative with learning disabilities, depending on the decision and the circumstances. Fully involving family carers ensures that the best interests of people who lack capacity are considered before decisions are made on their behalf.

Supporting a relative to make a decision

Some people with learning disabilities have difficulty making a decision but can make it themselves with the right support. Family carers are usually best placed to know what kind of support is needed in these situations and can either provide it to the relative themselves or advise others about how to do so. This might be by providing the relative with information about potential consequences of the decision, the options they have, by making information accessible, or helping them to communicate their decision.

Assessing a relative's capacity

Family carers may also assess the capacity of their relative with a view to acting or making a decision in their **best interests**. The Act expects carers to have a 'reasonable belief' that someone lacks capacity before acting or making a decision on someone's behalf. Assessment is simply about establishing why you have that 'reasonable belief' – deciding whether someone is able to make a simple decision is not a bureaucratic process.

A professional or paid worker may need to make a decision if they believe someone cannot make it for themselves. In these situations they are known as the '**decision-maker**' and it is their duty to ensure an assessment of the person's capacity is carried out *before* any decisions are made in a person's best interests. If the decision is a major one, they may ask a specialist (such as a psychologist or

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a speech and language therapist) to help them assess the person's capacity. Whoever carries out the assessment will often ask a family carer for advice and information to assist them, for example about the best way to communicate with the person.

→ *Read Section 5: Assessing capacity.*

Getting authority to be a substitute decision-maker

The Mental Capacity Act recognises that some people will be unable to make certain types of decisions. The Act creates mechanisms for 'substitute decision-makers' to make decisions about someone's finances or about their personal welfare. Family carers of people with learning disabilities often act as a **welfare benefits appointee** or as a **deputy** for a relative.

→ *Read Section 9: Getting authority to make decisions.*

Being consulted

Anyone intending to act in a person's best interests must consult those caring for the person or interested in their welfare, including family members. This requirement still applies even if the person's family no longer provide the principal care for that person – if they live in supported living, for example.

In limited situations it may not be practical or appropriate for the decision-maker to consult in this way (for example, where emergency medical treatment is required).

Family carers should be asked what they think would be in the person's best interests and about the person's wishes, feelings, values or beliefs, or how they made similar decisions in the past if they had the capacity to do this.

There are also things that family carers should *not* be asked by the decision-maker in these situations:

- to make the decision in question
- to give consent on behalf of a relative
- to be asked what they (the family carer) would do.

Remember that, although the decision-maker must take account of what others (including family carers) have said, they will have to balance this with other information to make their final decision.

Challenging a decision

If a family carer disagrees with an assessment of capacity or a decision that has been taken on behalf of a relative who lacks capacity, there are a number of ways they can challenge what has happened.

→ *Read Section 15: Challenging decisions.*

You may be interested in...



You can download a 'Guide for family, friends and other unpaid carers' (booklet OPG 602) on:

www.justice.gov.uk/guidance/protecting-the-vulnerable/mental-capacity-act/index.htm

SECTION

5

Assessing capacity

Before you make a decision on behalf of someone else, you must have a 'reasonable belief' that he or she lacks the **capacity** to make the decision for themselves. To establish whether your 'reasonable belief' is correct you make an **assessment** of their capacity.

Just because the person chooses to make a different decision from the one you would make, or makes one that you consider unwise, does not mean that they lack capacity. This cannot be used as the basis for a reasonable belief that they do lack capacity.

The word assessment can sound daunting, but it is straightforward and you probably do this already. For example, you will know which decisions your relative is able to make for themselves – what to watch on television, for example – which decisions they can make with some help, and which ones have to be made in their **best interests** – such as managing money or deciding on health care or where to live.

As a family carer, you may be involved in assessing the capacity of a relative in two ways:

- You may assess the capacity of your relative because you need to do something for them.
- Someone else (a professional or paid worker) may consult you about a relative's capacity. For instance, the person you are caring for might need to have an operation. The doctor might be unsure if they are able to make their own decision about this. Family members and others close to a person can provide valuable information to the doctor about whether that person could make the decision for themselves with support.

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The way that an assessment is carried out will depend on the type and importance of the decision under consideration. Where a professional or paid worker believes that someone lacks capacity to make a major decision, such as about moving home, they should make sure that a formal assessment of the person's capacity to make that decision is carried out. This may include getting expert advice from a psychologist or speech and language therapist.

Anyone assessing capacity has to answer a set of questions:

- Does the person who seems to lack capacity have a general understanding of what decision needs to be made?
- Do they have a general understanding of the consequences of this decision?
- Can they weigh up this information and use it to make a decision?
- Is there any way you could help them to make the decision for themselves?
- Is there any way you can help them communicate their decision or their wishes and feelings?

If an assessment has been carried out by someone else, you may want to check that the following considerations have been taken into account where a major decision has been made:

- ✓ Was expert help with the assessment of capacity required and was it sought? Such help might be provided by a psychiatrist, psychologist or speech and language therapist.
- ✓ Whether or not expert help was provided, responsibility for ensuring that an assessment is carried out remains with the decision-maker.
- ✓ The health and care staff supporting your relative should have received training to carry out assessments of capacity.
- ✓ Health and social care services must be able to show how they carried out an assessment. Where a major decision is to be made, details of the assessment should be written down.
- ✓ If your relative has a care plan, it should set out how issues of capacity are dealt with.

You may be interested in...



There is a website dedicated to assessing mental capacity. It has resources and an online audit tool that allows you to check how closely an assessment of someone's capacity meets the Mental Capacity Act **Code of Practice** that workers must follow.

Visit: **www.amcat.org.uk**



A guide about when to conduct an assessment of capacity – you click your way through options to get advice on whether or not an assessment is required.

<http://bit.ly/cj96kb>

www.communitycare.co.uk/static-pages/articles/guide-to-mental-capacity-assessments

SECTION

6

Best interests

The Mental Capacity Act says that anything done to or on behalf of someone with a learning disability who lacks capacity to make a particular decision for themselves must be in their **best interests**. What does this mean?

“When working out what is in the best interests of the person who lacks **capacity** to make a decision or act for themselves, **decision-makers** must take into account all relevant factors that it would be reasonable to consider, not just those that they think are important. They must not act or make a decision based on what they would want to do if they were the person who lacked capacity.”

*The Mental Capacity Act **Code of Practice** para 5.7*

If you (or anyone else) are proposing to make a decision for a relative who lacks capacity, there is a process – a series of steps – to follow that helps determine what will be in that person’s best interests.

Family carers of people with learning disabilities should follow the process if they make a best interests decision on behalf of a relative. They will also need to understand how this process works if someone else is making a decision on that relative’s behalf.

For most day-to-day actions or decisions, the decision-maker will be the carer or worker most directly involved with the person at the time. If a major decision about finance, health or welfare needs to be made, the decision-maker may be someone else. If the decision is about where someone is going to live funded by the local authority, the decision-maker is likely to be a care manager representing the authority. Where the decision involves the provision of healthcare, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker.

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The decision-maker must ask people with an interest in your relative's welfare to be involved in the process: by giving their views, supporting your relative to be involved, or by giving expert advice. This will usually be a family member, or people who know the person well, including paid staff. The decision-maker must consult a **deputy** or **attorney** if one has been appointed, and anyone your relative said should be consulted.

→ *To find out more about the roles of attorneys and deputies, read Section 9: Getting authority to make decisions.*

Sometimes a best interests meeting will be held. This may be in addition to separate meetings held between the decision-maker and others involved in the process. The purpose of the meeting is to allow everyone involved to express their views about your relative's best interests. Whoever is making the decision, such as a doctor who is considering treatment, will then have to weigh up all the factors to decide what is in the person's best interests.

If the decision is a particularly complex one, or where there are very different views about what should happen, it may be chaired by an independent person. However, the responsibility for determining the person's best interests remains with the person who needs to make the decision.

These are questions you can ask to check if a best interests process has been followed:

- **Has my relative's capacity to make that particular decision been properly assessed?**

The best interests process can only be used once it is established that a person lacks capacity to make the decision for themselves. It should also be remembered that a best interests process cannot be used where someone with capacity has made what another person deems to be an unwise decision.

- **Will my relative regain capacity and be able to make the decision?**

Some people's capacity to make a decision comes and goes, depending on how they are feeling, if they are taking medication, even the time of day. If the decision does not need to be made straight away, you should consider whether it is possible that your relative will be able to make the decision at a later date.

- **Has my relative been involved as far as is possible?**

Just because your relative is unable to make the decision themselves, does not mean that they cannot contribute to the process. They may be able to express wishes and feelings that are relevant to the decision and should be given help to participate as fully as possible.

Sense guidance on how decision-makers should involve someone in decision-making:

- **Provide all relevant information.** Information should be tailored to an individual's needs and abilities. It must also be the easiest and most appropriate form of communication for the person concerned.
- **Communicate in an appropriate way.** All possible and appropriate means of communication should be tried. The Mental Capacity Act Code of Practice gives guidance to decision-makers on approaches to communication and seeking advice and support of interpreters and experts.
- **Make the person feel at ease.** To help put someone at ease, careful consideration should be given to both location and timing.
- **Support the person.** In some circumstances, individuals will be more comfortable when someone else is there to support them.

- **Have the wishes, feelings, beliefs or values of my relative been taken into account?**

It is important to establish whether your relative has expressed any views in the past that might affect the decision under consideration. This might be things they have written down, said to other people, or how they have behaved in similar circumstances in the past. Similarly, any beliefs or values that your relative is known to have held should be taken into account when considering their best interests.

- **Were there any other factors my relative would be likely to consider if they were able to do so?**

Family carers and others who know your relative well will be able to say if there were other factors that should be taken into account when his or her best interests are being considered. For example, proximity to family networks may be important when thinking about a move of accommodation.

- **Were the right people consulted?**

To address the questions listed above, a decision-maker will need to talk to people who know your relative well, including relatives and paid workers. Others may be able to contribute expert advice about ways to help your relative communicate, for example. It is therefore vitally important that the person making the decision makes every effort to establish the best people to consult in determining your relative's best interests.

- **Was the best interests decision recorded and communicated to people interested in your relative's welfare?**

All best interests decisions must be recorded and should be shared with people with an interest in the person's welfare. The decision-maker must also be able to account for the process used in determining a person's best interests. Many health and social care organisations will have a standardised format for recording decisions.

These are some other considerations that you may wish to bear in mind when considering a relative's best interests:

- There are some decisions that you can never take on behalf of your relative. These are usually to do with very personal issues such as entering into a sexual relationship, getting married, getting a divorce or adopting children.
- If the decision is about life-sustaining treatment, the decision must not be motivated by a desire to bring about your relative's death.
- Some best interests processes happen very quickly by necessity because of a medical emergency or a potentially dangerous situation. In these situations it may not be possible for a decision-maker to follow every aspect of the process or consult with family carers before acting.

→ *Read Section 16: **Safeguarding** and Section 17: **Deprivation of liberty safeguards** to find out more about what may happen in potentially dangerous situations.*

- If you are invited to take part in a best interests meeting, do not be afraid to ask the person chairing to clarify how the meeting will work and what will happen as a result of it.
- Think about what would help you feel the best interests meeting is comfortable and inclusive – do you have a preference about where it is held or who else is there?

If you are unhappy with the decision or the best interests process that has been used, you may wish to challenge what has happened.

→ *Read Section 15: **Challenging decisions**.*

You may be interested in...



There is an online tool called BRIDGET that allows you to check whether a best interests process has been followed. Completing it generates a printable report that indicates how closely the process used matches the guidance set out in the Mental Capacity Act **Code of Practice**.

www.bestinterests.org.uk



The British Psychological Society has published 'Best Interests Guidance on determining the best interests of adults who lack capacity to make a decision themselves'. It describes how to prepare for and hold best interests meetings.

www.bps.org.uk/publications/guidelines-for-practitioners/guidelines-for-practitioners.cfm



'Best Interests Guidance for England and Wales: Guidance for people who may have to participate in making decisions on behalf of people who lack capacity to do so for themselves'. This advice is aimed at staff working in health or social care such as doctors, nurses, psychologists, therapists, social workers, care home managers (and staff), families and advocates.

<http://bit.ly/ljU7w9>

www.bpsshop.org.uk/best-interests-guidance-on-adults-who-lack-capacity-to-make-decisions-for-themselves-england-and-wales-p708.aspx



2gether NHS 'Best Interests Pathway' flow chart shows how the best interests process should work if an assessment has shown someone lacks capacity to make a decision. It sets out the role of the decision-maker, who should be included in a best interests meeting, what to do if there is a dispute and how a decision to take an action should be evidenced.

www.2gether.nhs.uk/mca-best-interests-pathway

SECTION



Transition to adulthood

I am helping my son or daughter to plan for adulthood (transition)...

The process of becoming an adult is sometimes known as ‘transition’, a term widely used by education, health and social care services. The ages during which someone is deemed to be in transition vary: in law a person is recognised to be fully adult at the age of 18, although certain adult responsibilities are recognised from the age of 16. Some healthcare decisions (such as contraception) can be made by the young person from 14 if they have sufficient capacity (see **Fraser Guidelines**). For many young people with a learning disability planning for their adult future begins with their Post 14 Review.

The Mental Capacity Act applies to anyone aged 16 or over.

Parents of a child with learning disabilities will therefore need to be aware of the Act and its potential implications for their role in decision-making once their child reaches this age.

“My son has recently left school and he’s in the transition stage from children to adult services. Obviously when he was a minor I made most of the decisions for him, but as he is an adult, I’ve had to think very carefully when I made decisions whether it is in my son’s best interest and I hope I have done so.”

The Mental Capacity Act applies to any decision that needs to be made on behalf of someone who lacks **capacity** to make it themselves. During transition a series of important decisions affecting a young person with learning disabilities will have to be made:

- The young person will receive benefits in their own right as an adult. If they are unable to manage their finances, their parents will need to consider whether to become a welfare benefits **appointee**.

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- Where the young person lives may change. If he or she lacks capacity, no one person has authority to make this decision and it will usually be made by consensus between the family and local authority, taking the young person's views into account. Local authorities do not have the power to move a person somewhere a family think is not in the person's **best interests** and disputes about where a person should live may need to be resolved by the **Court of Protection**.
- If the young person lacks capacity to decide what to do during the day and who supports them, this may be agreed between the person's family, the local authority and a service provider.
- The local authority may discuss having a direct payment with the family so that the family arrange the person's service instead of the local authority. If the person lacks capacity to manage a direct payment, it can be paid to a family member (who is called a 'suitable person'). They do not need to be a **deputy** or appointee to be a suitable person. Remember, it is your decision as to whether you think your relative will get better support if you have a direct payment, and you can refuse to have one.

→ *Read Section 10: Managing finances.*

You should note that there are also certain decisions that the Mental Capacity Act says can never be made on behalf of someone else, whatever their age, usually because they are about intimate personal relationships. These include:

- consenting to marriage
- consenting to sexual relationships
- voting in elections.

As a parent of a young person with learning disabilities who lacks capacity to make one or more decisions, there are some changes in relation to decision-making that you will need to be aware of once they have turned 16:

- Other people may need to assess their capacity with a view to making a decision on their behalf. For example, a member of college staff may be weighing up whether a particular course is suitable for a student with severe learning disabilities. In such situations you should always be closely involved both in the **assessment** of their capacity, and the decision that is made in their **best interests**.
- You may need to make a decision in your son's or daughter's best interests, or you may be consulted by someone else about their best interests.

→ *Read Section 6: Best interests.*

- As a parent you should always support your son or daughter to be involved as much as possible in a decision made on their behalf, even if they do not have the capacity to make it themselves.
- You may seek authority to make certain types of decision for your son or daughter once they have turned 16 if they cannot make these themselves. Many family carers become a welfare benefits appointee or a deputy to manage their son's or daughter's finances.

→ *Read Section 9: Getting authority to make decisions and Section 10: Managing finances.*

Planning for the future

Family carers who have supported a young person with learning disabilities through transition suggest that planning how key decisions will be made after age 16 should begin as early as possible. Post 14 reviews are a good forum for starting to do this.

Some families have found person-centred planning and **circles of support** particularly useful tools for helping them and their relative with learning disabilities to think about both day-to-day decisions and the bigger ones affecting the relative's future as an adult.

You may be interested in...



SCOPE has published a study of the impact of the Mental Capacity Act on disabled young people with complex needs in transition. It is available to download at:

www.scie.org.uk/publications/mca/resources/research.asp

SECTION



Moving home

Moving home is one of the biggest decisions that anyone makes in their life. For many people with learning disabilities it can also be a very complex one because of all the factors that need to be taken into consideration when making the decision about where to move.

Factors to consider

These will include:

- Does the person want to or have to move?
- The financial resources available to them (their income, any savings and investments and so on).
- The suitability of the accommodation to meet the person's needs, such as level access or access to an open space.
- The location of the property – is it a neighbourhood that is familiar to the person? Is it safe? Is it within reach of essential facilities?

Moving home also involves planning how the person will live once they are settled in their new accommodation. This will mean thinking about:

- how the person's finances in relation to their accommodation will be managed
- how the support that the person will require to live in the home will be managed
- transport and access to essential facilities
- upkeep and maintenance of the person's home.

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

Moving home and the Mental Capacity Act

Family carers are likely to be closely involved in the move of any close relative with a learning disability, whether or not the person is able to make these decisions themselves. But where someone lacks **capacity** to make one or more of them, the family will be involved more or less directly in key decisions that need to be made.

There are some general principles about mental capacity covered in other sections of this pack that you should bear in mind when helping a relative who may lack capacity to move home:

- Each decision must be considered on its merits. Although your relative may not be able to make some decisions associated with moving home, he or she may be able to make others, especially some of the smaller ones. Anyone supporting your relative (including family carers) should always assume the person has capacity to make a decision until it can be shown otherwise through an **assessment of capacity**.

→ *Read Section 5: Assessing capacity.*

- With the right help and support (such as accessible information perhaps), your relative may be able to make a decision that they had been having difficulty making.
- If your relative lacks capacity to make a decision about moving home, anyone making that decision on their behalf must act in their **best interests**.

→ *Read more about this in Section 6: Best interests.*

- Because moving home involves a series of linked decisions, the Mental Capacity Act makes provision for several types of 'substitute decision-making'. These are roles that allow someone to make specific decisions for a person who lacks capacity to make them.

→ *Read more about this in Section 9: Getting authority to make decisions.*

- If you disagree with a decision about moving home that someone else, such as paid support staff or a professional has made on behalf of your relative, there are a number of ways that you can challenge what has happened.

→ *Read Section 15: Challenging decisions to find out more.*

There may be a number of options available to the person in terms of their occupancy status when they move. They may become:

- a sole or joint tenant of a rented property
- an owner occupier
- a resident of a care home
- a hospital patient.

Tenancy

If someone lacks capacity to agree to a tenancy, the tenancy may not be valid unless it is signed by a person who has authority to sign it on their behalf. This could be a court appointed **deputy** for property and affairs, someone with **lasting power of attorney** for property and affairs or **the Court of Protection** can agree a tenancy on the person's behalf.

→ *Read more in Section 12: Applying to be a deputy and Section 13: Lasting Power of Attorney.*

Owner occupier

If someone lacks capacity to sign a mortgage agreement or other contract to do with owning a property, they will need either a deputy or someone with lasting power of attorney for property and affairs to sign on their behalf.

→ *Read more in Section 12: Applying to be a deputy and Section 13: Lasting Power of Attorney.*

Specialist advice and information

Because housing can be a complex issue, and there are already good resources available to guide family carers about how they can use the Mental Capacity Act, we suggest that you follow the links below to get detailed information.

For specialist advice and information about the Mental Capacity Act and housing issues, we recommend that you look at the resources available from Housing Options, an independent advice and information service that provides practical help for people with learning disabilities and their families. Their website can be found at: www.housingoptions.org.uk/general_information/gi_welcome

A particularly useful guide produced by Housing Options is ‘Choice, Contracts and Mental Capacity Act 2005: Housing & Support Decisions for People with Learning Disabilities’. It looks at:

- how to encourage informed choice (and provide evidence) when supporting an adult with a learning disability with their housing and support choices, both before they move in, and throughout their tenancy or home ownership
- how best to support someone when they are entering into a contract for their tenancy/ownership, and for their support
- support for the owner or tenant in managing in their own home, help with understanding and keeping formal agreements and managing money.

You can download a copy at: www.housingoptions.org.uk/general_information/gi_publications_docs/valuing_people_now_publications/Choice-Contracts-MCA.pdf

Mencap has a factsheet that explains what a housing tenancy is, issues of capacity and the law surrounding housing tenancy and how it might apply to a person with a learning disability. It can be downloaded from: www.mencap.org.uk

You may be interested in...



SCIE TV has a series of films about the Mental Capacity Act, including one entitled Khurram's Move. This follows the process used to determine the best interests of a young man with severe learning disabilities who may have to move home. You can view the film at:

www.scie.org.uk/adults/mentalcapacity

SECTION

9

Getting authority to make decisions

The Mental Capacity Act makes provision for what is known as ‘substitute decision-making’, whereby someone has legal authority to make certain decisions on behalf of a person who lacks **capacity** to do so themselves. The most common types of decisions that need to be made on someone’s behalf relate to their **property and** (financial) **affairs**, or to their **personal welfare**.

As a family carer of a person with learning disabilities there are three types of substitute decision-making you should be aware of:

- If a person with learning disabilities is unable to receive and manage the welfare benefits to which they are entitled, you should inform the Department for Work and Pensions, which will appoint someone to do so on their behalf. A **welfare benefits appointee** is usually a family member or a paid worker.

→ *Read more in Section 11: Welfare benefits appointee.*

- Family carers of people with severe learning disabilities can make an application to become a court-appointed **deputy** because their relative lacks the capacity to make certain decisions. If granted, the deputy is empowered to make those decisions on the person’s behalf.

→ *Read more in Section 12: Applying to be a deputy.*

- A **Lasting Power of Attorney (LPA)** can be set up when a person says who they would like to make decisions for them if they lack or lose the capacity to make those decisions themselves. A person must have the capacity to donate the power in the first instance.

→ *Read more in Section 13: Lasting Power of Attorney.*

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

Anyone proposing to make a decision for a person who lacks capacity should always check no-one else has the relevant authority to make that decision. For certain healthcare decisions they may also need to check whether the person who lacks capacity has made an **advance decision to refuse treatment**.

You may be interested in...



‘Guidance on Direct Payments and Capacity’, a flowchart that summarises how to work out options for substitute decision making, signing agreements and contracts can be viewed at:

<http://bit.ly/mzQWle>

http://jipeast.org/attachments/547_PDF%20Guidance%20on%20Direct%20Payments%20&%20Capacity.pdf

SECTION

10

Managing finances

As with any decision, those relating to a person's finances must each be considered on their own merits, since many people with learning disabilities will be able to make some decisions about their money.

Family carers want to be sure that good arrangements are in place to protect the **best interests** of a relative who may lack **capacity** to make decisions about their finances. These may range from day-to-day decisions about shopping for food or clothes, to opening a bank account, managing benefits payments and buying a house.

Family carers buying items

Family carers may spend money on behalf of a relative who lacks capacity to purchase what the **Code of Practice** calls 'necessary goods or services' (there is a useful definition of this term at paragraphs 6.58 and 6.59 of the Code). For more costly items, such as arranging a holiday, family carers will be protected from liability if they follow the best interests principles of the Act when acting on behalf of a relative lacking capacity.

→ *Read Section 2: The five principles of the Mental Capacity Act and Section 6: Best interests.*

Family carers managing the finances of a relative who lacks capacity should keep good financial records, including bills and receipts, for all significant financial transactions carried out on behalf of a person who lacks capacity.

Some decisions may involve using a relative's savings or other assets – if, for example, they need to make substantial repairs to their property. In this instance, a family carer might need to apply to the **Court of Protection** for a court order authorising their proposed action.

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

Money plans

A financial assessment or money plan may be drawn up, detailing a person's capacity to make financial decisions, and how decisions can be made by, with and for that person. These are particularly useful for people who support adults with learning disabilities living independently, or planning to live independently. Housing Options and Dimensions have written an excellent detailed guide about this, available download from www.housingoptions.org.uk/general_information/gi_publications_docs/valuing_people_now_publications/my_home_and_money_2010.pdf

Circles of support

Circles of support bring together people who know and care about a person with learning disabilities to help them in their lives. A circle can help the person and any **decision-maker** (such as a **deputy**) think about financial decisions. In the film about managing finances Wendy Crane talks about how her son Niki's circle helped her demonstrate to the **Office of the Public Guardian** that she is fulfilling her duties as a deputy.

If a person lacks capacity to make all financial decisions, they need at least one of the following:

- a **welfare benefits appointee**
- someone with **Lasting Power of Attorney** to make decisions about their property and affairs
- a **deputy** for **property and affairs**.

Deputyship and Lasting Power of Attorney

It is important to remember that deputies and attorneys can only make decisions specified in the court order granting deputy powers or a Lasting Power of Attorney. The Challenging Behaviour Foundation's guide to applying for a property and affairs deputyship shows how an application might indicate the type of authority sought by a family carer.

Issue	Wording
Banking and managing property	To oversee all matters relating to the property and financial affairs of a relative
To sign mortgage forms	To enter into a mortgage agreement to purchase a property on behalf of a relative to enable better living conditions
To sign tenancy and/or mortgage forms	To sign any necessary deeds or documents on behalf of a relative to enable better living conditions

Discretionary Trusts

Discretionary Trusts are a way of putting in place financial arrangements to help support a relative without impacting on their relative's right to continue claiming benefits. A Discretionary Trust can also provide a way of owning property. Sometimes families decide that in the long-term they would like to be able to set up arrangements that allow their relative to continue to live at home with the necessary support. You can find out more about how to set up a Discretionary Trust at: www.housingoptions.org.uk.

Direct payments (or personal budgets)

A direct payment is made by a local council to people who would like to arrange and pay for their own care and support services instead of receiving them directly from the local council. A person must be able to give their consent to receiving direct payments and be able to manage them even if they need help to do this on a day-to-day basis. However, the Health and Social Care Act 2008 (s146) enables local authorities to make direct payments to a third party (such as a family carer) where the disabled person lacks the necessary mental capacity to consent to receiving the direct payment.

A family carer can be the recipient of a direct payment on behalf of a disabled child. To receive a direct payment themselves when they reach the age of 18, the disabled person must be able to consent to receive the direct payment (or the payment can be made to a third party).

To find out more about how direct payments relate to you as a carer, visit: www.carersuk.org/Information/Directpayments

What happens if I am not happy with what has happened?

Concern or disagreement about a person's finances may arise when, for example:

- a care provider says the person can make their own choice about money when their relative does not think they can
- paid staff are using the person's money in ways that a relative is not happy about
- someone questions the actions of an attorney or deputy appointed by the court.

Remember that someone else might question whether a family carer is using the money of a person who lacks capacity inappropriately or without proper authority.

In serious disputes the most appropriate action is to contact the **Office of the Public Guardian** for guidance and advice.

➔ *Read Section 15: Challenging decisions.*

You may be interested in...



‘No selling. No jargon. Just the facts about help with managing if you or someone you care for lacks mental capacity’ is a booklet available to download from the Office of the Public Guardian website:

www.publicguardian.gov.uk/decisions/decisions.htm



‘Guidance on Direct Payments and Capacity’, a flowchart that summarises how to work out options for substitute decision making, signing agreements and contracts can be viewed at:

<http://bit.ly/mzQWle>

http://jipeast.org/attachments/547_PDF%20Guidance%20on%20Direct%20Payments%20&%20Capacity.pdf



See Sense’s ‘Self Directed Support Factsheet 6’, subtitled Direct payments and personal budgets: Mental Capacity.

www.sense.org.uk/publicationslibrary/allpubs/direct_payments_factsheets

SECTION

11

Welfare benefits appointee

If your relative is aged 16 or over, lacks the **capacity** to manage their benefits and their only income is social security benefits, there will usually be no need for a **deputy** to be appointed. Your relative's benefits can be managed by someone appointed by the Department for Work and Pensions (the DWP). This person is called an **appointee**.

For this to happen an application should be made to the DWP, which will make an **assessment** of your relative's capacity before determining who is best placed to act as their **welfare benefits appointee**. If your relative lives with you, it is very likely that this will be you or another close relative. If he or she lives in residential accommodation or supported living, the best person to act as an appointee will vary from one situation to another. Very often this will be a family carer. It is good practice for it not to be someone directly connected with providing your relative's care.

An appointee is fully responsible for acting on the person's behalf in their dealings with the DWP. This includes:

- claiming benefits, including completing and signing any claim forms
- collecting/receiving benefit payments
- *and* reporting changes in the person's circumstances.

Appointees do not have authority to make wider financial decisions such as agreeing a tenancy on behalf of someone who lacks capacity to do so themselves or entering into other contracts on their behalf (for example, buying furniture).

→ See Section 12: *Applying to be a deputy*

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

You may be interested in...



The Department for Work & Pensions has more information about becoming an appointee at:

www.dwp.gov.uk

Or through the Benefit Enquiry Line:

0800 882 200

SECTION

12

Applying to be a deputy

A **deputy** is someone appointed by the **Court of Protection** with legal authority to make decisions on behalf of a person who lacks **capacity** to make these decisions for themselves. An application has to be made to the Court of Protection to become a person's deputy and there is a fee associated with this process. There is also an annual fee to cover the cost of supervision. The level of fees is linked to the person and not the deputy's assets. If the person's assets are low, fees can be waived or reduced.

There are two types of deputyship; property and affairs and health and welfare.

Property and affairs deputy

The property and affairs deputyship allows the deputy to manage the person's money. This type of deputy is routinely appointed by the Court of Protection where it is necessary for a person's finances to be managed on an on-going basis.

Decisions about property and affairs cover any possessions owned by a person as well as the money they have in income and expenditure. If the person's only income is welfare benefits, a deputyship is not always necessary, as their finances could be managed by an **appointee**.

→ *Read Section 11: Welfare benefits appointee*

Deputies only have authority to make those decisions agreed by the Court of Protection; for example, a deputy for property and affairs may have the authority to sign a tenancy agreement to rent a property, enter into a mortgage agreement to buy a property or make other financial decisions.

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

Health and welfare deputy

Health and welfare decisions can cover a person's healthcare, where they live, what clothes they wear, what they eat and anything needed for their general care and wellbeing.

There is no requirement for anyone to have the authority to make these decisions by being a deputy and people who lack capacity to make a decision concerning their health or welfare do not usually need to have a deputy. These decisions can be made through the **best interests** process.

A deputy for health and welfare may be necessary where a series of linked decisions needs to be made over time, perhaps relating to a medical condition.

Personal welfare deputyships are granted much less often than property and finance deputyships and permission is ordinarily required from the Court of Protection before you can make an application. If a family member wishes to become a health and welfare deputy, they need to be clear on the application why this would be better for their relative than the general best interests decision making process. Sometimes this is because of an urgent need for a decision on behalf of someone who lacks capacity.

To become a deputy

To become either type of deputy, a person must make an application to the Court of Protection, which will decide whether this arrangement is in the person's best interests. In most cases the application can be decided on the information given in the forms, without having to go to court.

Once appointed a deputy is supervised by the **Office of the Public Guardian**, which will investigate any complaints made about a deputy.

You may be interested in...



The Challenging Behaviour Foundation has produced a guide about deputyships, which gives useful tips about how to make an application to the Court of Protection:

www.thecbf.org.uk/news/news.htm#NewResources



Making an application to the Court of Protection, see:

www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/DG_176235

SECTION

13

Lasting Power of Attorney

A **Lasting Power of Attorney (LPA)** allows a person to appoint someone else – an attorney – to act on their behalf. A Lasting Power of Attorney document must be registered with the **Office of the Public Guardian** before it is legally recognised.

As a family carer of a person with a learning disability, there are two aspects of an LPA that you should be aware of:

- The first is that the person donating the power of attorney must have the **capacity** to do so. In practice this means demonstrating that they understand the nature of the powers they are donating and the consequences of doing so. Some people with learning disabilities do have capacity to say, for example, who they would like to look after their money. However, most people with severe learning disabilities will lack capacity to understand LPAs and therefore will not be able to set one up.
- The second aspect is that, while in most situations an LPA is only activated once the person loses capacity, the person may ask the attorney to act on their behalf for decisions relating to financial matters even when they still have capacity to make those decisions themselves.

There are two types of LPA:

An **LPA for property and affairs** allows an attorney to make decisions about how to spend a person's money and the way their property and affairs are managed, such as writing cheques, paying bills, and purchasing or renting property.

As a family carer you may wish to consider setting up an LPA for property and affairs so that you can be confident that any financial support you provide, or wish to provide, to your relative can continue if you lose capacity yourself to do this in the future.

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

An **LPA** for **personal welfare** decisions empowers an attorney to make decisions about someone's healthcare and welfare. These decisions can only be taken on their behalf once they lack the capacity to do so themselves. The sorts of decision that an attorney might be required to make include:

- where the person is to live, or
- whether a care home is best for them and which one, or
- how the person spends their time, including decisions about using short breaks or going on holiday.

An attorney may be given the power to make decisions about healthcare that the person might have made for themselves, including accepting, not accepting, or stopping treatment.

People with a progressive illness may decide, while they still have capacity, that they wish to refuse particular treatment in the future – this is called an **advance decision to refuse treatment**. This decision must be respected unless a later LPA grants the authority to override it.

You may be interested in...



Carers UK has more information about how to make an application for an LPA at:

www.carersuk.org/Information/Makingdecisionsonsomeonesbehalf/PowerofAttorney



'What is a Lasting Power of Attorney?' See:

www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingarrangementsincaseyoulosementalcapacity/DG_185921

SECTION

14

Decisions about healthcare

The Mental Capacity Act covers all decisions that affect the health and social care needs of someone who may lack **capacity**. Where the decision involves the provision of healthcare, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the **decision-maker**.

Healthcare staff must adhere to the principles of the Act and carry out their decision in the person's **best interests** as defined in the Act.

Family carers have a crucial role to play in ensuring that a relative's best interests are protected.

→ *Read more about how family carers must be involved in decision-making in Section 4: Involving family carers, Section 5: Assessing capacity and Section 6: Best interests.*

Health action plans

Family carers can play an active role helping their relative to think through what should happen if they require healthcare in the future. Making a **Health Action Plan** can be helpful in a number of ways by:

- informing those supporting the person (social care and healthcare staff) about the person's medical history and any underlying conditions that might need to be taken into account
- indicating the person's preferences and wishes
- suggesting ways to help the person or put them at ease in situations where they are stressed or upset
- listing people to be consulted in emergencies or in the event of specific illnesses.

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

To find out more about health action planning, visit the Valuing People Now website: www.valuingpeoplenow.dh.gov.uk/content/health-action-plans

Urgent healthcare decisions

Healthcare may be required in an emergency situation when it is not possible for a medical practitioner to pursue all of the steps required of a best interests process and they will make a decision to treat the person. In these situations healthcare staff should still try to communicate with the person and tell them what is happening, even if they cannot or do not understand or respond.

Court appointed personal welfare deputies

Most **personal welfare** decisions can be made using the best interests principles set out in the Mental Capacity Act outlined in *Section 6: Best interests*. Family carers may consider applying to the **Court of Protection** to become a personal welfare **deputy** for a relative who lacks capacity. The Court of Protection may only choose to appoint a personal welfare deputy where a series of linked health or welfare decisions need to be made, or where there are serious disputes about what is in the person's best interests.

→ *Read Section 12: Applying to be a deputy.*

Sense has produced a checklist of questions that family carers can ask on behalf of a family member when faced with a potentially serious health decision:

- What is the condition that needs to be treated?
- What is the decision that needs to be made?
- What are the options for treatment?
- What are the effects of treatment?
- How will this treatment affect the person's quality of life – physical, material, social, emotional, and spiritual abilities and interests?
- How does that person experience value and meaning in their own life – this might be radically different from our own e.g. wind on their face, gentle touch, food?
- Is a second medical opinion needed?

Advance decisions to refuse treatment

The Mental Capacity Act provides for people with capacity to refuse in advance certain types of treatment if they are unable to make that decision at a future date. This is called an **advance decision to refuse treatment**. Because the refusal of treatment may result in the end of the person's life, there are strict rules about how advance decisions work.

In summary (for more detail you should consult the Code of Practice), an advance decision to refuse treatment must be valid, it must be applicable (making clear which treatment is being refused and in which circumstances) and must be followed.

There are special requirements for making advance decisions to refuse life-sustaining treatment. Such advance decisions must be in writing, signed and witnessed and the person making the advance decision must have stated that the decision is to apply even if life is at risk. If someone makes an advance decision, it should be reviewed from time to time to ensure that it continues to reflect their views.

You may be interested in...



Mencap has developed a resource aimed primarily at families and carers of people with profound and multiple learning disabilities (PMLD), focusing on securing the best outcomes for people with PMLD in dealing with healthcare services and gaining a better understanding of their rights.

www.mencap.org.uk/page.asp?id=21253

SECTION

15

Challenging decisions

Family carers may disagree with a decision that has been made about their relative who lacks **capacity**. These are some of the reasons why a family carer might seek to challenge a decision.

- The decision was not in the relative's **best interests**.
- There is disagreement about whether the relative had capacity to make the decision in question.
- Insufficient efforts were made to find people who know the relative well and who could be consulted.
- The relative should have been supported in a way that allowed them to be more involved.
- The relative's wishes and beliefs were not taken into consideration by the **decision-maker**.
- The decision did not have to be made at that time because the relative could have made the decision at a different time or in different circumstances.
- Someone with the appropriate authority to make the decision (a **deputy**, an **attorney**, an **appointee**) was in place and should either have been asked to make the decision or should have been consulted.
- An **IMCA** was engaged inappropriately (because there were family members or others who could have been consulted).
- The process of making the decision was not recorded properly.

Family carers who disagree with a decision often feel unsure how to go about challenging what has happened. Here are some practical tips about what you can do:

- Note down the name of person who made the decision and find out as much as you can about the procedure that has been followed leading up to the decision.

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

- Many problems can be resolved quickly and easily by having a discussion with the person who made the decision. Where family carers have not been consulted or feel insufficiently involved, the decision-makers should take their views into account once this has been pointed out to them.
- If you cannot resolve the problem in this way, keep a record of what has been said and by whom.
- Seek advice and information to clarify what you can do and how to go about it. In addition written information, many carers prefer to speak to someone directly, either on the phone or face-to-face.
- Every health and social care organisation (including independent care services registered with the Care Quality Commission) will have a formal complaints procedure that must consider issues raised about mental capacity. Information should be readily available about how to make a complaint. In healthcare settings the local Patient Advice and Liaison Service (PALS) will be able to help you make a complaint. If you have made a complaint about the NHS, you may be able to get support from the Independent Complaints Advocacy Service (iCAS).

You may suggest, or it may be suggested to you, that the dispute can be resolved in a number of ways:

- by involving an advocate to act on behalf of the person who lacks capacity to make the decision
- getting a second opinion
- holding a formal or informal best interests case conference.
- obtaining legal advice: some family carers prefer to obtain legal advice through the Citizen's Advice Bureau or from a qualified solicitor.

The **Code of Practice** says that, where there is a serious dispute that cannot be resolved, local authorities or health trusts should make an application to the **Court of Protection** rather than waiting to see if families challenge a decision made by a professional or paid worker. A family carer may make an application to the Court of Protection for a ruling and, although you can do this yourself, it is advisable to seek legal assistance before doing so.

Family carers sometimes want to challenge care staff or organisations for allowing their relative to make a decision that the family disagree with. This is a complex area because the Mental Capacity Act is very clear about protecting the rights of a person to make what others might consider to be an **unwise decision** if they have capacity to make the decision.

In such situations, you may want to check that:

- your relative's capacity to make the decision was assessed properly.

→ *Read Section 5: Assessing capacity*

- the decision did not place your relative or others at risk of harm. If it did, there may be an adult **safeguarding** issue, or the Mental Health Act may apply.

→ *Read Section 16: Safeguarding and Section 17: Deprivation of Liberty Safeguards (DoLS).*

You may be interested in...

The handbook 'Carers and their rights: the law relating to carers' which has a chapter on making a complaint and notes that carers may make a complaint on behalf of a relative who lacks the capacity to make a complaint about their own care. The handbook is published by Carers UK and is available to download at:

www.carersuk.org/Professionals/ResearchLibrary/Evaluationofrights/CarersandtheirRights-theLawrelatingtoCarers

SECTION

16

Safeguarding

Safeguarding is the term used for a range of activity to do with protecting an adult's right to be safe. Safeguarding includes prevention of abuse, minimising risk of harm, recognising and reporting crime and abuse. Local authorities have the main responsibility for safeguarding adults and children. All agencies and individuals are expected to follow their local multi agency guidelines in recognising and reporting abuse. They are also expected to take action to reduce the risk of harm, crime and abuse.

The Mental Capacity Act (MCA) provides a valuable framework for safeguarding adults that:

- recognises independence i.e. protects people from others making decisions on their behalf if they can make those decisions themselves
- provides protection for a person who lacks capacity, in that any decisions that have to be made must be made in their best interests and place the least restrictions possible on them.

The third principle of the Mental Capacity Act states:

“a person is not to be treated as unable to make a decision merely because he makes an unwise decision”

If an **assessment of capacity** indicates someone has capacity to make a particular decision (i.e. they understand the risks and implications of making it or not making it), their decision has to be recognised. This applies even if others regard the decision as ‘unwise’.

There will still be a requirement to manage risks associated with the person's decision.

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

There are other considerations in safeguarding procedures that relate to the Mental Capacity Act. An assessment of capacity may be needed in relation to the following:

- whether they want to involve the police or other agencies or pursue civil action
- whether they consent to information about them being shared and how it is held.

If the person does not have capacity to make some or all of these decisions, others may need to make best interests decisions on the person's behalf.

Ultimately the **Court of Protection** can appoint a **deputy** to make certain decisions on behalf of a person who lacks capacity.

Independent Mental Capacity Advocates (IMCAs)

IMCAs are usually only appointed for people who lack capacity to make a significant decision and who do not have family or friends that can be involved. However in safeguarding procedures the local authority or health authority can use their discretion to involve an IMCA although there are family and friends. For example an IMCA may be used if:

- it is not practical to consult family or friends because it is too difficult for them to participate formally, they feel they do not know the person well enough, they would not involve the person in the decision-making process or are not willing to help with the specific decision to be made
- family members or friends may be implicated in abuse.

The Office of the Public Guardian

The **Office of the Public Guardian** helps protect people who lack capacity by:

- managing registers of **attorneys** (for Lasting Power of Attorney) and **deputies**
- supervising deputies
- managing Court of Protection Visitors who support the role of deputies
- dealing with complaints about deputies or attorneys.

Criminal offences

The MCA introduced new criminal offences of ill treatment or wilful neglect of a person who lacks capacity to make relevant decisions by *any* person (section 44 of the **Code of Practice**).

You can get more information about your local Safeguarding Adults Team, and Multi Agency Guidelines and Procedures can be found, on your local authority website. You can also request this information by phone from your local Safeguarding Adults Team, whose details will also be online – search under Safeguarding Adults Team.

You may be interested in...



Although entitled ‘Recognise and report elder abuse’ advice on the Direct.gov website is useful for family carers who have concerns about safeguarding. See:

www.direct.gov.uk/en/Pensionsandretirementplanning/Over50Healthandwellbeing/SupportAndYourEverydayHealth/DG_10026831

‘IMCA – Appropriate to consult – a guide for health and social care staff’ explains when an IMCA may be appointed although a person has family or friends. See:

[www.voiceability.org/images/uploads/VAIS01%20Appropriate%20to%20Consult%20Guidance\(1\).pdf](http://www.voiceability.org/images/uploads/VAIS01%20Appropriate%20to%20Consult%20Guidance(1).pdf)

SECTION

17

Deprivation of Liberty Safeguards

The **Deprivation of Liberty Safeguards (DoLS)** became law in April 2009 as an amendment to the Mental Capacity Act 2005. There is a separate Code of Practice for DoLS. They are relevant in some circumstances to people who lack **capacity** to make particular decisions.

The safeguards specifically protect the rights of people in care homes and hospitals who lack capacity to make decisions about their care or treatment:

- where care or treatment can only be provided in a way that amounts to a **deprivation of liberty** (Article 5 – Human Rights Act) and
- where the Mental Health Act (1983) is not appropriate.

The main purpose of the DoLS is to safeguard people in these settings from unauthorised deprivation of their liberty. The DoLS also provide a framework to ensure a person's **best interests** are properly represented in assessing, authorising and managing a deprivation of their liberty.

If it is necessary to take action to deprive someone of their liberty in other settings, an application to the **Court of Protection** is required.

There is a difference between someone having a restriction placed on them in their best interests and a deprivation of liberty and this will vary depending on individual circumstances. Care homes and hospitals must find ways to support people that minimise any restrictions on them and avoid the need to apply for a DoL, wherever possible.

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

The Code of Practice for DoLS identifies the following factors as indications that a care home or hospital should apply for a DoL:

- restraint, including sedation during admission
- staff exercise complete and effective control for a significant period
- staff exercise control over assessments, treatment, contacts and residence
- the person is not allowed to be cared for by others or live elsewhere
- a request from family or other carers for the person to live with them is refused
- the person's social contacts are restricted.

Supervisory Body

If some or more of the above apply, the care home or hospital must make an application to their **Supervisory Body**. The Supervisory Body for a care home is the local authority and it is the Primary Care Trust (PCT) for a hospital. Some local authorities and PCTs have a single point of contact for DoLS applications. (At the time of printing it is not clear who will take over this role when PCT's no longer exist).

The Supervisory Body is responsible for ensuring that an assessment process (prescribed by the Code of Practice) is carried out. The process of assessment and subsequent authorisation:

- ensures human rights
- gives representation to the person
- gives a right of appeal
- limits the timescale of the deprivation of liberty
- ensures that least restrictive options are considered.

The Supervisory Body will make a decision about whether to authorise the deprivation of liberty.

A care home or hospital can issue themselves with an urgent authorisation to take effect immediately. However, they must apply to the Supervisory Body for a standard authorisation assessment, which must be carried out within 7 days

If authorisation is refused, the hospital or care home will need to provide the care or treatment in a less restrictive way that does not amount to a DoL.

The Court of Protection will be the final decision maker where there is dispute or when an appeal has been made.

DoLS are monitored by the **Care Quality Commission**.

You may be interested in...



DoLS Code of Practice:

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_095894.pdf



Mental Capacity Act 2005 Deprivation of Liberty Safeguards. A guide for family, friends and unpaid carers:

www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_087309.pdf



You can also find information about DoLS and who to contact in your Local Authority or PCT on their websites or by phoning your local authority customer services. For example see Worcestershire County Council's 'The Deprivation of Liberty Safeguards Assessment, a guide for family and friends' on:

www.worcestershire.gov.uk/cms/social-care-and-health/disabilities-and-health/deprivation-of-liberty/advice-for-service-users.aspx

SECTION

18

Words and phrases included in this information

Advance decision to refuse treatment – a decision to refuse specified medical treatment, made in advance by a person who has the capacity to do so. This decision will apply at a future time when the person lacks capacity to consent to or refuse the specified treatment. Specific rules apply to advance decisions to refuse life-sustaining treatment.

Appointee or welfare benefits appointee – someone appointed under Social Security Regulations to claim and collect benefits on behalf of a person lacking capacity to manage their own benefits

Assessment of capacity – the process described by the Act and the Code of Practice to establish whether someone has the capacity to make a decision. No decisions can be made on behalf of someone else under the Act unless an assessment of capacity has been carried out. Most of the time family carers who have known their relative all their life will have a reasonable belief that they know what decisions a person can make for themselves. Sometimes specialist help from a psychologist or a speech and language therapist will be required, but it remains the responsibility of the person proposing to make the decision (the ‘decision-maker’) to ensure that an assessment is carried out.

Attorney – a person appointed under a Lasting Power of Attorney (LPA) who has the legal right to make decisions within the scope of their authority on behalf of the person (the donor) who made the Power of Attorney.

Best interests – any decision made, or anything done, for a person who lacks capacity must be done in their best interests.

Capacity – the ability to make a decision about a particular matter at the time the decision needs to be made.

Care Quality Commission (CQC) – England’s independent regulator of health and social care provided for everyone – in hospitals, care homes and people’s own homes – by the NHS, local authorities, private companies and voluntary

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www.hft.org.uk/Family_Carer_Support/MCA_Resource_Guide

organisations. CQC also seeks to protect the interests of people whose rights are restricted under the Mental Health Act

Carer – someone who provides (unpaid) care.

Circle of support – a circle of support is a group of people who agree to meet on a regular basis to support a friend or family member.

Code of Practice (Mental Capacity Act) – provides guidance on how the Mental Capacity Act 2005 works on a day-to-day basis. It has case studies and explains in more detail what the key features of the law are. Certain categories of people have a legal duty to have regard to the Code, including health and social care professionals, court-appointed deputies and attorneys under LPAs.

www.publicguardian.gov.uk/mca/code-of-practice.htm

Consent – agreement, for example, to a care plan or treatment regime. For consent to be legally valid, the person giving it must have the capacity to take the decision, have been given sufficient information to make the decision and not have been under any duress or inappropriate pressure.

Court of Protection – is a superior court of record and is able to set precedents (set examples to follow in future cases). It has the powers to:

- decide whether a person has capacity to make a particular decision for themselves;
- make declarations, decisions or orders on financial or welfare matters affecting people who lack capacity to make such decisions;
- appoint deputies to make decisions for people lacking capacity to make those decisions;
- decide whether a Lasting Power of Attorney (LPA) is valid;
- remove deputies or attorneys who fail to carry out their duties;
- hear cases concerning objections to register a LPA and make decisions about whether or not an LPA is valid.

Decision maker – a person making a decision on behalf of a person lacking capacity to make the decision.

Deprivation of Liberty Safeguards (DoLS) – the framework of safeguards under the Mental Capacity Act for people who need to be deprived of their liberty in a hospital or care home in their best interests for care or treatment and who lack the capacity to consent to the arrangements made for their care or treatment.

Deputy – a person appointed by the Court of Protection with authority prescribed by the Court to make decisions on behalf of a person lacking capacity to make particular decisions.

Donor – a person who makes a Lasting Power of Attorney.

Fraser guidelines and Gillick competency – refer to a legal case which looked specifically at whether doctors should be able to give contraceptive advice or treatment to under 16-year olds without parental consent. But since then, they have been more widely used to help assess whether a child has the maturity to make their own healthcare decisions and to understand the implications of those decisions. Most health and social care agencies will have a checklist to help their staff assess a child's competence in this respect.

Independent Mental Capacity Advocate (IMCA) – a person who provides support and representation for a person who lacks capacity to make specific decisions. They are mainly a safeguard for people who do not have family or friends who can represent them.

Lasting Power of Attorney (LPA) – a power created under the Mental Capacity Act appointing an attorney (or attorneys) to make decisions about a person's personal welfare (including healthcare) and/or property and affairs.

MCA – the Mental Capacity Act 2005

Office of the Public Guardian (OPG) – an executive agency sponsored by the Ministry of Justice, OPG provides information and guidance to individuals and their families, social and healthcare professionals and legal practitioners on all aspects of mental capacity policy. Court-appointed deputies are supervised by the OPG.
www.publicguardian.gov.uk

Personal welfare – decisions about a person's healthcare, where they live, what clothes they wear, what they eat and anything needed for their general care and well-being. Many acts of care are to do with personal welfare.

Property and affairs – any possessions owned by a person (e.g. a house or flat, jewellery or other possessions), money from income, savings or investments, and any expenditure.

Safeguarding – incorporates the concepts of prevention, empowerment and protection to enable adults who are in circumstances that make them vulnerable, to retain independence, well-being and choice, and to access their right to a life free from abuse and neglect.

Unwise decision – a person cannot be deemed as lacking capacity simply because they make a decision which someone else disagrees with or considers unwise. This is one of the five key principles of the Mental Capacity Act.

Welfare benefits appointee – see appointee.

