

Sibs

For brothers and sisters
of disabled children and adults



Decision-making

A guide for adult siblings of people with lifelong disabilities

- When your brother or sister can't make a decision, who does?
- Can you make decisions on their behalf?
- What does 'mental capacity' mean?

Sibs is the UK charity for brothers and sisters of disabled children and adults
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Welcome

Welcome to Sibs, the UK charity for brothers and sisters of disabled children and adults. Growing up with a brother or sister who has a lifelong disability can be a complex and challenging experience. Siblings often juggle multiple responsibilities and rarely receive recognition for their role. We've written this guide specifically with you in mind and we hope that it helps guide you through your questions. It will be particularly relevant to siblings whose brother or sister is learning disabled and/or autistic.

The guide assumes that your brother or sister is aged 18 or over, and lives in England, Wales, Scotland or Northern Ireland. If you're reading this, it's likely that you give emotional or practical support to your brother or sister. Siblings are used to coming second (or third, or fourth...) to the needs of another, so make sure that you seek support for yourself too. Go to www.sibs.org.uk/adultsiblings to find out more.

More guides from Sibs

Other guides available in this series include:

- Behaviours that challenge
- Coping with managing care
- Future planning
- Getting a care needs assessment
- Making a complaint
- Managing money
- Savings, wills and trusts
- Talking to parents

All available to download at www.sibs.org.uk/guides

More support from Sibs

You're not alone! Did you know there are over 1.7 million adult siblings in the UK?

- Meet other siblings at a support group www.sibs.org.uk/groups
- Chat with other siblings on our private Facebook community www.sibs.org.uk/siblife
- Download our eBook 'Self-care for siblings' www.sibs.org.uk/ebook

Disclaimer

We have made every effort to ensure that the information in this guide is accurate and up-to-date. Sibs cannot be held responsible for the outcome of any actions you may take as a result of reading this guide. This guide does not replace legal advice. Written March 2024.

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Someone said my brother 'lacks capacity' because he has a learning disability. What do they mean?

'Mental capacity' refers to a person's ability to make decisions. Whether someone lacks capacity is determined on a decision-by-decision basis. For example, your brother may have the capacity to decide what to eat, but may not have the capacity to decide whether to have an operation or not.

Your brother can't be labelled as 'lacking capacity' in all areas. If someone suggests that your brother 'lacks capacity', your next question to them could be '*lacks capacity for what decision?*'

Your brother's diagnosis is not the deciding factor. It's not the fact that he *has* a particular disability, but *how* that disability affects his ability to:

- Understand information about a particular decision
- Remember that information long enough to be able to make the decision
- Weigh up the information available to make the decision
- Communicate the decision.

A person must be assumed to have capacity until proven otherwise. Every practicable step must be taken to support a person to make their own decision, such as using their preferred type of communication or allowing extra time. A person is also allowed to make an 'unwise decision'.

An unwise decision is a decision that others might consider inappropriate, but that the person still wants to go ahead with. Wanting to make an 'unwise decision' isn't proof that your brother or sister doesn't have capacity. But it could be appropriate to take the time to check that they're able to understand and retain relevant information, weigh up the consequences and communicate their choice. There's an example of this on page 13.

Different laws in the UK countries govern mental capacity:

- In England and Wales this is the [Mental Capacity Act 2005](#)
- In Scotland this is the [Adults with Incapacity \(Scotland\) Act 2000](#)
- In Northern Ireland this is the [Mental Capacity Act \(Northern Ireland\) 2016](#)

When my parents die, am I legally responsible for making decisions for my sister?

No. You don't have any legal duties to make decisions on behalf of your sister. It's your choice whether or not to become involved.

My Dad and I still make all the day-to-day decisions for my autistic non-verbal sister. Can we keep doing this?

It's often assumed that when a disabled child becomes an adult, parents, siblings and other close family members can continue to make decisions for them as they always have. You and your family might think of yourselves as 'next of kin', but the law doesn't recognise that next of kin have the right to make decisions for someone else. All adults have the right to make their own decisions wherever possible and mental capacity laws apply to everyone, not just paid carers or professionals.

If a person is unable to make a decision for themselves, the law states that others can act in their 'best interests'. This means involving the person as far as possible and taking into account their wishes, feelings and values. The views of the person's family and carers should also be taken into account. Your knowledge of your sister will help you judge whether she can make a decision or not.

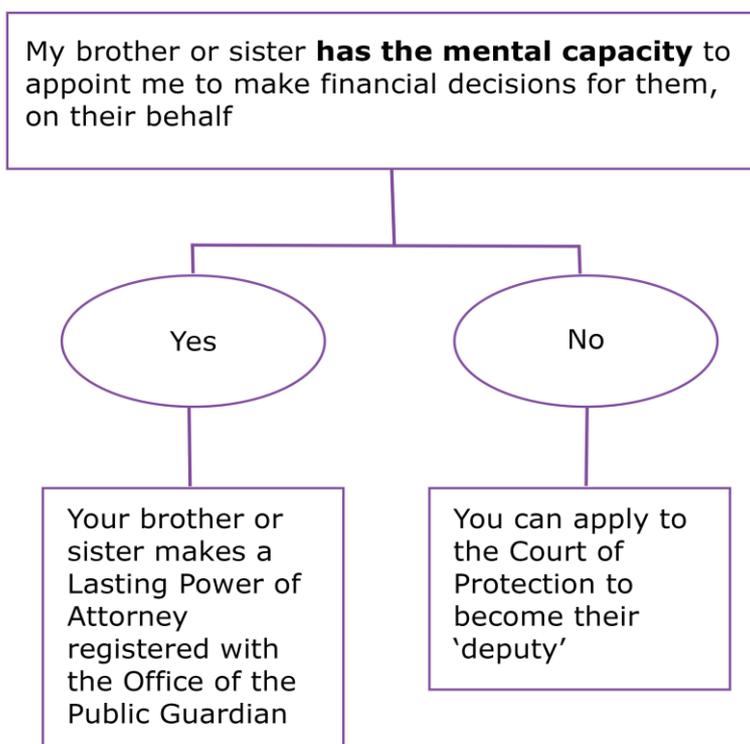
So as long as you are acting in your sister's best interests, you and your Dad can continue to make most day-to-day decisions on her behalf.

My sister can't make financial decisions, and I'd like to do this on her behalf. Do I need to get permission from the court?

If you want to help your sister manage her benefits, then you can become her appointee. You apply to become an appointee through the [Department of Work and Pensions](#), and there is no cost to this. Being an appointee doesn't cover savings or managing property – for this you would need a different permission. Visit www.gov.uk/become-appointee-for-someone-claiming-benefits for more information and to apply to become an appointee.

If you want to help your sister with bigger financial decisions, like managing savings or property, then you will need to apply for permission to do this. The process and the cost of this varies depending on which country you live in:

England and Wales

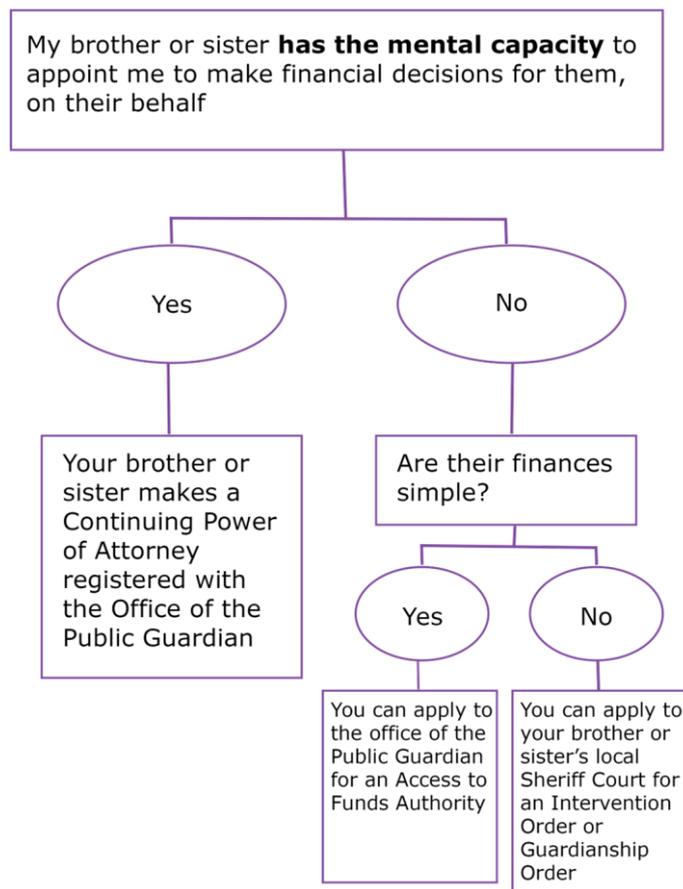


England and Wales

Find out more

- Lasting Power of Attorney and Deputyship www.gov.uk/government/organisations/office-of-the-public-guardian

Scotland

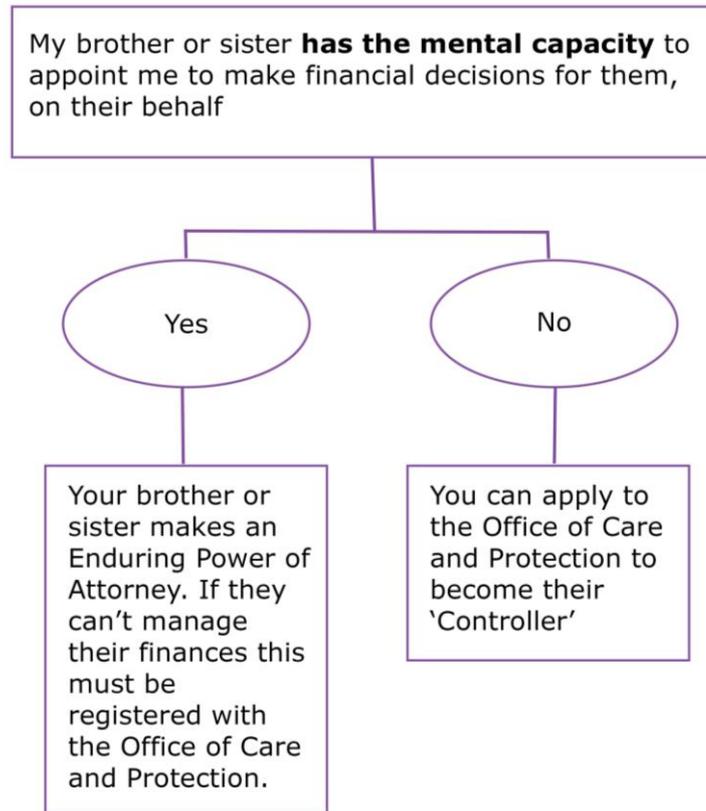


Scotland

Find out more

- Continuing Power of Attorney
www.publicguardian-scotland.gov.uk/power-of-attorney/power-of-attorney/types-of-power-of-attorney
- Access to Funds Authority
www.publicguardian-scotland.gov.uk/access-to-funds/acfl/what-is-meant-by-access-to-funds
- Intervention Order (for a one-off decision)
www.publicguardian-scotland.gov.uk/intervention-orders/about-intervention-orders/what-is-an-intervention-order
- Guardianship Order (for an ongoing basis)
<https://www.publicguardian-scotland.gov.uk/guardianship-orders>

Northern Ireland



Northern Ireland

Find out more

- Enduring Power of Attorney
www.justice-ni.gov.uk/articles/information-enduring-powers-attorney-epa
- Controller
www.justice-ni.gov.uk/articles/how-apply-become-controller

My brother can't make important decisions about his health and I'd like to do this on his behalf. Do I need to get permission from a court?

There are different laws in the UK countries that determine the permission you need. Different fees will apply.

England and Wales

If your brother **does not have the capacity** to make decisions about his health, you can apply to the Court of Protection to be his Health and Welfare Deputy. These are dealt with on a case by case basis, so the judge will be looking closely at the reason why you're asking to become his deputy to decide if it's in his best interests to appoint a Health and Welfare deputy. For example, if the person needs ongoing help to make decisions, or where it can be hard for others to communicate with him.

Find out more

- Become a deputy

www.gov.uk/become-deputy

Scotland

If your brother **does not have the capacity** to make decisions about his health, you can apply to the Sheriff Court to be his Welfare Guardian.

Find out more

- Guardianship

<https://www.publicguardian-scotland.gov.uk/guardianship-orders>

Northern Ireland

In Northern Ireland there is no way to give a person legal power to make healthcare decisions on your behalf.

My brother is 34 years old. My parents still treat him like a baby, but I think he could do so much more with his life. What can I do?

If your brother's abilities haven't changed since he was a child, it may be that your parents have slipped into a routine of still treating him like a child. When a person has high care needs – and needs that can seem similar to a much younger person – it can be difficult for parents to step outside of this routine and see their son or daughter as an adult in their own right.

Mental capacity laws recognise that all adults have the right to make decisions for themselves wherever possible. Your parents may not realise that they no longer have the automatic legal right to make decisions for your brother as they did when he was a child. Speak to your parents about this as it's important that they are aware of mental capacity laws – for their own benefit as well as your brother's.

In terms of improving your brother's quality of life, start by suggesting activities that you feel he would enjoy. Start small – even everyday things like giving your brother a choice of two different drinks offers him more control over his life. It may be easier for your parents, and your brother, to take an introduction to new things gradually. When you're talking to your parents about local groups or activities you think he'd like, try and leave some written information or a website for them to re-read and think about.

If you want to spend time with your brother and help him to enjoy more activities, you can. You and your brother are adults in your own right. You don't legally need permission from your parents to have a relationship with your brother.

I want to help with the decision-making around my sister's care but my parents don't involve me. What can I do?

Your views are important. You have the lived experience of growing up with your sister. Your parents, family friends and any health or social care professionals involved with your sister's care haven't had the same experiences as you and don't know your sister in the same way. If you have suggestions you would like to share in a decision-making process you can contribute these as an individual in your own right. Any decisions which are made in your sister's best interests should be made whilst collaborating with those who know her well – including siblings. Let any professionals involved with your sister's care know that you would like to be involved and to include you in invitations to meetings.

I want to see my brother but my parents won't let me. I know he wants to see me too – where do I stand in terms of the law?

You and your brother are both adults and no one has the right to stop you having a relationship. Your parents cannot prevent him from seeing you without good reason.

If you feel there is a long-standing family issue that has caused tension for some time, it may be best to contact Adult Social Care in your brother's authority*/local health and social care trust** and explain that you would like a social worker to mediate a family meeting.

A social worker can complete a mental capacity assessment to determine if your brother can make a decision about whether to see you or not. If your brother is able to decide this, then the social worker can talk to your parents about arranging contact. If your brother is not able to decide this, then a best interests meeting can be held and the social worker should support this.

You may feel that there is no good reason for your parents preventing you from seeing your brother and that they are controlling him. This is a safeguarding issue, and you must ask a social worker to investigate this further. Visit www.sibs.org.uk/safeguardingadults for more information.

*England, Wales and Scotland

**Northern Ireland

My brother's support workers don't make him brush his teeth at night because he hates doing it. They say it's his decision not to do it, but I'm worried for his health.

It depends on whether your brother is able to understand the long-term implications of not brushing his teeth. If he does – and he still chooses not to – then yes, it is his decision to make. If he doesn't – then a best interests decision needs to be made and he needs to be supported in looking after his teeth.

You know your brother well and will probably be aware of his ability to understand the long-term consequences. Discuss this with the support workers and see if they can support your brother to brush his teeth in other ways – using a particular paste, brushing to music or doing it at a different time of day. You will be able to give them ideas on what might work and what won't.

If the support workers are unresponsive to this, contact Adult Social Care for advice. They can carry out a formal mental capacity assessment for your brother. They can hold a meeting with support workers to ensure a new method for supporting your brother to brush his teeth is included in his care plan.

I don't agree with a best interests decision that my sister's care home has made about her.

If you don't agree with a decision that's been made, you can ask for a best interests meeting to discuss the situation with staff members. You can give your perspective and ask them to discuss theirs in more detail. Care home staff should be documenting such decisions and be able to justify them.

If you still disagree with the decision, you can make a complaint in writing to the care home manager, clearly stating what you feel your sister's best interests are in this situation. If you believe that your sister is at risk of neglect or abuse you can contact Adult Social Care to make a safeguarding referral.

Find out more

- Sibs guide – *Making a complaint*
<https://www.sibs.org.uk/guides>
- Taking action on safeguarding concerns
<https://www.sibs.org.uk/safeguardingadults>

SIBLING EXPERIENCE: “I really don't think that's a good idea Aaron.”

My brother Aaron is 27-years-old and has Down's syndrome. He works 5 hours a week at a local coffee shop, which he loves. He lives independently with support from agency carers, our parents and me – we are all nearby. One Saturday, Aaron goes out with his support worker Dave. Aaron asks Dave to help him buy £50 worth of lottery tickets.

Dave feels that £50 is a lot of money to spend on lottery tickets, and he is unsure if Aaron understands the risks. Dave talks to Aaron more about the decision and gauges that Aaron does understand he could lose all his money. Aaron decides he still wants to spend £50 on the lottery, so together they buy the tickets. When they get home, Dave writes about the decision in Aaron's care folder.

Dave worked in line with mental capacity laws in this situation. He saw the risk, and wasn't sure if Aaron understood. He supported Aaron to make the decision for himself, by explaining the risks to him in a way he could relate to. By writing down what happened, Dave has made other carers and family members aware.

To some people, spending £50 on lottery tickets may be considered 'unwise'. However, all aspects of life involve risk taking. Learning from our mistakes is something everyone has the right to – including people with a learning disability. Risk taking is part of developing as a person and no one should be unfairly deprived of that. Mental capacity laws aim to empower people, and allowing a person to make an 'unwise' decision is part of that.

SIBLING EXPERIENCE: “How can we cause Sunita the least distress during her operation?”

My sister Sunita is 75-years-old and has cerebral palsy and a severe learning disability. She lives in a residential home and recently fell and went to hospital with a broken hip. I was so worried about her.

Staff from the residential home gave the hospital Sunita's 'hospital passport' – a short booklet that says what Sunita likes and dislikes, her habits and routines and things she is afraid of. This was helpful to the hospital staff, who learnt immediately that Sunita is afraid of needles.

Sunita needed an operation to fix her hip and doesn't have the capacity to decide whether to accept treatment. My husband and my daughter and I met with the hospital staff, and agreed that the operation should go ahead in Sunita's best interests. I appreciated the time they took to listen to our opinions.

The doctor acknowledged Sunita's fear of needles and allowed extra time to give the anaesthetic. She allowed me to stay with Sunita, so that I could comfort her. A numbing cream was used, so that the area where Sunita had the injection could be desensitized. I felt relieved to be able to be there for Sunita at such a difficult time.

The hospital staff have followed mental capacity laws in this situation. They have taken the views of family members into consideration and acted in Sunita's best interests. Because they have provided treatment they know Sunita will not like (giving the injection) they have taken the least restrictive options to make her as comfortable as possible (allowing extra time, using numbing cream, allowing her sibling to be there).

SIBLING EXPERIENCE: “Stefan doesn't understand the long-term consequences.”

My brother Stefan is 45-years-old and has Prader-Willi syndrome, learning disabilities and displays behaviour that others find challenging. He recently moved from living at home with our Dad into a group home. Stefan lives with three other men who have learning disabilities and they receive 24 hour support. Stefan is the only person in the group home who has Prader-Willi syndrome.

When Stefan first moved to the group home, my Dad and I met with Stefan's key worker to discuss his care plan. We explained that because of Stefan's condition, he was unable to make decisions about the quantities of food he ate.

My Dad has always restricted what Stefan ate – keeping locks on the cupboards at home and providing 24 hour supervision – so that Stefan didn't gain dangerous and life-threatening amounts of weight. To people who don't know about Prader-Willi syndrome, this can be hard to understand and sound really strict. But it's absolutely essential, as the condition means that Stefan just doesn't have the ability to understand the long-term consequences of weight gain.

The key worker listened to this and included a restricted diet into Stefan's care plan. However, after a few weeks, Dad and I started to notice that Stefan had been gaining weight. We spoke to the staff, and it turned out that when Stefan was going to the local shop to buy a magazine, he wasn't closely supervised and had been stealing food and hiding it.

We asked for closer supervision of Stefan, but Stefan's key worker and the staff at the home felt that Stefan was allowed to make unwise decisions and should experience the natural consequences of stealing and hiding food. They said that he needed to learn to be more honest with staff over time. They also said that because they were not allowing Stefan into the kitchen and they were restricting his food at meal times there was nothing more they could do.

Dad and I really disagreed with this decision and felt there was quite a misunderstanding from staff about the seriousness of Prader-Willi syndrome. I feel that the staff should be given the training to understand the condition properly. Dad and I feel worried about this all the time. We have placed a complaint in writing and also contacted Adult Social Care to request a meeting, to formally assess Stefan's capacity around this issue. We continue to work with Stefan's staff, which is very difficult at times when we disagree.

Many siblings are in similar situations and some decision-making can take a great deal of time and effort to sort out. A formal meeting to assess Stefan's capacity is the next step in this situation.

Find out more

England and Wales

A straightforward guide to the Mental Capacity Act

<https://www.scie.org.uk/mca/introduction/>

Code of practice giving guidance for decisions made under the Mental Capacity Act 2005

<https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice>

The Mental Capacity Act 2005 in full

<https://www.legislation.gov.uk/ukpga/2005/9/contents>

Scotland - Adults with Incapacity (Scotland) Act 2000

A straightforward guide to the Adults with Incapacity (Scotland) Act 2000

<https://www.careinfoscotland.scot/topics/your-rights/legislation-protecting-people-in-care/adults-with-incapacity-scotland-act-2000/>

Adults with incapacity: code of practice for local authorities

<https://www.gov.scot/publications/adults-incapacity-scotland-act-2000-code-practice-local-authorities-exercising-functions-under-2000-act/>

The Adults with Incapacity (Scotland) Act 2000 in full

<https://www.legislation.gov.uk/asp/2000/4/contents>

Northern Ireland - The Mental Capacity Act (Northern Ireland) 2016

A straightforward guide to the Mental Capacity Act (Northern Ireland) 2016

<https://www.health-ni.gov.uk/mca>

Codes of Practice which provide practical information for how the Act works

<https://www.health-ni.gov.uk/mca-codes-practice>

The Mental Capacity Act (Northern Ireland) 2016 in full

<https://www.legislation.gov.uk/nia/2016/18/contents>

Next steps

What two actions will you take this month as a result of reading this guide?

1.
2.

Feedback

We would love to hear what you thought of this guide. Drop us a line at info@sibs.org.uk

About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

Being a sibling can be a complex and challenging experience. You are not alone. Visit our website, follow us on social media, and sign up to our mailing.

Website www.sibs.org.uk

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Mailing list sibs.org.uk/subscribe

Instagram [SibsCharity_uk](#)

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