



Decision-making and the law: When your brother or sister can't make a decision, who does?

A brief guide to **mental capacity** for adult siblings
of people with lifelong learning disability and/or autism

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Registered charity number 1145200. Limited company number 7834303.

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What's in this guide about mental capacity?

This guide is for adult siblings of someone with a lifelong learning disability and/or autism. It briefly outlines common questions we receive from adult siblings about decisions made for or by their brother or sister. It does not replace legal advice.

Trying to understand the laws around decision-making is often a complicated and exhausting experience, even when the outcome is positive. If there is further difficulty – for example, if the people involved in the decision-making disagree strongly – then it can add significant distress.

This guide aims to highlight best practice – what the law advises and the procedure people should receive. However, we acknowledge that this is not always what happens in reality.

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk to meet other siblings at a support group or become a volunteer support group facilitator yourself.

The information in this guide was accurate at the time of writing – March 2018

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

No. You do not have any legal duties to make decisions on behalf of your sister. It is your choice whether or not to become involved.

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?*'

In addition, your brother's diagnosis or disability is not the deciding factor. It is not the fact that he has a learning disability, but how the learning disability affects his ability to:

1. Understand information about a particular decision
2. Remember that information long enough to be able to make the decision
3. Weigh up the information available to make the decision
4. 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. Different laws in the UK countries govern whether or not someone has mental capacity to make a particular decision. Visit the links at the end of this document.

My Dad and I still make all the decisions for my sister. Can we keep doing this?

It is often assumed that when a child with a learning disability and/or autism 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.

You do not have any legal duties to make decisions on behalf of your sister. It is your choice whether or not to become involved.

All adults have the right to make their own decisions wherever possible. Your knowledge of your sister will help you judge whether she can make a decision or not.

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

Sometimes you might need to have special permission to make decisions for your sister, for example using her bank account or consenting to a medical procedure. Links to more information on the different types of special permissions required in the different UK countries are at the end of this document.

Mental capacity laws apply to everyone, not just paid carers or professionals.

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. If you feel they will disregard your information, contact Adult Social Care and ask to speak to a social worker regarding the issue. Hearing about legal information from a professional may have a different impact to hearing it from a family member.

In terms of improving your brother's quality of life, start by suggesting activities that you feel he would enjoy. Start small, for example by offering more daily choices – such as asking if he would prefer orange or apple juice. It may be easier for your parents, and your brother, to take an introduction to new things gradually. When talking to your parents about local groups, activities or services you feel your brother would benefit from, try and leave some written information for them to re-read and think about.

If you want to spend time with your brother, you can. You and your brother are adults in your own right. You do not 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 have not had the same experiences as you and therefore cannot offer insights 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 professionals (e.g. learning disability nurse) 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 or sister's local authority 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 liaise with your parents over 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 contact the local authority and ask a social worker to investigate this further. Visit www.sibs.org.uk for further information on safeguarding adults.

Do I need to go to court to get permission to make decisions for my sister?

Many decisions made on behalf of someone who lacks mental capacity don't involve the decision-maker using any specific legal powers, e.g. choosing what to eat for lunch. You know your sister well and will probably be aware of many of her preferences already. For some more complex decisions, including some financial and healthcare decisions, you may need to apply for special permissions depending on the circumstances and country. Different laws in the UK countries govern this. Visit the links at the end of this document.

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 does not – then a best interest's 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 provide information for them on what may work and what may not.

If the support workers are unresponsive to this, contact Adult Social Care for advice. They can complete a formal mental capacity assessment and document this. They can facilitate a meeting with support workers to ensure a new method for supporting your brother with teeth brushing 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.

I've heard about something called 'Deprivation of Liberty Safeguards' or 'DoLS' – what does this mean?

Note: Deprivation of Liberty Safeguards only apply in England and Wales.

The Deprivation of Liberty Safeguards (known as the 'DoLS') were added to the Mental Capacity Act 2005 to protect people's human rights when they are deprived of their liberty in health and social care. A person is deprived of their liberty if they are subject to 'continuous supervision and control' and they are not free to leave the place where they live. This affects a lot of people with conditions such as dementia, learning disabilities, brain injuries and mental health problems.

Although the name sounds bad, the law was intended to help people who are deprived of their liberty and their families. It was created because of a case when a person with autism was deprived of his liberty in a hospital and his family and carers could not get him out again. The safeguards include having independent assessments of mental capacity and best interests, getting help from an independent advocate, and legal aid to go to the Court of Protection if people disagree.

(Paragraph above printed with permission from Lucy Series, Cardiff University)

The Deprivation of Liberty Safeguards are currently under review. The government is due to publish a response to recent recommendations from the Law Commission that they are replaced by a new scheme called the Liberty Protection Safeguards. Visit the links at the end of this document.

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

My brother Aaron is 27-years-old and has Down syndrome. He works 5 hours a week at a local coffee shop, which he loves. He lives independently with support from agency carers, his 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 the money. Aaron decides he still wants to spend £50 on the lottery, so together they buy the tickets and return home. Dave documents the decision in Aaron's care folder.

Dave is working in line with mental capacity laws in this situation. Dave has identified a risk, and was not sure if Aaron understood this. Dave supported Aaron in making the decision himself, by explaining the risks to him in a way he could relate to. Whilst Dave disagreed with the decision, he recognised that it was Aaron's decision to make. By documenting the decision on his return, Dave has made other carers and me and my family aware.

To some people my brother's decision to spend his money in this way may be deemed 'unwise'. Mental capacity laws aim to empower and protect people who may not be able to make some decisions for themselves. Dave has recognised that just because Aaron is making what seems to be an unwise decision, it does not mean he lacks capacity.

All aspects of life involve risk taking. Learning from our mistakes is something everyone has the right to – including people with learning disability. Risk taking is part of developing as a person and no one should be unfairly deprived of that.

Codes of practice have to be followed by staff on how to work with the mental capacity legislation. See the links at the end of this document.

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 with clear details on 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. The hospital staff have followed mental capacity laws in this situation. They have acted in my sister’s best interests but are taking the least restrictive options available and making Sunita as comfortable as possible. I felt relieved to be able to be there for Sunita at such a difficult time.

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 my 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. Through further discussion with staff, it appeared that when Stefan was accompanied 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.

Further reading on mental capacity legislation

England and Wales - Mental Capacity Act 2005

Rough guide to the Mental Capacity Act 2005

<https://thesmallplaces.wordpress.com/2017/08/24/a-rough-guide-to-the-mental-capacity-act-2005/>

On deputyship and lasting power of attorney

<https://www.gov.uk/government/organisations/office-of-the-public-guardian>

Code of practice

<https://www.justice.gov.uk/downloads/protecting-the-vulnerable/mca/mca-code-practice-0509.pdf>

Information on the proposed changes to Deprivation of Liberty Safeguards (DoLS)

<http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-8095#fullreport>

Scotland - Adults with Incapacity (Scotland) Act 2000

Information about the act and on welfare guardianship and financial guardianship

<http://www.mwscot.org.uk/the-law/adults-with-incapacity-act/>

Code of practice

<http://www.gov.scot/Topics/Justice/law/awi/010408awiwebpubs/cop>

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

This is not in force yet as the Northern Ireland Assembly is still in suspension, so this link is temporary:

<http://www.legislation.gov.uk/niu/2016/18/contents>

Taking action on safeguarding concerns

<https://www.sibs.org.uk/support-for-adult-siblings/safeguarding-concerns/>

A guide to confidentiality in health and social care

<https://digital.nhs.uk/article/1226/A-Guide-to-Confidentiality-in-Health-and-Social-Care->

Next steps in supporting yourself and your disabled brother or sister

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

1.
2.

Further support

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk for more information, to talk to someone about sibling issues, or to meet other adult siblings at a support group.

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.

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Sibs relies on donations and grants to support siblings – please consider making a donation through our website.