

1. Making decisions



Decision-making and planning for the future

Thinking about the future life of your son or daughter when you are no longer around to support them is one of the most difficult things, practically and emotionally. However, it is important to face this challenge, as decisions may need to be made regarding where they will live, how they may be supported, how their finances will be managed and who will be responsible for keeping an eye on things. If you do not broach the subject, then at some point someone else will, and they are less likely to do it with all the unique knowledge and understanding that you have gained over the years and that a formal assessment will probably not provide.

Parents and other family carers play a key role in decision-making, so it is helpful to have an understanding of the legislation and practice that relates to it. With this you will be in a good position to ensure that you are included in decisions and that the best decisions are made. It will also give you an insight into how and why professionals are making decisions on behalf of your relative. Decision-making usually works best when it is a partnership between the person, their family and people who are paid to support them.

People with learning disabilities have a huge variation in their ability to make decisions but the information in this section is relevant to all families, including those who feel their relative has a limited ability to express their views. Most people can show both positive and negative preferences to a person, a place or an activity and this ability can be invaluable when making decisions.

This section looks at:

- Decision-making under the Care Act
- an overview of the Mental Capacity Act;
- shared decision-making: involving your relative in making decisions;
- ‘best interests decisions’;
- challenging decisions;
- involving other people in decision-making;
- other people who have authority to make decisions (lasting powers of attorney and Court of Protection);
- advance decisions to refuse treatment.

Decision-making under the Care Act

In the Care Act, local authorities must involve people in decisions made about them and their care and support. Regardless of how complex a person’s needs, they must help people to express their wishes and feelings, weigh up their options and assist them in making their own decisions. If your relative has care and support needs and would have substantial difficulty in being involved in processes such as assessments, care and support planning and reviews, then the local authority must make sure there is an appropriate individual or independent advocate to support them. Often family carers will be the appropriate individual but if you don’t feel confident to do this you could say this to the local authority and ask for your relative to have an independent advocate to support them in the care and support planning process. An independent advocate must have the skills to involve your relative and cannot be someone who is already working with your relative in a paid capacity.

Overview of the Mental Capacity Act

The Mental Capacity Act, which covers England and Wales, was introduced in 2007.

'Mental capacity' is another way of saying the ability to make a decision. It is helpful to have an understanding of the Mental Capacity Act and the meaning of 'best interests decisions' as these underpin the way everyone working with people with learning disabilities should be approaching decision-making.

As a family carer the Act is relevant if you need to:

- support your relative to make a decision;
- make a decision or act on your relative's behalf (acting in their best interests);
- question or challenge a situation where someone else, such as a care manager or support provider, makes a decision or assessment of capacity that you do not agree with.

If you understand the key principles of the Act you will find it easier to make sure that your relative is involved as much as possible in decisions that affect them and that these decisions are the right ones for them.

The Act has five key principles that define the way decision-making should be approached:

1. It is assumed that a person has capacity to make a decision unless it is shown otherwise. It is also important to understand that the ability or 'capacity' to make a decision is looked at for each decision: no one is ever assumed to lack capacity for all decisions; before anyone can make a decision on behalf of someone, it needs to be shown that the person does not have the capacity to make that decision.

2. A person should be given as much support as possible to make a decision – this may involve thinking about different ways of asking a question or giving information (see section below on shared decision-making).
3. People have the right to make unwise decisions – the fact that someone makes a decision that seems unwise to others, or that others do not agree with, does not mean that the person lacks capacity.
4. Any decision made on a person's behalf must be made in their best interests.
5. Any decision made on a person's behalf should aim to limit their rights and freedoms as little as possible.

The Mental Capacity Act has a Code of Practice that provides guidance to professionals in health care, social care and housing as well as staff providing care. Whilst the Code of Practice applies less to family carers, it provides a helpful framework to guide everyone. It sets out the responsibilities of a decision-maker (see 'best interests decisions' below) and also guidance on assessing the capacity of a person to make a decision.

Finding out if your relative can make a decision

A person is assessed as being unable to make their own decision if they cannot do one or more of the following four things:

- Show some understanding of the information given to them to make the decision.
- Retain that information long enough to be able to make the decision.
- Weigh up the information and use it to make the decision.
- Communicate their decision – this could be by talking, using sign language or movements such as blinking an eye or squeezing a hand.

Shared decision-making: involving your relative in making decisions

It is important to always look for ways to support your relative to make decisions and to be involved in the decision-making process in whatever ways they are able. These decisions may be about their current life or the things they would like to happen in the future. There are several ways in which you can achieve this, depending on what might work for your relative and your family. Here are some ideas and suggestions that families have found have worked for them:

- Give your relative as many opportunities as possible to make decisions about smaller issues and to express their preferences: the more decisions they make, the easier they will find it.
- Break down big decisions into many smaller decisions which they might be able to make.
- Keep a written log of the situations and approaches that helped, such as time of day or environment, and which didn't, and then use what you've recorded when thinking about bigger decisions. This information can also be used by other people (and can continue to be used if you are no longer able to be involved).
- Learning about your relative's preferences may well begin to shape bigger decisions. For example, giving them opportunities to keep in touch with friends or meet new people may reveal who they get on well with. This information could influence a decision about who they live with.
- You may feel there is someone who is good at supporting your relative in making decisions. If so, your relative can ask for them to attend meetings, such as support planning or reviews, with them.
- If you feel your relative needs support from someone other than yourself, you could check whether there are any local advocacy organisations providing citizen advocacy or peer advocacy.
- Ask whether your relative is getting the right support with communication. If you feel there is a lack of knowledge and understanding about their communication, you could ask for a referral to be made to a speech and language therapy service.
- Try different resources such as the Books Beyond Words series or easy-read information such as the Housing Options booklet 'My Place to Live'.
- Look at the information in Section 2 on person-centred planning. This explains how to learn more about a person and what works for them.
- Use the ideas in the 'Involve Me' guide (details at end of this section) written for families and staff to include people with profound and multiple learning disabilities in decision-making and consultation.

Best interests decisions

The Mental Capacity Act sets out a process to ensure that a decision made for people who have been assessed as not having the capacity to make it themselves is made in their best interests. Best interests does not mean what you would choose if you were in their situation. Instead it is about knowing their values, wishes, aspirations—what you think they would choose if they did not lack capacity. This includes decisions made by families as well as social workers and care professionals.

If your relative lives at home with you, you will probably be the decision-maker for many of the day-to-day decisions. If they are in supported living or residential care, a paid worker is likely to be more involved in making day-to-day decisions.

However, for bigger issues such as finance, social care or health, it is likely that a professional, who should have expertise in Mental Capacity Act issues, will be the decision-maker. For example, for a decision regarding moving into accommodation funded by the local authority, it is likely that a care manager (social worker) would be the decision-maker acting for the local authority. For a health decision, such as whether to have a specific treatment, it is likely that a medical professional will be the decision maker.

The decision-maker is expected to get the views of people with an interest in your relative's welfare, including family members, paid staff and other people who know them or have specialist knowledge. If your relative has a deputy or attorney (see page 23-24), they must also be consulted.

These people might help by:

- supporting your relative in getting involved in decisions;
- giving their own views;
- giving expert advice.

As a family carer you may be able to help by providing information, or you may be the best person to find out more from your relative to contribute to the decision. A best interests meeting may be held for big decisions, such as deciding where your relative might live. This meeting would provide everyone with an opportunity to give their views.

The solicitors, Irwin Mitchell, have produced a leaflet to help anyone who feels they are not being appropriately consulted about the welfare of their loved ones. It includes two template letters to help family members who have not been involved or are concerned they will not be involved in a best interests decision-making process (see Information at end of section).

Challenging decisions

There may be situations where you wish to challenge a decision or need to find a way to resolve a dispute. This might happen:

- if you think you have not been consulted when you feel you should have been;
- there are disagreements about whether someone has the mental capacity to make a decision;
- a decision is made which you do not think is in the best interests of your relative;
- if there is disagreement, perhaps among family members or between family and a professional, about a decision such as what is in a person's best interests.

In these situations you could:

- keep a record of any disagreements;
- involve an independent advocate (not an Independent Mental Capacity Advocate) who can help to make sure your relative's wishes are properly understood;
- use the formal complaints process of the relevant service – for example the NHS, your local authority, a voluntary or private sector service (see page 106 for information about making a complaint);
- get advice from the Office of the Public Guardian;
- go to the Court of Protection.

Decision-making and person-centred planning

You may agree that your relative is unable to make a decision, but you disagree with the suggestions that are being made on their behalf. In this case, it is helpful to keep a written log of what works or doesn't work for them. This information can be used to back up or rule out the options that are being looked at. If you have gathered this information through person-centred planning (see Section 2) and have involved other people who are important to your relative, it is likely to have more influence.

Involving other people in decision-making about the future

It helps to consult with other people regarding future options. Although parents sometimes say they feel it is unfair to involve other people in decision-making as they think the responsibility sits with them, we have found that wider family and friends are willing to be involved and often appreciate being asked.

It may be that your son/daughter already has quite a few people involved in their lives, so it is not difficult to decide whom you might ask for support. You could consider asking your other sons or daughters, other relatives and family friends (especially if they are of the same generation as your son/daughter), your son/daughter's friends or people who have worked with or currently support them.

Why it helps to involve other people:

- Talking things through with others may throw up new options and ideas.
- You can get emotional and practical support as a family when it gets stressful: for example, if you are in disagreement with your local authority.
- They may know things about your son/daughter that you don't know; they may see them with different people and in different places.
- They can question your assumptions: for example, that another son or daughter will take on a certain role, or that siblings don't want to be responsible in the future. They need a chance to say what they can and can't do.
- They may welcome the opportunity to get involved and this may lead to long-term commitment and support.

For more ideas about involving other people look at 'Building a circle of support' in Section 3.

Other people who have authority to make decisions

Some of the ways in which other people can make decisions on behalf of your relative are outlined below. If you are considering using any of them, you should explore the additional sources of information listed at the end of the section and/or get professional advice.

Lasting powers of attorney

A lasting power of attorney (LPA) is a legal document appointing one or more people to be an individual's attorney, either to make decisions about their property and financial matters (called a property and affairs power of attorney), or their personal welfare, including medical treatment (called a health and welfare power of attorney). They can only be made by someone aged 18 or over.

A person needs to have the mental capacity to create an LPA. This means they need to understand the nature of what they are doing as well as the implications. A good test for this is to consider whether your relative is able to talk about their future and express their wishes. Most people with severe learning disabilities would not have this capacity so this option would not be open to them. A Court of Protection deputy would be the best solution in this case (see below).

Family carers may also wish to create their own LPA so that someone is already in place to help them, should they be unable to deal with their finances at some time in the future.

Attorneys must be over 18. Ideally at least one of the attorneys should be younger than your relative and live reasonably nearby; it could be a family member, friend, work colleague or a professional. It is not a good idea to choose family members who live abroad as this can cause delays in dealing with paperwork. Decisions made by an attorney must be made in the person's best interests and the attorney would be expected to involve family members in the process. Property and affairs attorneys must not be bankrupt and should be someone who can be trusted to make decisions about your relative's finances.

You can specify how the attorneys are to carry out the work: whether they make all the decisions together or whether they can act independently of each other. This will depend on the circumstances of the person creating the power of attorney and their ongoing needs.

A health and welfare LPA is set up in the same way as a lasting power of attorney for property and affairs. It allows the attorney to make some decisions about matters relating to the person's health and welfare if or when they are not able to make such decisions themselves. The decisions may concern the person's medical treatment, how their health care is managed, where they live and how their living arrangements are managed (particularly in a care home or supported living). They might also involve more detailed aspects of their life, such as daily care and diet.

To make an LPA the person needs to obtain the forms and guidance from DirectGov. These forms should be returned to the Office of the Public Guardian for checking and registration; an LPA can only be used once it has been registered with the OPG.

Enduring powers of attorney

Before 2007, when lasting powers of attorney were introduced, it was possible to create an enduring power of attorney (EPA). This allowed an attorney to deal with someone's financial affairs, but not their health and welfare. The same test of mental capacity applied but the enduring power of attorney did not have to be registered until the person creating it became mentally incapable. It is advisable to ask a solicitor to check whether any enduring power of attorney that you or your relative may have is correctly executed and still valid.

Court of Protection

The Court of Protection is a specialist court for all issues relating to people who may lack capacity to make specific decisions. Where there is a disagreement about a person's capacity to make a decision that cannot be resolved informally, the Court can make a declaration about the person's capacity to make this decision. It can also make one-off decisions, for example in relation to the providing, withdrawing or withholding of serious medical treatment. The Court is also responsible for the appointment of deputies to make on-going decisions.

Court of Protection deputyship

If your relative does not have the mental capacity to either manage their own finances and property or to create an LPA, the only option available is to apply to the Court of Protection for a deputy to be appointed. This will not usually be needed where the person has no property or savings, because their benefits can be managed by an 'appointee' appointed by the Department for Work and Pensions. The Court will decide whether the appointment of a deputy is in the best interests of your relative.

Unless there is an emergency, the process of applying for a deputy to be appointed is lengthy, involves a lot of paperwork and can be costly. Usually it is a family member or close friend who applies to be appointed as a deputy, but if there is a significant amount of money or property involved, a solicitor can be appointed as a professional deputy. Only professional deputies are allowed to charge for the work they do; lay deputies may only reclaim out-of-pocket expenses.

The Court of Protection allows the deputy to manage your relative's money. A deputy can also make other decisions if these have been agreed by the Court of Protection; for example to sign a tenancy agreement on a rental property.

Deputies can also be appointed for health and welfare but this is much less common as most decisions can be covered by the best interests process.

Advance decisions to refuse treatment

An advance decision to refuse treatment (ADRT), sometimes known as a living will or advance directive, is a statement that a person writes specifying what medical treatment they would not want to receive at some time in the future. It is made whilst the person has the capacity to make such decisions.

There is no special form or format for an ADRT but you may want to get professional help from a solicitor or health care professional. Further details are available at NHS Choices <http://www.nhs.uk/Planners/end-of-life-care/Pages/advance-decision-to-refuse-treatment.aspx>

To make a valid ADRT the person must:

- be over 18 years of age;
- have mental capacity at the time of making the statement;
- state exactly what treatment they do not want to receive;
- explain why and when their wishes should apply;
- have made the directive without anyone influencing the decision;
- have not done anything to contradict the statement after signing it.

Your relative may appreciate support to think about and make an ADRT; they may have received a specific treatment that they would not wish to go through again, for example chemotherapy. An ADRT may be particularly important if they have a life-limiting condition or are in the very early stages of dementia.

Other types of advance statements can also spell out the kind of care a person would wish to receive in certain circumstances. These statements are not legally binding, but should be influential when deciding what treatment is in the person's best interests.



Questions to ask

Are there any organisations or groups in our local area that run classes that support people with learning disabilities to make decisions?

Is there someone in the health team who can support our relative with communication/developing a communication passport?

Is there someone who can advise us if our relative has the capacity to make a lasting power of attorney (LPA) or an advance decision to refuse treatment (ADRT)?

Is there someone who can look at the LPA or ADRT to advise us whether the person's wishes/decisions are clear?

Whom to ask

The learning disability community team, local Mencap or advocacy group should know if this is happening locally.

Ask whether health team practitioners, such as a speech and language therapist, can do this.

Contact the learning disability community team (care manager or health practitioner).

As above.

Notes



To find out more you could look at

Hft's Family Carer Support Service can provide free one-to-one support by telephone, email or letter on issues to do with decision making (Phone 0800 801 0448 or email familycarersupport@hft.org.uk).

Hft's **Using the Mental Capacity Act: a resource for families and friends of people with learning disabilities** (2011) is a very useful guide designed for families and includes video clips explaining specific issues. The link below provides details of how to order the booklet and DVD (which are free) or download them.
<http://www.hft.org.uk/mcaguide>

Mencap (with the involvement of the Challenging Behaviour Foundation) has produced information on the Mental Capacity Act for families of people with profound and multiple learning disabilities. There is a lot of useful information about health decisions. This is available as a download from the website.
<http://www.mencap.org.uk/news/article/keeping-within-law-mental-capacity-resources>

Office of the Public Guardian, **Making decisions. A guide for family, friends and other unpaid carers.**
<http://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/opg-602-0409.pdf/>

Involve Me is a project carried out by Mencap to find ways of involving people with profound and multiple learning disabilities in decision-making and consultation. There is a practical guide for family carers and paid workers, including video clips, which is available on the website.
<http://www.mencap.org.uk/node/13182>

A guide has been produced by SCIE and ARC for support staff and managers that includes information about LPAs, deputies, appointees and bank accounts: **Guidance on money management for people who may lack capacity to make some decisions about how their money is used** (2011). This is available from ARC's website: <http://arcuk.org.uk/publications/guidance-on-money-management/>

Best Interest Decision Tool produced by Irwin Mitchell Solicitors for individuals who feel that they are not being appropriately consulted about the welfare of their loved ones. A leaflet and template letters are free to download at <http://www.irwinmitchell.com/activities/best-interest-decisions-tool>