



Mental Capacity Act resource pack

For family carers of people with
a learning disability

How to find your way around this guide

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www.mencap.org.uk

Links to external documents on the internet are highlighted in blue.

Assessor

Words that are highlighted in green link to the glossary of terms in section 11. You can go back to the page you came from by clicking on the button in the bottom left of each page in section 11.

Introduction



Welcome to the *Mental Capacity Act* resource pack for family carers of people with a learning disability.

Why has this pack been produced?

Family carers have told Mencap that they want to know more about decision making for their relative with profound and multiple learning disabilities (PMLD). The Social Care Institute for Excellence (SCIE) has given Mencap the funds to produce this resource about the *Mental Capacity Act (2005)* and practical decision making for young people and adults

with PMLD. The resource will concentrate mainly on health decisions, as Mencap is campaigning for better access to healthcare for everyone. The resource is written for family carers of people with PMLD who are unable to make many major decisions themselves.

What does profound and multiple learning disabilities mean?

People with profound and multiple learning disabilities:

- have more than one disability
- have a profound learning disability
- have great difficulty communicating
- need high levels of support
- may have additional sensory or physical disabilities, complex health needs or mental health difficulties
- may exhibit behaviour that challenges us.

You can find a fuller explanation of this and the challenges that people with profound and multiple learning disabilities face at www.pmldnetwork.org

What does the Mental Capacity Act say about making decisions?

The act is about how decisions are made concerning adults. It applies to all people who are 16 and over in England and Wales. There are different rules for children. The law says that we must help people to make their own decisions wherever possible. When a person cannot make their own decision, other people have to decide what is in their **best interests**. Often the person's family will make these decisions but sometimes other people must make the decision. If it is a medical decision, this will be made by the doctor. Sometimes the local authority will make some decisions. Anybody making 'best interests' decisions on behalf of a person with profound and multiple learning disabilities must consult with the person's family. You can learn some more about the act in section 1.

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Can't I just go on making decisions for my relative as I have done since they were a child?

No. The *Mental Capacity Act* is a law which affects all of us. The law says that every adult, whatever their disability, has the right to make their own decisions wherever possible. There are many important decisions that people with profound and multiple learning disabilities will not be able to make for themselves. This act provides a legal way for people to make decisions for adults when they lack the capacity to do so themselves. It provides guidance to make sure that decisions taken in this way are in the person's best interests. You can learn more about this in section 4.

Do I need to get the legal power to make decisions for my relative?

You will usually not need to do this as decisions can usually be made using the best interests decision-making process. There are, however, some circumstances where you do need to have formal legal powers to make decisions. For example you

can be made an appointee to deal with simple money matters such as handling benefit payments. If more complicated financial decisions are needed, such as opening a bank account, signing a tenancy agreement or getting a mortgage, being an appointee is not enough. You will need to consider becoming a deputy. You can find out more about this in section 5.

Is this just a way for the government to take control and cost me money?

No. This law is to protect people and make sure everyone is treated fairly. For many everyday decisions, for example choice of food or activities, and some bigger decisions such as medical or housing situations, you or other people will be able to make decisions in your relative's best interests. When other people need to make best interests decisions for your relative, you should always be consulted. For some decisions (often where large amounts of money are involved) there must be somebody appointed to take decisions on their

behalf. This person is called a deputy. You can apply to become the deputy. There are some costs involved with this. Most of these costs are not paid by the deputy, but come from the funds of the person being supported.

When should I start thinking about all this?

As soon as possible. The *Mental Capacity Act* is designed to respect the rights of both you and your relative. Most of the act applies to people from the age of 16 upwards. Transition into adult life can be a stressful and emotional time and there is a lot to think about. There are many important changes to face as your relative becomes an adult. It is worth thinking about the *Mental Capacity Act* and what it means for your relative as early as you can. This is so you can plan for adult life and things are not left to the last minute.

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It all seems a lot to get my head round

It is – but you don't need to become a legal expert. What you do need to know is that you have an important role in making sure that decisions involving your relative are taken in the right way. The act has been in force since 2007 and lots of professionals are still not getting everything right. You may need to remind professionals of their responsibilities under the act. You can help others who need to take best interests decisions by sharing the wealth of information you have about your relative. You will always continue to play a vital role in keeping your relative at the centre of decisions in their life.

Where should I start?

You can start anywhere you want in the pack. You may prefer to look at the video clips about people's stories first. You can then look at the different sections to find out more about some of the things mentioned in the clips. On the other hand, you may prefer to find out some facts first by reading the other sections.

It is entirely up to you. This pack will help you think about this important topic. There are lots of links to other resources and sources of information to look at. The best source of information can often be another family carer who has been through some of the issues before you. Always remember however, that everyone is an individual and situations change, so talk to people involved with your relative at the time.

Is this really all that important?

Yes. This is a law that is important for everyone concerned with supporting vulnerable adults to live fulfilling lives. It is a law that protects both you and your relative. All providers of registered care are regulated by the Care Quality Commission (CQC) as to how well they comply with the act. The CQC checks to see that:

- people make decisions about their own lives whenever possible, or are included in such decisions at all other times

- any decisions that have to be made on a person's behalf are always made in their best interests
- all staff are aware of their duties and responsibilities under the act
- people's human rights are respected.

By understanding some of the important principles of the act, as a family carer you will be better able to speak up for your relative, ask the right questions and make sure they are kept at the centre of all decision making.

What does this mean for family carers?

The *Mental Capacity Act* is an important law that affects every adult in England and Wales. It protects people who are vulnerable and supports them to take as much control over their lives as possible.

As a family carer you need to think about how the act will impact on the life of your relative when they are an adult. The

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act gives you an opportunity to plan for decision making throughout their lives.

You will have a major role to play in decisions made for your relative. This is either because you will be making best interests decisions for them or because you will be consulted when other people do so.

There are some important decisions, especially involving large amounts of money, where somebody must be given the legal powers to make the decision. It's a good idea to plan who you wish to do this.

We hope this information is useful for you and your relative.

Mencap would like to thank:

- SCIE for funding this resource
- Sue Thurman for her invaluable contributions regarding the *Mental Capacity Act* and for authoring sections 1-7
- Pete and Wendy Crane, Margaret Cook and Gail Hanrohan for their insights as carers and their invaluable role in the project advisory group
- our other valued project advisory group members: Alison Picton (SCIE), Lucy Virgo (Mencap), Bella Travis (Mencap), Louisa Whit (Mencap) and Jill Eddleston (CLEAR)
- Mike, Julie and Rebecca Ormian, and Jean and Victoria Wilson, for allowing us to film their experiences
- Littlemouse Films.



A quick guide to the resource

What are you interested in?

The right resource

What are you interested in?

The right resource

We're his parents – can't we just decide for him?



Here's what the *Mental Capacity Act 2005* says about making decisions when you are an adult:

“The *Mental Capacity Act 2005* is a vitally important piece of legislation, and one that will make a real difference to the lives of people who may lack mental capacity. It will empower people to make decisions for themselves wherever 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. It also allows people to plan ahead for a time in the future when they might lack the capacity, for any number of reasons, to make decisions for themselves.”
Lord Falconer, foreword to the *Code of Practice*

In 2005, an important piece of law was passed that applies to everyone living in

England and Wales. The *Mental Capacity Act* came into force in 2007. It covers all adults aged 16 and above¹. The main purpose of the act is to provide a legal framework for adults to make decisions about their lives in two ways:

- The act says that adults have the right to make their own decisions wherever possible. If they are unable to make their own decisions, then others may act for them but the adult must still remain at the centre of any decisions made in their **best interests**.
- The act also provides ways in which people (or in some circumstances, their family) can plan ahead for decisions that need to be taken in their best interests.

The phrase ‘mental capacity’ used in the act refers to our ability to make decisions. These can be everyday decisions about what to eat or what clothes to wear. They can also be bigger decisions about where to live, how to spend money or what medical treatment to have. The

1. Some parts of the act only apply to people when they are 18.

Mental Capacity Act is concerned with all decisions, apart from a small number of very personal and important decisions where it is not possible for somebody to decide for someone else (for example getting married or consenting to sex).

The *Mental Capacity Act* recognises that some people can have the capacity to make some simple choices, whilst not being able to make more complex decisions. Also some people vary from day to day or even during the day as to the decisions they can make and are described as having ‘fluctuating capacity’.

Any decision taken about a person’s capacity is always taken in relation to a particular decision at a given time. This means a person can have capacity for some decisions in their life, but not others.

There is also a **Code of Practice** for the *Mental Capacity Act*. All professional staff have a legal duty to follow the *Code of Practice*. This *Code of Practice* also provides support and guidance for you as a family carer.

The act has five important principles:

- **Principle 1 – A presumption of capacity.** Every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise. This applies to all adults, whatever their ability or disability.
- **Principle 2 – Individuals should be supported to make their own decisions.** An adult should not be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success.
- **Principle 3 – Unwise decisions.** Adults have the right to make decisions that others might regard as unwise or eccentric. You cannot treat somebody as lacking capacity simply because you disagree with their decision.

- **Principle 4 – Best interests.** When an adult does lack the capacity to make their own decisions, others may make a decision on their behalf. Any decisions taken must be in their best interests.
- **Principle 5 – Less restrictive option.** Any ‘best interests’ decision taken on behalf of an adult should interfere as little as possible with their rights and freedoms. Each decision has to take account of all the circumstances, and take the least restrictive course of action available.

The *Mental Capacity Act* provides a way in which a person’s capacity to make decisions can be assessed – **the two-stage test**. This test is carried out by the person involved in the decision to be taken. It is not a test carried out by a single professional expert.

The *Mental Capacity Act* provides a checklist for deciding what decision is in a person’s best interests if they are

unable to make a decision themselves. This is an important way in which family carers can be sure that any decisions are taken in the person's best interests (not simply in other people's best interests).

The *Mental Capacity Act* also provides a range of ways in which people can formally act for those unable to make their own decisions. For example:

- **Attorneys** appointed under **Lasting Powers of Attorney** (LPAs) – these are people chosen by the person themselves to look after their health, welfare and/or financial decisions, if at some time in the future they lack capacity to make those decisions for themselves. You have to be 18 or over to both appoint and be an attorney.
- **Deputies** appointed by the **Court of Protection** – these are people appointed by the court to make decisions, where a person does not have the capacity to choose an attorney. A family member can

be the deputy. The court will agree what powers the deputy can have, according to the circumstances of the person concerned.

There are other ways in which the *Mental Capacity Act* protects adults who lack capacity for important decisions in their life.

- **The Court of Protection** can take important decisions affecting an adult where there is no agreement on what is in their best interests. The court expects to be used as a last resort where a local agreement cannot be reached, or where the decision is so serious it can only be taken by the court.
- **The Public Guardian** – the role of the Public Guardian is to protect people who lack capacity from abuse. The Public Guardian is supported in this role by the **Office of the Public Guardian** (OPG). The OPG has a number of important roles, including

maintaining registers of attorneys and deputies, and supervising deputies. The Direct.Gov website is an important source of information about the *Mental Capacity Act*

(www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/index.htm).

- **Independent mental capacity advocate (IMCA)** – IMCAs are advocates who are available by right to some people who lack capacity to make some important decisions. This includes decisions about where to live and serious medical treatment. IMCAs are available when the adult does not have family or friends who can represent them.
- **Advance decisions to refuse treatment** – the act allows adults to decide in advance about refusing a specific medical treatment should they lack capacity in the future. This can only be done by people who are 18 or above, and cannot be done on their behalf by somebody else.

- **A criminal offence** – the act introduces a new criminal offence of ill treatment or wilful neglect of a person who lacks capacity.

What does this mean for family carers?

You need to know about the *Mental Capacity Act* if you live in England and Wales and are the family carer of someone (aged 16 or older) who is unable to make some decisions.

As a family carer, you do not have to wait until your relative turns 16 before you think about this. There are things you can do to plan for decision making in their adult life.

If your relative cannot make their own decisions as an adult, you can continue to make many decisions for them in their best interests as you have always done.

However you cannot automatically make decisions for them in all aspects of their



life in the way you could if they were a child. Other people may need to make decisions in their best interests. You should always be consulted.

For some decisions, you can apply to be given the legal power to make decisions by becoming a deputy. You will need to think whether this will be necessary for your relative.

This pack will help you think about what actions you may wish to take.

Finding out more about the Mental Capacity Act

- *Making decisions: a guide for family, friends and other unpaid carers* (OPG602). Available from the Office of the Public Guardian as a free download at www.publicguardian.gov.uk/docs/opg-602-0409.pdf
- *Making Choice a Reality: The Impact of the Mental Capacity Act on Young People in Transition to Adulthood* – a study by SCOPE available as a free download at www.scie.org.uk/publications/mca/files/makingchoiceareality.pdf
- *A brief guide to the Mental Capacity Act (2005): Implications for people with learning disabilities*. Available from British Institute of Learning Disabilities www.bild.org.uk (£10.00) or as a free download at www.scie.org.uk/publications/mca/files/bild-mca.pdf
- *Mental Capacity Act 2005 Code of Practice*. A hard copy is available for £15 from The Stationary Office www.tsoshop.co.uk. It is also available to download free from the Office of the Public Guardian website: <http://webarchive.nationalarchives.gov.uk/+http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf>
- Social Care Institute of Excellence's Mental Capacity Act resource – online resource with lots of information you can freely download, available at www.scie.org.uk/publications/mca/index.asp
- *The Mental Capacity Act 2005: Guidance for providers* – guidance from the Care Quality Commission www.cqc.org.uk/publications.cfm?fde_id=16388

So who decides if my relative can make a decision?



“My daughter can’t make any decisions for herself – she is too disabled. I have to decide everything for her.”

“He knows his own mind and always lets us know what he wants.”

As a family carer you know your relative very well and are used to the various, often subtle, ways in which they communicate their likes and dislikes, needs and wishes. It can feel strange or even hurtful that other people become more involved in decisions about your relative once they become adults. This is not because your views are no longer important, but because the law says your relative must be treated as an adult. Part of this involves following the principles of the *Mental Capacity Act*. The act says some important things about how to decide whether adults are able to make their own decisions (often described as having **capacity**).

Decision-by-decision assessment

The *Mental Capacity Act* says that the judgement about whether a person has the capacity to make their own decisions has to be taken on a decision-by-decision basis. This recognises that people with a learning disability should be encouraged to make whatever decisions they do have the capacity to make, rather than it just being assumed that they cannot make any decisions. It also recognises that people can change over time. While there will obviously be some people with profound and multiple learning disabilities who will always lack capacity for big decisions, it is important to give everyone the opportunity to be involved as much as possible in decisions about their lives. If your relative cannot make their own decision, someone else must make the decision on their behalf, in their **best interests**.

Involving people as much as you can

The act encourages us to start from the position of assuming the person has capacity. This does not mean making tokenistic assumptions about the person and reminds us not to decide that someone lacks capacity simply based upon age, appearance, condition or behaviour alone. We know that people with profound and multiple learning disabilities will not be able to make many important decisions. Even when somebody does not have the capacity to make their own decision, the need to follow the best interests framework makes sure they remain the centre of decision making. You can find out more about ways to involve people with profound and multiple learning disabilities in decisions about their lives through the work of the [Involve Me](#) project.

Anyone can assess capacity

In the past, the assessment of whether people could make their own decisions was left to 'experts' – often psychiatrists



or psychologists who decided, as a result of their assessment, whether or not the person had capacity. The *Mental Capacity Act* has changed that. The person who should assess capacity is called the **assessor**. The assessor is usually the person who will have to make the **best interests decision** if the person is found to lack capacity. For many day-to-day decisions, this will be the person most directly involved with the adult at the time – such as a family member or paid carer. For medical treatment, the doctor or other healthcare staff who will be carrying out that treatment is the assessor.

What is the test for capacity?

The test for capacity introduced by the *Mental Capacity Act* is called the **two-stage test**. This test will need to be carried out when a person's capacity is in doubt. As a family carer, you will normally be fairly sure about whether your relative can make a decision themselves or not. You will use your knowledge of your relative to make a 'reasonable belief' judgement about their capacity for any

Two-stage test of capacity

Stage 1. Is there an impairment of or disturbance in the functioning of the adult's mind or brain? If the answer is yes (as it will be for people with profound and multiple learning disabilities) you can 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?

If, after making every effort to help and support the adult to make a decision, the answer to any of these four questions is 'no' then you can conclude the person does not have the capacity for that decision.

given decision. For these more everyday decisions, there is not usually a need to record it formally, but you could still use the principles to help you decide whether the person has the capacity to make the decision. If the decision to be taken is

complex or very important, the two-stage test should be used. These decisions may be ones where you are not the decision maker, including decisions about medical treatment. The results of this assessment must be clearly documented and justified.

What if people disagree about the assessment?

The assessment must be made on the balance of probabilities – is it more likely than not that the person lacks capacity? Carers and care workers do not have to be experts in assessing capacity, but should be able to show they have a ‘reasonable belief’ that the adult they care for lacks capacity to make the decision. This means that even where a formal process for assessment has not been written down, you should be able to explain why you believe the person lacks capacity for that decision. Your decision can be challenged by others, just as you can challenge an assessment that somebody else has made. If disputes cannot be settled locally, the **Court of Protection** can become involved to make a final judgement. There is more about the Court of Protection, and what to do if you are not happy with a decision, in section 7.

What does this mean for family carers?

You will be the assessor of whether your relative has the capacity to make their own decisions about the day-to-day care and support you provide. When you do this you are in fact doing a mental capacity assessment. For many decisions this doesn’t have to be a formal or difficult task. Your decision is based on your ‘reasonable belief’ about your relative. You should seek the views of others as appropriate.

You are not the assessor for decisions that other people have to act upon, such as medical treatment or choice of accommodation. The two-stage assessment will be required if there is any doubt about your relative’s capacity. This does not mean you are not involved with the decision. You can provide vital information about your relative to help the assessment. Your views must be sought by others who are assessing your relative’s capacity to make a decision.

Sometimes people may have different opinions about whether a person can make their own decisions. In this case, the two-stage test is required. If you are not happy with the outcome of this assessment you can apply to the Court of Protection to decide.

Finding out more about assessing capacity:

- *Assessment of Capacity in Adults: Interim Guidance for Psychologists April 2006*. Available to buy on www.bps.org.uk
- *Assessing Mental Capacity – A site to help everyone improve the way they assess mental capacity*. Available at www.amcat.org.uk

They can't do it on their own, but they should be involved



The *Mental Capacity Act* is very clear that before you decide someone lacks the capacity to make a decision, you must take all possible steps to help them make the decision themselves. For some people with a learning disability this means taking simple steps such as:

- communicating with them in the best way to help them understand and express themselves, and using different ways of communicating, such as signs or symbols
- giving them lots of extra time to think and respond, breaking decisions down into simple steps and, if necessary, repeating the conversation several times
- using the person who can communicate best with the person to talk to them, as well as thinking about the best place and time to communicate
- getting assistance or advice from people who know the person well (such as a family carer or a close friend) or

from people who can offer specialist skills (such as a speech and language therapist, advocate or interpreter).

For people with profound and multiple learning disabilities, because of the severity of their learning disability, these steps will not be enough to help them make all their own decisions. It may also be difficult to think of ways to involve the person as fully as possible in a **best interests decision** you make for them. Just because somebody cannot make a decision by themselves does not mean they will not play a part in the decision-making process. They should always be at the centre of any decision. Even when someone else is responsible for making the decision, you will also play a vital part in making sure this happens.

As a family carer you have a wealth of information and knowledge that can help your relative to be at the centre of decisions. Section 8 of this resource will give you lots of ideas to help with the important role you can play.

Example: A doctor wants to take blood from an adult with profound and multiple learning disabilities. The adult cannot understand the information needed to give consent. The doctor cannot ask a family carer to consent for them as, under the law and rules for consent, adults have to give their own consent. This does not mean the doctor should just make the decision. It does not mean the doctor should just say he or she is unable to take blood. The *Mental Capacity Act* says they are able to carry out the test if it is in the person's best interests. You will be able to give information about your relative that will inform the doctor to make the decision.

Helping people to be involved

The first step to making sure this happens is to remind people involved in the decision that your relative has the right to be involved. You could mention, for example, what you have learned here about the principles of the *Mental Capacity Act*, or other laws you might know about such as the *Equality Act 2010*. There are also other resources you may find helpful:

- *Getting it right* (Check if your local health community has signed up to this charter www.mencap.org.uk/gettingitright)
- The PMLD Network campaign which includes the right to be heard www.pmldnetwork.org

The next step is to find creative ways to involve your relative if they don't have the ability to make their own decision. The video clips of people's stories in section 12 will give you more ideas about how to go about this. Sometimes the simplest ideas are the most effective.

A photo or video clip on your mobile phone of your relative can remind a professional they are considering a real person and not just a medical problem. A well-constructed person-centred plan reminds everyone whose life it is. There are lots more ideas and examples in section 8.

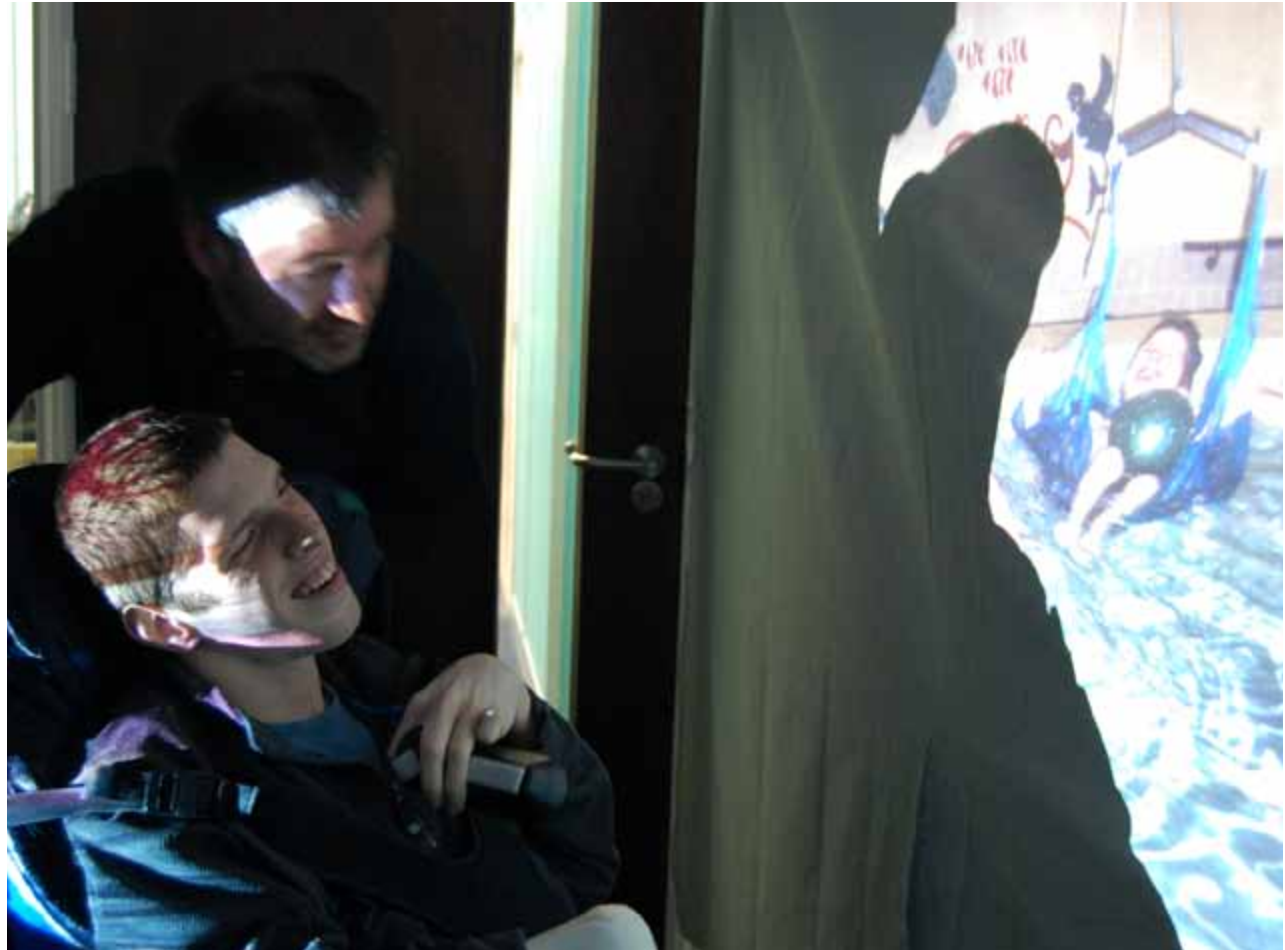
Example: You have learnt ways in which your relative participates in the decision to take their medicine, from them indicating their willingness and readiness to do so. You can help staff to make sure they involve your relative when they give them their daily medicine by helping to create a page in their communication passport that describes this process in words and pictures. Staff can use this to learn how to recognise your relative's communication signals and how to offer them their medicine in the most respectful way.

Family carers have a vital role in making sure people are fully involved in important decisions about their lives. You have known your relative longer than everyone. The *Mental Capacity Act* recognises that, and makes it a legal obligation to consult you when making a **best interests decision**. This will be covered in more detail in section 4.

What does this mean for family carers?

You have a lot of information about your relative that will help to keep them at the centre of decision making. This can include communication passports, health action plans and hospital passports. Make sure these are developed and kept up to date.

It is hard to ignore somebody that you can see. Think of creative ways to make sure people making decisions know your relative well. This might mean taking them to appointments, showing photos or video clips of them or using any of the communication and health tools described in this pack.



If necessary, remind professionals of their obligation to involve your relative in decisions about their life. The *Mental Capacity Act* can help you do this. The *Equality Act* is another law to remind people about their obligations.

If you are uncertain how best to involve your relative in a particular decision, ask for support. This could be from a speech and language therapist or a paid worker who knows your relative well. It could also be from somebody who understands the decision to be taken.

You can find out more about involving others in decision making

- **Involve Me** – a three-year Mencap project about how to creatively involve people with profound and multiple learning disabilities (PMLD) in decision making. There is more information available at www.mencap.org.uk/invoveme
- **Communication for Involvement – a toolkit**. This toolkit helps to facilitate communication and involve people with Rett syndrome more in decisions about their own lives. Find out more at www.rettuk.org/rettuk-public/rettuk/families/therapies/speech-and-language.html
- **Getting it right** – a campaign by Mencap for equal healthcare for all people with a learning disability. More information can be found at www.mencap.org.uk/gettingitright
- **Supported Decision Making: A guide for supporters** – a booklet about supporting others to be involved in decisions. You can download it free at [www.paradigm-uk.org/Resources/9/2/9/Supported%20Decision%20Making%20\(Final%20Online%20Version\).pdf](http://www.paradigm-uk.org/Resources/9/2/9/Supported%20Decision%20Making%20(Final%20Online%20Version).pdf)
- **PMLD Network** – a group of people committed to improving the lives of people with profound and multiple learning disabilities and making sure they are fully included in society. Their website is full of useful information, visit www.pmldnetwork.org
- **Equality Act 2010: What Do I Need to Know?** – download the quick start guide free from www.equality-ne.co.uk/downloads/668_disability-guide.pdf

But don't I already act in my relative'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 best interests.”

Code of Practice, page 66

You will often hear people say they are acting in a person's **best interests**. Of course we all think we are acting in someone's best interests when we try our best for them. But sometimes one person's idea of best interests may differ from another's. It all depends on what is meant by best interests.

Consider a common and difficult decision that often has to be taken for a person with profound and multiple learning disabilities. They are having difficulty swallowing food and drink – should they be fed via a tube into their stomach?

- The dietician may think it is in their best interests to be tube fed to improve their nutrition.
- The support worker may think it is not in their best interests to be tube fed because of the restrictions it will place on the person's activities.
- The speech and language therapist may think it is in their best interests to be tube fed to minimise the risk of food ending up on their lungs with potentially lethal consequences.
- The parent may feel that the person's greatest pleasure is food and so may feel it's not in their best interests to be tube fed.
- The doctor may be still undecided because of the risk of the procedure balanced against the possible benefits.

How do you decide? Whose views are more important? What would the person themselves want?

The *Mental Capacity Act* says the person who takes the decision on behalf of the person is called the **decision maker**. There are at least seven factors the decision maker must think about when making a decision on behalf of a person who lacks the capacity to take their own decision. Using these seven factors as a checklist helps to make sure a balanced decision is taken. Doing so, means considering everything equally, with the aim of finally doing what is in the person's best interests (rather than in the best interests of finance, medicine or even the views of the most assertive person).

The seven factors

One way to remember the seven factors that a decision maker must take into account is to remember the word **REFLECT**²

R	Consider whether the adult can regain capacity.
E	Encourage and enable participation of the adult throughout the decision.
F	Take into account the adult's past and current feelings about this decision.
L	Is life-sustaining treatment an issue?
E	Show equal consideration and non-discrimination .
C	Consider all relevant circumstances .
T	Take the views of others into account.

This is not the same as a consensus decision. The decision maker is the person who will take action following the decision. They are given the responsibility of making the decision, having listened carefully to everyone's views. There may be different views. It is their responsibility to listen and weigh up all these views before coming to their decision.

Regaining capacity

In some cases, it is in the person's best interests to consider whether they are likely to regain capacity (for example, after receiving medical treatment or perhaps developing new skills). If this is the case, the decision may be able to be delayed until then. This is unlikely to be relevant for most decisions involving people with profound and multiple learning disabilities.

Encouraging and enabling participation

A **best interests decision** must always include the person as much as possible. For adults with profound and multiple

² Adapted from an original idea by Jenny White, a community learning disability nurse from Leicestershire Partnership NHS Trust



learning disabilities this does not simply mean them attending meetings. The **Involve Me** project looked at a range of creative ways to involve people in decisions about their lives as fully as possible. As a family carer you may well have lots of other ideas about how to do this for your relative.

Feelings and beliefs

A best interests decision always takes the person's feelings, likes, dislikes, preferences, wishes, values and culture into account, as far as these can be recognised. You are in a very good position, as a family carer, to share this information with the person who is the decision maker. You could use one of the **communication tools** described in section 8.

Life-sustaining treatment

The act says that when making a best interests decision you must not be motivated in any way by a desire to bring about a person's death if the decision concerns life-sustaining treatment. This means the decision maker must not

make assumptions about the person's quality of life. You may need to think about this factor when considering end of life care (see section 6).

Equal consideration

The act says that the decision maker must also not make assumptions about the person's quality of life or what might be in their best interests simply because of their age, appearance or condition. This is an important principle to ensure people are treated with respect and as valuable people. This is a very strong message in Mencap's *Getting it right* campaign on improving healthcare for people with a learning disability.

All circumstances

A best interests decision should take everything into account, and consider all the things that the person who lacks capacity would, if they were able to make the decision themselves. It will look at risks and benefits, positive outcomes and any other factors that may play a part in coming to the final decision.

Considering the views of others

The decision maker should consult others who may take a view about the decision. This will always include family carers and could also include health and social care staff, close family and friends, as well as anybody appointed as a deputy. Such people could be expected to have a view on what they feel to be in the person's best interests. They could also inform the decision maker about how the person best communicates their feelings and wishes. For decisions about major medical treatment or where the person should live, and where there is no family or friend who can speak up for the adult, an **independent mental capacity advocate** must be consulted.

What does this mean for family carers?

You will take best interests decisions for your relative, in the daily care and support you provide as a family carer, if you have a reasonable belief that they cannot make these decisions themselves.

Where other people act as decision maker, you must be consulted in any best interests decision taken for your relative. You should also represent what you know to be your relative's view as far as you are able.

When people take time to listen carefully to each other, there is often agreement about what is in the person's best interests.

If there is disagreement, and you are not happy about a best interests decision taken for your relative, you should raise your concerns. There is more information about this in section 7.

Finding out more about best interests:

- *Best Interests: Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves* – available at www.bpsshop.org.uk
- *Social Care Institute of Excellence's Mental Capacity Act resource* – an online resource with lots of information you can freely download, available at www.scie.org.uk/publications/mca/index.asp

Who makes decisions when my relative can't?



The *Mental Capacity Act* is clear that people should be free to make their own decisions. When a person is not able to make all their own decisions, then the act also makes it possible for others to act in the person's **best interests** for many everyday decisions. This will include family members and carers making decisions about what happens in the family home, the doctor making medical decisions and care workers making decisions about care offered in a care service.

For certain decisions, it may be necessary for you to gain the legal authority to make decisions on your relative's behalf. This is to protect your relative and make sure decisions are made in their best interests.

The act makes it possible for a person who has **capacity** to choose a person ahead of time to be their **attorney**, with a **Lasting Power of Attorney (LPA)**. This person (the attorney) can then make decisions on their behalf should they lose capacity in the future. This could

be for decisions about their **property and affairs** or for their **personal welfare** (also called health and welfare), or both. Information on how to apply for an LPA, including downloadable forms to complete, can be found on the Directgov website www.direct.gov.uk.

However, appointing an attorney will not be possible for people with profound and multiple learning disabilities as they lack the capacity to do so. For adults who do not have the capacity to make such a decision, the act provides another way for somebody to have the legal authority to make decisions on their behalf. This is by becoming a **deputy**. You can become a deputy on behalf of somebody who lacks capacity by applying to the **Court of Protection**.

What is a deputy?

A deputy is someone (often a family member), appointed by the Court of Protection, who has legal authority to make particular decisions for someone who lacks capacity. This can be for a



one-off decision or to take ongoing responsibility for making decisions on a person's behalf.

Should I apply to become a deputy?

It depends on your relative's circumstances. **Not everyone will require a deputy.** A deputy can be appointed to take decisions related to property and affairs. This includes decisions about somebody's property, possessions, income and spending.

- **A deputy may not be necessary for property and affairs** if the adult only receives benefits and does not have any property or savings. The person's finances can be managed by somebody appointed as an **appointee** by the Department for Work and Pensions. If you need more information on what you can do as an appointee you can go to www.direct.gov.uk or call the Benefit Enquiry Line: 0800 882 200.

- **A deputy will be necessary for property and affairs** if more complex financial matters exist. For example, the adult is looking at alternatives to residential care and there is a need to sign tenancy or mortgage agreements. Another example is handling savings or inheritances.

In some limited circumstances, a deputy can be appointed to take decisions about personal welfare. These are any decisions about an adult's health, general care and well being.

- **A deputy is often not necessary for personal welfare.** Most welfare decisions can be made using the best interests decision making process. As a parent you retain an important role in this process and your views are always taken into account.
- **A deputy may be necessary for personal welfare** in a few situations, for example when a series of decisions

is needed over time (such as for medical treatment) or where there is serious disagreement between family members and services.

Becoming a deputy

To become a deputy to allow you to make specific decisions on behalf of your relative, you will need to apply to the Court of Protection. You can get the forms from their website www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingdecisionsforsomeoneelse/DG_176235 You will need to download:

- *COP application pack 1* to apply to be a property and affairs deputy
- *COP application pack 3* to apply to be a personal welfare deputy
- *COP application pack 5* to apply to be a deputy for both.

Alternatively you can phone 0300 456 4600 and request hard copies.

Is there any help?

There is a guide to the process of applying to the Court of Protection called *Making an application to the Court of Protection (COP42)*. You can phone the Court of Protection helpline (0300 456 4600) with general questions. Your social worker or carers' group may also be able to assist. It is usually possible to complete the forms without needing to involve a solicitor. If you do feel you need to involve a solicitor there will be additional costs to the process.

How long will it take?

Once you have completed and submitted the forms to the Court of Protection, the court will then ask you to inform certain people about your application. It is helpful to remember that although this is all dealt with by a court, usually this is all done by correspondence and you will usually not be required to attend a court building. If the court agrees you may become a deputy it will issue a **deputy order** describing your powers. It will then send you several copies of the order so you can show you have the

authority to act on behalf of the person for the agreed decisions.

The Office of the Public Guardian monitors all deputies to ensure they act in the best interests of the person who lacks capacity. It takes into account the amount and complexity of the money you will handle, your relationship and contact with the person, your past experience as a deputy, the types of decisions you will be taking

and the number of other people involved in supporting the person. Based on this, a decision is taken about the level of supervision you will receive. There are four different levels of supervision and you will be informed in writing as to which level of supervision you have been allocated and what this will involve. There is more about this in *A guide to Supervision of Deputies (OPG507)*. The whole process should take about 21 weeks.

Handy hint: obtaining forms and leaflets

Does the reference number start with COP?

- Download from Her Majesty's Court Service website www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/Makingdecisionsforsomeoneelse/DG_176235
- Phone 0300 456 4600 for hard copies.

Does the reference number start with OPG?

- Download from Directgov website www.direct.gov.uk
- Phone 0300 456 4600 for hard copies.

Keeping records

You will need to keep records about the decisions you make as a deputy and the money you spend. You may also be required to provide a report to the **Public Guardian**. You will be given information about this when you are given your deputy order. You may also receive visits from a **Court of Protection visitor**. This is all so the Public Guardian knows you are fulfilling your role properly and is to protect the person you are representing.

What does it cost?

You will need to pay an application fee of £400 to the Court of Protection when you apply. You are responsible for this payment yourself, although depending on your financial circumstances you may be eligible for a reduction or even waiving of costs. You can find details about this in the form *Court of Protection – Fees, exemptions and remissions (COP44)*.

Once appointed as a deputy, it costs a further £100 to place you on the register and a further annual supervision fee. The

amount of the supervision fee depends on what level of supervision you have been given. It currently ranges from no fee to £800 for the highest level of supervision. These fees are payable from the funds of the person you are representing. Depending on the person's financial circumstances, there may be a reduction or even waiving of costs. You can find details about this in the form *Public Guardian – Fees, exemptions and remissions (OPG506)*.

You may also be required to take out insurance to protect the funds of your family member to cover any loss as a result of your actions. This will vary according to the amount of money you are managing.

What does this mean for family carers?

You need to consider whether it will be necessary for you or someone else to become a deputy for your relative – especially for financial matters. This is



normally only necessary when complex financial matters are involved (including entering contracts, agreeing to tenancy or dealing with savings or inheritance not in trust.)

It is very helpful to think about this at an early stage and not wait until the last minute – remembering that it can take up to six months for an application to be processed.

In most situations it is not necessary to become a deputy for personal welfare decisions, as these decisions can be taken by best interests decision making. It is important to remember that, as family carer, you **must** be consulted by the decision maker if a best interests decision is being taken.

Find out more:

Applying to become a deputy

- *Making an application to the Court of Protection (COP42)*
- *Court of Protection – Fees, exemptions and remissions (COP44)*
- *Getting legal authority to make decisions about money, property and welfare* Challenging Behaviour Foundation, May 2010
www.thecbf.org.uk/pdf/GettingLegalAuthoritytoMakeDecisionsAboutMoneyPropertyandWelfare.pdf

Being a deputy

- *Office of the Public Guardian – Fees exemptions and remissions (OPG506)*
- *A guide for Deputies appointed by the Court of Protection (OPG 510)*
- *A guide to supervision of Deputies (OPG507)*

Being an appointee

- Department for Work and Pensions guide on deputies, appointees and attorneys. www.dwp.gov.uk/publications/specialist-guides/agents-appointees-attorneys/ The specific section on appointees can be found at www.dwp.gov.uk/docs/part-05.pdf

What about other types of decision?

The principles of the *Mental Capacity Act* cover most decisions in life, ranging from whether a person takes sugar in their tea to whether they undergo surgery. This pack has mainly focused on health decisions. This is because we know that for many people with profound and multiple learning disabilities these are very important decisions that impact on their quality of life. Mencap's **Getting it right**³ campaign aims to ensure that all people with a learning disability get fair health treatment and care. One aspect of this is making sure that healthcare staff are aware of their role and responsibilities under the act.

There are many other decisions in the lives of people with profound and multiple learning disabilities. The diagram shows some of these.

As a family carer you have probably become accustomed to making many



³ Mencap's *Getting it right* healthcare campaign
www.mencap.org.uk/gettingitright

such decisions for your relative as they have grown up. There are different rules about decision making for children and adults. If your adult relative does not have the **capacity** to make a decision, a **best interests decision** will need to be made on their behalf. You have the right to be involved in this process.

There are also some decisions known as **excluded decisions** which can never be taken as best interests decisions on behalf of another adult. This is either because they are so personal to the adult concerned, or because they are governed by other laws. Most of these decisions are unlikely to be very relevant for most people with profound and multiple learning disabilities. They include decisions about consent for sexual relations, marriage, civil partnership, divorce, adoption, voting and consent to fertility treatment. Although these decisions are excluded from the best interests process, an adult's capacity to make these decisions must still be assessed where there is any doubt about

Find out more:

Making decisions about housing and support

Choice, Contracts and Mental Capacity Act 2005: Housing and support decisions for people with learning disabilities: A practical guide from Housing Options. Download it from under the documents tab

www.valuingpeoplenow.dh.gov.uk/valuing-people-now/housing

Insights – resources from the National Development Team for Inclusion

www.ndti.org.uk/publications/ndti-insights/

This includes a variety of documents to download, including the *Real Tenancy Test* about things to consider when planning housing and tenancies for people, when to use different types of tenancy and how to handle issues of capacity.

Making decisions about end of life

Best Interests at End of Life by Christine Hutchinson and Julie Foster, May 2008

www.scie.org.uk/publications/mca/files/lancspct.pdf

Advanced Decision to Refuse Treatment (NB These can only be made by people who have capacity) www.adrtnhs.co.uk

Best practice in end of life care produced by the North Staffordshire palliative care project. www.mencap.org.uk/endoflifecare

their capacity. Also action to protect a vulnerable person may still be taken if it is a case of keeping the vulnerable person safe from harm.

Any further questions?

The Learning Disability Helpline is an advice and information service for people with a learning disability, their families and carers. It also provides information and advice to anyone wanting to know about learning disability issues and services.

Call the Learning Disability Helpline on 0808 808 1111.

Find out more:

Making decisions about finances

Making Money Easier – work by United Response and ARC
www.making-money-easier.info/

Wills and trusts – advice from Mencap
www.mencap.org.uk/willsandtrusts

Banking on good decisions – advice from the Mental Health Foundation
www.mentalhealth.org.uk/publications/?entryid5=61150&char=B (full version)

Banking decisions for people who lack capacity to make decisions – the British Bankers Association
www.bba.org.uk/publications/entry/banking-for-people-who-lack-capacity-to-make-decisions-england-and-wales/leaflets/

Financial Decision-Making: guidance for supporting financial decision-making by people with learning disabilities – a book by Irenka Suto, Isabel Clare and Anthony Holland, Ref: ISBN-9781904082963 available from www.bildservices.org.uk/acatalog/Books_Practical_support_for_better_lives.html



“Failure to follow the law is very serious and all organisations should be checking their staff are meeting requirements under the Mental Capacity Act and its Code of Practice.”

Six Lives progress report, 14 October 2010

The *Mental Capacity Act* has been in force since 2007 and lots of professionals are still not getting everything right. In October 2010 the Department of Health published a progress report on the recommendations made in the *Six Lives* report.⁴ The report says that there are still some concerns that need to be addressed.

In many places, complaints procedures remain difficult to understand and use, take too long and do not show what is going to change as a result of investigations. There are also examples of failures by healthcare staff to comply with the *Mental Capacity Act* and the *Code of Practice*. Everyone needs to work together to make sure people are both enabled to make their own decisions and respected

and kept safe when they cannot. It is important that you are able to raise any concerns you have to the right people.

People who may lack **capacity** tend to be more vulnerable to having decisions made which are not in their “**Best Interests**” and outside of the *Mental Capacity Act*, but which suit others. This can lead to neglect, abuse, fraud or crime.

If you are concerned that someone making a decision on behalf of your relative has not followed the principles of the *Mental Capacity Act*, then you should raise your concerns. In the first instance it is always best to do this informally with the person or organisation concerned. If this fails then you should consider a formal complaint.

Since 2009 the NHS and local authorities have operated a simple two-stage process for complaints. You can find out more about how to complain about NHS and social care services on the **Care Quality Commission** (CQC) website www.cqc.org.uk

⁴ *Six Lives* (2009) was a report on the deaths of six people with a learning disability first highlighted by Mencap in their 2007 report *Death by indifference*.

Remember that, by law, **all** social care services have to have a complaints procedure and arrangements for dealing with complaints. This applies to private and independent organisations.

There are some services that can help you with complaints or worries about the NHS. The **Patient Advice and Liaison Service (PALS)** is an NHS service which can provide information and support in raising concerns and if necessary making complaints about the NHS.

If you have concerns about a criminal act then you should contact your local police station. This could, for example, be where you suspect fraud or theft, physical harm or neglect being caused to your relative. You should also inform social services at the same time so they can support the vulnerable person during any investigations.

If you are concerned about the behaviour of an **appointee** and the collection or use of social security benefits you should contact the **Department for Work and**

Pensions. You can get information about this at your local Job Centre Plus.

If you are concerned about the behaviour of an **attorney** or **deputy**, you should contact the Compliance and Regulation Unit at the **Office of the Public Guardian** on their dedicated phone line for reporting concerns: **020 7664 7734**.

The Court of Protection

Sometimes people cannot agree what will be in somebody's best interests or whether somebody has capacity or not. Sometimes it is a particularly difficult decision. In these situations an application can be made to the **Court of Protection** to make a ruling on what should be done. Local authorities and NHS bodies should make such an application in the case of a dispute over what should happen. If they fail to do this, you are entitled to make your own application, in your own right or on behalf of your relative. You can seek legal advice if you wish, but this is not essential. There will be a charge for the application,

normally payable by the person making the application to the court.

What does this mean for family carers?

You need to know about how to raise concerns and complain if you are concerned about decisions being made on behalf of your relative.

You should never be afraid to ask questions, raise concerns or even make complaints if you feel your relative is not being treated well. There are a number of steps you could take. You can find out more at www.mencap.org.uk/mentalcapacityact

In the case of disagreements that cannot be resolved, the Court of Protection can be asked to make a final judgment.



Find out more:

- The Care Quality Commission website has a helpful section about complaining about services: www.cqc.org.uk/contactus/howtoraiseaconcernorcomplaint.cfm

You can download a leaflet on complaints about health or social care services:

www.cqc.org.uk/_db/_documents/20100527_Complaints_providers_final.pdf

- BILD have produced an online resource about complaints and people who find it difficult to speak up for themselves called *Hearing from the Seldom Heard*. www.bild.org.uk/humanrights_seldomheard.htm

- You can learn more about PALS at www.pals.nhs.uk/

- For more information about the Court of Protection visit: www.direct.gov.uk/en/Governmentcitizensandrights/Mentalcapacityandthelaw/UsingtheCourtofProtection/index.htm and www.hmcourts-service.gov.uk/infoabout/court_protection/index.htm

What can help me to involve my relative in making decisions?



There is a range of tools and resources that has been developed, which can support you to collect evidence and demonstrate the best ways of working with your relative. These include:

- health action plans
- hospital passports
- communication passports
- person-centred plans.

The common principle for all of these resources is that they keep the person with profound and multiple learning disabilities (PMLD) at the centre of all decision making. Importantly, they can help inform health practitioners about what would be in your relative's **best interests** if a decision needs to be made about their care or treatment and they are assessed as lacking the **capacity** to consent to this.

To help you complete the resources, and plan for the future, you may want to bring together a group of people who know your relative well. This is known as a circle of

support. You may want to start by working on the tool that you feel would be the most helpful to you and your relative.

In this section, we have included examples of each resource, which you can use to get you started. You might also find that health practitioners in your area have developed their own templates.

What is a health action plan?

A health action plan is a personal plan about what your relative needs to do to stay healthy. It lists any help that they might need to do this and explains any support they might need. The plan can help you to work with healthcare professionals to get the support and treatment that is right for your relative.

A health action plan should describe your relative's day-to-day state of health. For someone with PMLD this is extremely useful for health practitioners assessing and treating your relative.

A health action plan can contain information about your relative's:

- general health
- pain management
- medication
- mobility
- dental care
- sight and hearing
- toileting habits and needs
- mood and mental state
- exercise plans
- diet.

Links to health action plans

Health Action Planning good practice guide
www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_096507.pdf

Leicestershire Learning Disabilities Partnership Board
www.betterlives.org.uk/default.aspx?page=19957

What is a hospital passport?

A hospital passport is used to document essential information about your relative should they need to go to hospital. It is a useful and convenient way for staff to find out helpful information about your relative in order to treat them in a way that is appropriate and make the experience as comfortable for them as possible.

You can include who should be consulted for best interest's decisions about the persons treatment and their contact details

Links to hospital passports
http://easyhealth.org.uk/sites/default/files/hospital_passport.pdf

What is a communication passport?

A communication passport is a very useful way to help others understand how your relative communicates. It presents your relative as an individual and draws together information from past and present, and from different contexts, to help staff understand and interact with your relative more effectively. Your relative's preferences and preferred means of communication can be recorded in a communication passport.

Links for communication passports
www.communicationpassports.org.uk/Home/

www.communicationmatters.org.uk/page/communication-passports

CALL Centre has produced a template you can use:

www.communicationpassports.org.uk/Resources/Creating-Passports/Templates/Assets/Downloads/Adult_A5.ppt

What is a person-centred plan?

Person-centred planning is a way of building a shared understanding of a person and their life. It supports people to be part of their community. In person-centred planning the person is the focus, with professionals taking a background support role. A person-centred plan (PCP) should focus on someone's gifts, what they are good at, what they love and the positive effects they have on others.

There are lots of different types of PCPs – from one-page profiles, which give a summary of who someone is, their likes and dislikes and other important information, to paths – which explore people's goals and dreams. PCPs can be paper documents or use photos, film, music and objects to bring it to life for your relative and the people around them.

Links to PCPs:

www.helensandersonassociates.co.uk/reading-room/how/person-centred-planning.aspx



How can these tools and resources help inform decision making?

It is likely that many health care decisions will have to be made in your relatives lifetime. They may not always have the capacity to make these decisions. As we have looked at in this resource, when a person lacks capacity to make a decision, a decision must be made for them in their best interests.

To make a **best interests decision** the decision maker must gather as much information about your relative as possible. The tools and resources that we have looked at in this section provide a wealth of easily accessible information that can be used to inform the decision.

You can include information about who needs to be involved in a best interest's decision and their contact details.

For example:

- A health action plan can give healthcare staff a clear picture of your relative's day-to-day state of health. This can be of huge importance when assessing your relative and making decisions about their treatment.
- A hospital passport can help ward staff to support your relative on a daily basis. For example, how they like to be positioned, how they sleep, how they should be supported at meal times and so on.
- A communication passport can help healthcare staff to communicate in a way that your relative can best understand. It can show the best way of approaching them. Photos and film can show the small things they do. It can show and describe how your relative shows happiness, sadness, pain and discomfort. The communication passport can describe any communication aids and how they can be used.



- A Person Centred Plan gives a more rounded view of your relative – not just their health needs but how their health impacts on their daily life, as well as their likes, dislikes and personality.

Remember, where other people act as decision maker, you must be consulted in any best interests decision taken for your relative.

What is a circle of support?

A circle of support is a group of people who agree to meet regularly to help your relative accomplish goals that they would be unable to reach on their own. It is made up of people who your relative knows, likes and trusts. They work together on a voluntary basis to develop plans for your relative, such as a Person Centred Plan, and make sure they are put in to action. The members of the circle can advocate on behalf of the individual, and support them to communicate their decisions.

“My planning circle was started by the people who know me well. It was initiated as a direct result of my changing physical health needs which were dominating my life. My planning circle challenged the medical practitioners and other professionals in order that my voice be heard. Throughout this difficult period of emotional adjustment, I managed to develop my plan into a multimedia format. My plan has enabled me to be acknowledged as a person who has complex health issues but has clear views on how future care packages should be delivered.”

Amrien’s story, Building Community through Circles of Friends, Christine Burke, Foundation for People with Learning Disabilities, 2006.

You can check with your local authority to see if they offer any support to set up circles, or contact the Circles Network at www.circlesnetwork.org.uk

Find out more:

www.valuingpeoplenow.dh.gov.uk

Mencap carers’ card
www.mencap.org.uk/carerscard

DISDAT is a tool that professionals use to monitor and spot signs of pain and discomfort. It would be helpful to familiarise yourself with it – information you have about how your relative communicates is vital for DISDAT.

DISDAT can be used alongside health action plans, communication plans and hospital passports to support professionals to better identify pain and take steps to manage it effectively

www.disdat.co.uk/

What about healthcare decisions?

People with PMLD have a legal right to equal healthcare. However, recent studies such as Mencap's *Death by indifference* have highlighted that these rights are not always respected. The subsequent investigation by the health service and local government ombudsmen reported considerable failures in services leading to situations in which people with a learning disability were treated less favourably. The Department of Health recently published a report on progress to improve healthcare for people with a learning disability. One of the major concerns was the failure of healthcare services to comply with the *Mental Capacity Act* for healthcare decision making.

As we saw in section 1 of this resource, the *Mental Capacity Act* has five key principles. The five principles must inform all medical decisions involving your relative who may or may not be able to make these decisions themselves. For example, whether they should be given medication if they are resisting it, or whether they should have major surgery.



Supporting people with PMLD to make their own healthcare decisions

People with PMLD are unlikely to be able to make healthcare decisions. Healthcare staff must make every effort to encourage and support your relative to make decisions for themselves. This means taking time to explain the risks and benefits of different options and working with you to find the best way of communicating with your relative.

What happens if my relative cannot make a decision about their healthcare?

If your relative is assessed as lacking **capacity** to make a decision about their healthcare, a decision will be made in their **best interests**. The responsibility for making **best interests decisions** sits with the nurses and doctors providing the treatment, unless you have been appointed as a **personal welfare deputy** for your relative. Very few personal welfare deputies exist as most healthcare decisions can be made using the best interests principle.

You can find out more about deputies in section 5 of this resource.

The doctor or healthcare professional should make every effort to involve the person with PMLD as much as possible in this decision. Their past and present views must be sought, for example their thoughts about an extended stay in hospital or having treatment under local anaesthetic. This could be through talking to you to find out more about who they are or thinking carefully about how they communicate about the proposed treatment. Written information is useful for the decision maker to take away and think about – this may include communication passports or hospital passports. You can find out more about these tools in section 8 of this resource.

The healthcare professional making the decision must also consult with people who know your relative well. You can help identify what your relatives wishes might be and how they would manage any treatment proposed eg, staying still for an X-Ray.

Avoiding discrimination

When making a best interests decision, doctors and health professionals must avoid discrimination. The **Code of Practice** states *“You should not make assumptions about someone’s best interests simply on the basis of the person’s age, appearance, condition or behaviour.”*

If a health decision is influenced by assumptions about the quality of life of people with PMLD, this is discrimination. Everyone should have equal access to treatment. Equal does not mean the same. Health services should make ‘reasonable adjustments’ to support your relative to access health services. This may include having longer appointments or having a side room on a ward if the person doesn’t like lots of people around.

“Victoria was rushed into A&E after a series of seizures. She wasn’t responding to medication and needed to be put on a ventilator. The doctor came up and spoke to us. It took me a moment to realise that he was questioning whether we should go ahead with treating Victoria.

“He was suggesting that it wasn’t worth trying to save her. He didn’t know our lovely 33-year-old daughter and all the quality of her young life. I sometimes wonder what might have happened if I hadn’t told him how good her life was when she was well, about her social life and the people who love her.”

Jean, mother of Victoria

By ensuring that best interests decisions cannot be made on behalf of your relative without considering their wishes and feelings, and giving family members and carers a legal right to be consulted about these decisions, the *Mental Capacity Act* aims to change the practices that lead to experiences like those of Jean and Victoria.

Healthcare treatment that involves restraint

When making best interests decisions, healthcare staff must try to limit restrictions on your relative’s rights and freedoms. In a healthcare context this means trying to avoid using any form of restraint when giving treatment, but sometimes it may be in your relative’s best interests to do this. Examples of restraint, which at the time may be appropriate, include:

- firmly holding your relative
- giving your relative a sedative
- using bed rails to stop your relative falling out.

There are limits to how much restraint can be used in the best interests of your relative before additional safeguards are required.

Challenging healthcare decisions

If you want to challenge a decision that has been made about your relative’s capacity, or a best interests decision that has been made, you can ask for a second opinion or use the hospital’s formal complaints procedure. In cases of serious disagreement, NHS trusts should make an application to the **Court of Protection**. You can find out more about this in section 7 of this resource.



Further information

Mencap's *Getting it right* campaign aims to ensure that all people with a learning disability are treated fairly in health treatment and care. One aspect of this is making sure that healthcare staff understand the law and what their role and responsibilities are in line with the law.

The campaign started because Mencap's *Death by indifference* report showed that people with a learning disability were not getting equal access to healthcare and treatment. It showed the serious consequences this can have.

We hope that our campaign will help ensure that all doctors and health professionals do understand the law and act in line with it.

We think it is very important that families also understand the law, which is why we have written this resource. We want families to understand that they should be involved in the best interests decisions made about their relative's treatment and we want them to understand the steps they can take if they are not happy with a decision made.

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5. There is information about the *Getting it right* campaign at www.mencap.org.uk/gettingitright



Annual health checks are starting to be offered by GPs to all people with a learning disability. The annual health checks help to monitor existing conditions and spot early warnings for any new conditions. Checks include:

- physical health
- medication
- mental health
- transition reviews (where appropriate)
- epilepsy (where appropriate).

In order to perform an annual health check, the healthcare professional will need to seek your relative's consent. Many people with PMLD will lack **capacity** to consent to a health check. In this circumstance a decision about whether to perform the health check should be made in your relative's **best interests**. You can support the decision-making process through the use of the tools in section 8.

Being invited for an annual health check

You can arrange an annual health check by booking an appointment with your GP. It has been recommended that GP practices send out a pre-health check questionnaire to help you and your relative prepare for the check. This will ask for information about your relative's diet, medication and relevant medical history.

You could also contact your GP to ask questions about the check and what you can do before the appointment.

The appointment

There are reasonable adjustments that you can ask for to ensure that the appointment and experience is as comfortable for your relative as possible. Examples include:

- visiting the surgery before the appointment so your relative can get to know the environment without having an examination

- meeting their health practitioner without tests being undertaken
- ensuring the examination room is big enough and laid out in a way that facilitates the person's wheelchair if they have one
- a home visit
- appointments at times when the surgery is quieter
- support from a learning disability nurse if you are concerned about specific tests – for example if your relative doesn't like needles. A desensitisation programme is a good example of a way of involving someone in decisions about their treatment and giving them every chance to understand what is happening.

Can I accompany my relative to the health check?

If you believe that it is in your relatives best interests to attend any healthcare appointments you may do so. If the



Healthcare Professional disagrees they must explain why they do not think it would be in your relatives best interests. The General Medical Council (GMC) advises doctors to: *“Consider the views of people close to the patient on the patient’s preferences, feelings, beliefs and values, and whether they consider the proposed disclosure to be in the patient’s best interests.”* It is unlikely that a healthcare professional will prevent you from accompanying your relative.

What if my relative appears to be refusing to have tests?

If your relative has been assessed as lacking capacity to consent to having a particular test, for example a blood test, and then shows signs of refusing to have it, a decision about whether to have the test must be made in their best interests. The healthcare professional is responsible for making this decision but you must be consulted and the wishes and feelings of your relative taken into account. There may be simple steps that can be

taken to enable the test to be done, for example making sure that you stay in the room and talk your relative through the procedure. If you have them, you can show the doctor their health action plan, communication passport or person-centred plan as well as talking through important points to help everyone think about the best way to get the tests done.

Does the doctor have to tell me the results of any tests my relative has?

There is no legal right to be informed of the results of any test your relative has as part of their healthcare unless it is in their best interests. The GMC advises that it is reasonable to assume that people would want their closest family to be aware of any health issues that Healthcare staff can and should share healthcare information and records with when it is in the best interests of your relative. This is particularly so if, as a result of the tests, a decision needs to be made about treatment.

You can find out more about assessing capacity and best interests decision making in sections 2, 3 and 4 of this resource.

Find out more about medical consent:

Confidentiality guidance:

Disclosures about patients who lack capacity to consent

www.gmc-uk.org/guidance/ethical_guidance/confidentiality_57_63_patients_who_lack_capacity.asp

A guide to the meanings of words and terms used about communication and mental capacity.

Advanced decision to refuse treatment (ADRT)

A decision to refuse a specific medical treatment in whatever circumstances specified. This can include the choice to refuse treatment even if doing so might put your life at risk. It can only be made by somebody who has capacity and is aged over 18.

Appointee

A person appointed by the Department for Work and Pensions to take responsibility for the benefit of an adult who lacks capacity to manage their own affairs. An appointee can be an individual or an organisation, such as a local authority or a firm of solicitors.

Assessor

The person carrying out the capacity assessment.

Attorney

A person or group of people appointed under a Lasting Power of Attorney to have the legal right to make certain agreed decisions on behalf of another adult. You can only appoint or be an attorney if you have capacity and are aged 18 or over.

Best interests

Guidance on the definition of best interests is contained in chapter 5 of the Code of Practice. For a decision to be in somebody's best interests you must consider all seven aspects mentioned in this chapter (summarised as REFLECT).

Best interests decision

A decision made or anything done for an adult who lacks capacity to make a specific decision must be in the person's best interests.

Capacity

A person's capacity (or lack of capacity) refers specifically to their ability to make a particular decision at the time it needs to be made (see mental capacity).

Capacity assessment

This is the assessment that must be carried out to determine whether somebody has the ability to make a particular decision (see two-stage test).

Care Quality Commission (CQC)

The independent regulator of health and social care in England. The CQC regulates the care provided by the NHS, local authorities, private companies and voluntary organisations.

Code of Practice

The *Code of Practice* is the practical guidance to support the *Mental Capacity Act*. It explains how the act will operate on a day-to-day basis and offers examples of best practice to

carers and practitioners. All paid staff have a legal obligation to follow the *Code of Practice*.

Court of Protection

The Court of Protection is a specialist court that can make decisions for adults who do not have the capacity to do so themselves. The court may become involved because:

- it is a particularly difficult decision
- people disagree about what action to take and the disagreements cannot be resolved
- situations where ongoing decisions may need to be made about the personal welfare of a person who lacks capacity.

The Court of Protection can also appoint people as deputies to take decisions for people for one-off or ongoing situations.

Court of protection visitor

A person who visits to advise and monitor deputies. They can provide reports to the Court of Protection and the Office of the Public Guardian.

Criminal offence

The *Mental Capacity Act* introduced a new criminal offence of ill-treatment or wilful neglect of a person who lacks capacity, carrying a potential prison sentence of up to five years.

Decision Maker

The person who takes the decision on behalf of the person.

Department for Work and Pensions (DWP)

The government department responsible for welfare, employment and pensions issues. It can make people appointees to manage the benefits of people who cannot do this themselves.

Deputy

A person appointed by the Court of Protection to manage the property and affairs and/or personal welfare of an adult who lacks capacity to make certain decisions themselves. Deputies are appointed when the adult cannot or has not granted anyone a Lasting Power of Attorney.

Deputy order

The document which sets out the powers the Deputy has been given. You are sent several copies when you are appointed as deputy.

Getting it right

Getting it right is Mencap's campaign for equal healthcare for people with a learning disability. To find out more or join the campaign to go www.mencap.org.uk/gettingitright

Ill treatment or wilful neglect

It is an offence under the *Mental Capacity Act* to:

- deliberately ill-treat an adult who lacks capacity or be reckless in the way you treat or fail to treat them (whether or not harm is caused)
- wilfully neglect an adult by failing to carry out an act you know you have a duty to do.

This applies to anyone involved in caring for the adult, for example family carers, healthcare and social care staff, attorneys and deputies. Penalties for either offence range from a fine to a sentence of imprisonment of up to five years.

Independent mental capacity advocate (IMCA)

An IMCA works with and supports adults who lack capacity, and represents their views to the people working out their best interests. They must be appointed when the adult has no family or friends to consult about decisions about serious medical treatment and changes of accommodation.

Involve Me

Involve Me is a three-year project about how to creatively involve people with profound and multiple learning disabilities in decision making. The project is supported by the Renton Foundation and is being run by Mencap in partnership with the British Institute of Learning Disabilities (BILD).

Lasting Power of Attorney (LPA)

Sometimes a person will want to give another person the authority to make decisions on their behalf. An LPA is a legal document that allows them to do so, and the decisions made by the person named in this document (the attorney) are as valid as ones made by the adult themselves. The *Mental Capacity Act* replaced Enduring Power of Attorney with LPA. There are two forms of LPA – one for property and financial affairs and one for personal welfare.

Mental capacity

To have mental capacity means to have the ability to make a particular decision at the time it needs to be made. Mental capacity can vary according to the decision to be made and the time the decision is to be taken. Mental capacity can also fluctuate with changes in a person's situation.

Office of the Public Guardian (OPG)

Supports the Public Guardian in registering attorneys and supervising Court of Protection appointed deputies.

Patient Advice and Liaison Service (PALS)

An NHS service which relays concerns or issues raised by patients to NHS managers. It also provides information and advice about local health services and other relevant organisations.

Personal welfare

Personal welfare decisions are any decisions about a person's healthcare and anything needed for their general care and well being. Attorneys and deputies can be appointed to make decisions about personal welfare on behalf of an adult who lacks capacity.

Personal Welfare Deputy

A person appointed by the Court of Protection who has legal authority to make particular decisions for someone who lacks capacity.

Property and affairs

An adult's belongings, income, savings, investments and any expenditure. Attorneys and deputies can be appointed to make decisions about property and affairs on behalf of an adult who lacks capacity.

Public Guardian

The Public Guardian is supported by the Office of the Public Guardian to supervise deputies, keep a register of deputies, attorneys, and investigate any complaints about them.

Two-stage test

The test for capacity involves two stages. The first is to establish if there is an impairment of or disturbance in the functioning of the adult's mind or brain. If the answer is yes, you can move to the second stage, which considers if the impairment or disturbance results in the adult lacking the capacity to make a particular decision. This is done by considering whether they can **understand, retain and weigh up** information to make and then communicate their decision. If the answer to any of these four questions is no, they are considered to lack capacity for that decision.

