

Sibs

For brothers and sisters
of disabled children and adults



Managing money

A guide for adult siblings of people with lifelong disabilities

- If your brother or sister can't manage their money, who can?
- Do you need permission to manage their money?
- What financial support is available?

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
- Decision-making
- Future planning
- Getting a care needs assessment
- Making a complaint
- Savings, wills and trusts
- Talking to parents

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

More support from Sibs

You're not alone! Did you know there are over 1.7 million adult sibling 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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My sister can't make financial decisions, and I'd like to do this on her behalf.

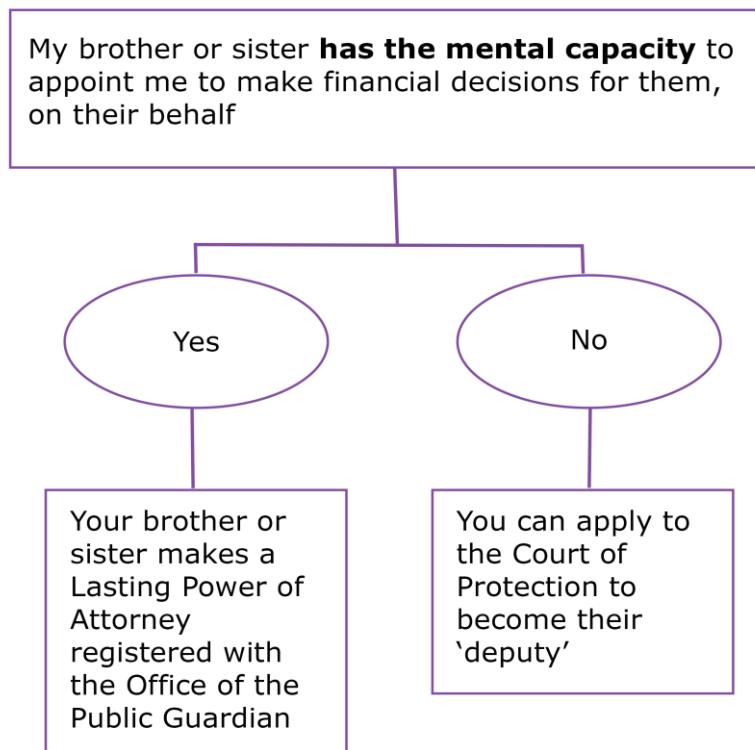
Do I need to get permission from the court?

It depends what decisions you want to help with. It may be that your sister is able to make some decisions (such as buying a sandwich when she is hungry) but needs support with others (such as spending or investing a large amount of money). Your sister's ability to make these decisions is referred to as her mental capacity. If you haven't already, read our guide on decision-making before continuing with this one (you can download it at www.sibs.org.uk/guides).

1. **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.
2. **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.

See diagrams on pages 5, 6 and 7.

England and Wales

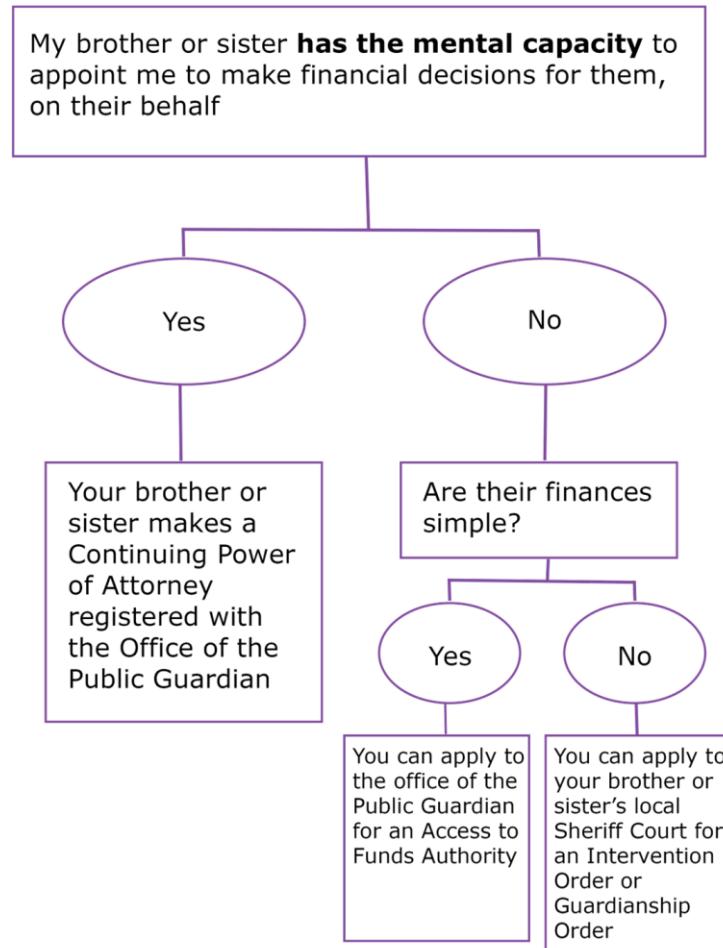


England and Wales

More information:

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

Scotland

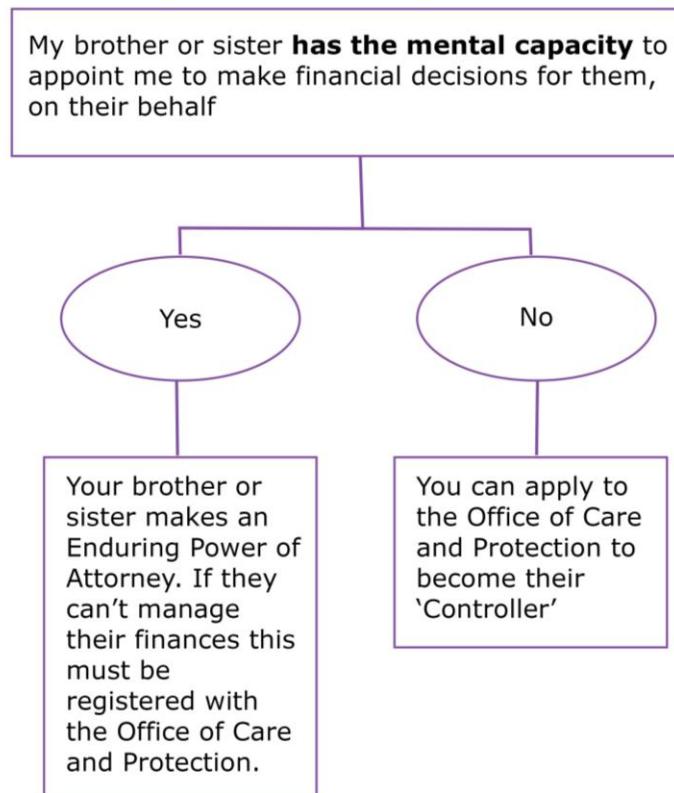


Scotland

More information:

- 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/acf1/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

More information:

- 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

When my parents die, am I legally responsible for managing my brother's finances?

No. You do not have any legal duties to manage your brother's finances. It is your choice whether or not to become involved. Your brother's day to day finances and arrangements for care may be managed by the local authority*/local health and social care trust** or by an Individual Service Fund (ISF). If your parents want to leave money to your brother they can set up a trust, which can be managed by a solicitor.

*England/Wales/Scotland **Northern Ireland

My brother has learning disabilities. Can he have his own bank account?

If your brother has the ability to understand what is involved with having a bank account in his own name, then yes, he can open and use a bank account. Banks can offer support with this by providing information in an accessible format, providing a chip and signature card (e.g. if a person has difficulty remembering a PIN number) and allowing a person to bank in a branch rather than only online or by telephone. It may also support your brother to have a different type of account, for example one in which he cannot become overdrawn.

How can I make sure my sister is receiving all the benefits she is entitled to?

What your sister is entitled to will depend on her needs, income and savings. Your sister needs to be assessed for financial support and you can get more information by contacting Adult Social Care in your sister's local authority. You can get detailed information on different types of benefits, who is eligible and how to apply from [Disability Rights UK](#). You can also use an [online benefit calculator](#) to get an estimate of what your sister could be entitled to.

Here is a general overview of some benefits that may apply:

- [Personal Independence Payment \(PIP\)](#) aims to help with the additional costs that disabled people face, as a result of their disabilities. It is tax-free and it is not means-tested
- [Attendance allowance](#) aims to help with personal care. To be eligible for attendance allowance your sister must be aged 65 and over and have physical or mental disabilities
- [Universal credit](#) is a payment to help with living costs. It is not specific to disabled people. A person may be eligible for universal credit if they have a low income or are out of work

Find out more

- Benefits calculator
benefits-calculator.turn2us.org.uk/AboutYou
- Disability Rights UK – benefits information
www.disabilityrightsuk.org/how-we-can-help/benefits-information/factsheets/welfare-reform-factsheets

I am the main carer for my brother. What financial support can I get?

It depends on your circumstances, where you live and how many hours a week you are caring for your brother. You can get detailed information on different types of benefits for carers, who is eligible and how to apply from [the Carers Trust](#) and [Carers UK](#). You can also use an [online benefit calculator](#) to get an estimate of what you could be entitled to.

Here is a general overview of some benefits that may apply:

- [Carer's Allowance](#) is a weekly payment for people who spend 35 hours a week or more caring for somebody who is also in receipt of certain benefits. It's not means-tested but there are limits on the amount of hours you can work in the week. If you receive Carer's Allowance, you will automatically receive National Insurance credits. You don't have to live with your brother to be claiming Carer's Allowance. If someone else (such as a parent) also cares for your brother, then only one of you can claim Carer's Allowance
- You may also be eligible for [Universal Credit](#), depending on your income
- [Carer's Credit](#) may be helpful if you aren't eligible to receive Carer's Allowance and spend 20 hours a week or more caring for your disabled brother. Carer's Credit helps to fill in the gaps in your National Insurance contributions. Whilst this isn't direct financial support, receiving credits may help you in future if you apply for National Insurance based benefits yourself, or State Pension

You can also request a [carer's assessment](#) from your local authority. This addresses your needs as a carer, not the needs of your disabled brother. If you are eligible for support, you will have a care and support plan that outlines what you need and how these needs will be met. Even if your brother is not eligible to receive support – you might be. The support could include things like respite care for your brother so that you can have a break from caring.

Find out more

- Carers Trust – benefits advice
carers.org/money-and-benefits/intro
- Carers UK – benefits advice
www.carersuk.org/help-and-advice/financial-support
- Benefits calculator
benefits-calculator.turn2us.org.uk/AboutYou
- Carer's allowance
England, Wales, Scotland www.gov.uk/carers-allowance
Northern Ireland www.nidirect.gov.uk/articles/carers-allowance
- Universal credit
www.gov.uk/universal-credit
- Carer's credit
www.gov.uk/carers-credit
- Carer's Assessment
www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment

My brother has savings. Will he have to pay towards the cost of his care?

And will this also affect what benefits he can receive?

It depends on where your brother lives and how much he has in savings. Some benefits (such as Universal Credit) are means-tested and capital such as savings and property will be taken into account alongside income. Other benefits (such as PIP) are not means-tested. Use a [benefits calculator](#) to gauge how your brother's savings may affect what benefits he can claim.

Care and support from the local authority is means-tested. The local authority can challenge and reclaim money from a person, if they have concerns that someone has intentionally decreased their overall assets to avoid paying for their care (e.g. by transferring their savings to another person).

England – the government sets different financial thresholds, to determine whether a person will pay towards their care or not. These are called the ‘upper capital limit’ and the ‘lower capital limit’. If someone has less than the lower capital limit in savings, they will not pay towards their care. If they have between the lower and upper limit, then they will need to contribute a certain amount (and how much they pay will be determined by a financial assessment). If they have more than the capital limit, then they will have to fund the full cost of their care. To find out the current upper and lower capital limits as set by the government, visit www.gov.uk

Wales – charges vary between local authorities and they must publish information about their charging procedure. Most people will be expected to pay something towards the cost of their care.

Scotland - charges vary between local authorities. Most people will be expected to pay something towards the cost of their care (personal care for over 65s is free). The value of your home is not counted as capital.

Northern Ireland – charges vary between Health and Social Care Trusts. Care for over 75s is free.

I've heard about personal budgets. What are they?

In England and Wales, a personal budget is an amount of money that is provided by your local authority to meet your disabled brother or sister's needs. In Scotland and Northern Ireland, a personal budget is referred to as self-directed support.

The amount of money is specific to the individual based on their needs at the time of their care needs assessment – it is not dependent on their diagnosis. However, the local authority should be able to give you a rough idea of what your brother or sister may be entitled to (an indicative budget).

These are the main ways that your brother or sister's budget could be received and managed:

1. The local authority holds the budget and arranges and pays for the care and support services for your brother or sister.
2. You or another family member receives a Direct Payment and you arrange and pay for the care and support for your brother or sister. Your brother or sister will need a specific bank account for this that you have legal permission to manage. In some local authorities you can use a third party to receive and manage the payments on your brother or sister's behalf.
3. A mixed budget – the local authority keeps some of the budget and arranges some services; you receive some budget as a Direct Payment and arrange some of the care and support for your brother or sister.

You and your brother or sister should be involved in decisions about how the budget is spent.

In England, some people may *also* be identified as having health care needs as well as social care needs. They may receive a personal health budget, a personal social care budget (as described above) or a combination of the two. Personal health budgets are not available in Wales, Scotland or Northern Ireland.

Find out more

- Personal budgets - an overview for England and Wales
www.disabilityrightsuk.org/personal-budgetsthe-right-social-care-support
- Self-directed support
Northern Ireland www.hscboard.hscni.net/sds/
Scotland www.sdsscotland.org.uk
- Personal health budgets (England only)
www.england.nhs.uk/personal-health-budgets/

My sister receives direct payments to pay for her support workers. Will this affect her benefits?

No, receiving direct payments will not affect the benefits your sister is entitled to. Direct Payments are an agreed amount of money given directly to your sister (or nominated person) from her personal budget. The aim of Direct Payments is to give people more choice over the support they receive – for example, by employing their own support workers - rather than the local authority arranging and paying for this directly. The money received does not count as income and does not affect other benefits. It is solely to be spent on the agreed care and support needs (e.g. a support worker), so your sister may need to keep receipts to show how the money has been spent.

My mum normally pays my sister's carers using direct payments, but she's now struggling to manage this. Is there another way we can organise this?

Your mum is currently classed as an employer. She has to fulfil her responsibilities as an employer including paying salaries and pensions, keeping track of hours worked, and doing a staff rota if more than one person is employed. Here are some options:

- Your mum can continue with the role and use a local payroll service to do the staff salary payments and related employment paperwork. This is still a large task and if your mum is finding it harder to manage paperwork as time goes on, we wouldn't recommend this
- You can take on the role of being the nominated person to receive and manage the direct payments as well as the employer role
- Your sister's direct payments can be used to get care and support through an agency so that the agency takes on the employer role
- Your sister can have her budget held by the local authority and they can arrange and pay for your sister's care and support

There are pros and cons for each of these and as a family you'll need to discuss what's best for your sister versus how manageable each option is for you and your mum.

Find out more

- Information on direct payments from Carers UK
www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments

My sister has been in and out of hospital recently and she has complex ongoing healthcare needs. Is she eligible for continuing healthcare funding from the NHS?

NHS continuing healthcare funding is available in England, Wales and Northern Ireland (not Scotland) to people who need care outside of hospital and who have certain complex ongoing health care needs.

The funding can be used to cover health care needs such as personal care and therapy. Eligibility is not based on a particular diagnosis but on the person's level of need. You can request an assessment from your sister's GP or local authority. They have a duty to carry this out, even if there is only a small chance she may be eligible.

Four factors are taken into consideration when a person is assessed:

- Nature of needs – specific needs and what is required to meet them
- Intensity – how severe the needs are
- Complexity – how different needs may interact and the skill required to manage this
- Unpredictability – the difficulty of predicting changes to needs

Read more about NHS continuing healthcare [here](#) before requesting an assessment.

Find out more

- NHS continuing healthcare
www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/
- Free, independent advice on NHS Continuing Healthcare Funding
www.beaconchc.co.uk/

My brother is less able to walk and I think he needs some adaptions to his house. What support might be available for this?

Your brother may be eligible for a specific grant from the local authority. What is available will depend on which of the UK countries he lives in and what his needs are.

In England, Wales and Northern Ireland you can apply to the local authority for a disabled facilities grant. In Scotland, The Housing (Scotland) Act 2006 allows local authorities to provide a grant for home adaptations required due to disability. Contact your local authority to find out what may be available to your brother.

Find out more

- More information on different housing grants available across the UK
www.disabilityrightsuk.org/housing-grants

- Disabled Facilities Grant (England, Wales, Northern Ireland)
www.gov.uk/disabled-facilities-grants

I'd like to buy my sister some sensory equipment. Is there somewhere I can get a grant for this?

If your sister is not able to receive funding for this from the local authority (for example, from her personal budget) you can search for grants at grants-search.turn2us.org.uk/

For some grants, you may need evidence from a health and social care professional – such as an occupational therapist – to demonstrate that your sister may benefit from the item and that the local authority are unable to fund it. If you can't find a grant that is specifically for disabled people continue to search for grants for people on a low income or people who live in your local area generally.

I think my brother is being pressured to hand over money to a ‘friend’, and I’m worried they are taking advantage of him.

Try and find out more information about the situation. Is there someone else you can speak to within your brother’s local community who supports him? They may have similar concerns to you and it can help to share and discuss these.

Take notes on the dates and times of incidents, who was involved and what happened. Keep a record of your brother’s mood or any changes in behaviour that concern you too. This may help you build a case if you need to and also firm up your evidence if you are worried about whether your concerns are real or not.

Being pressured to hand over money is financial abuse. This is a safeguarding concern and needs to be reported to the local authority.

Find out more

- Take action on safeguarding concerns www.sibs.org.uk/safeguardingadults

My sister’s ongoing prescription costs are mounting up. What help is available?

If you haven’t already, see if your sister is eligible for a [medical exemption certificate](#). These are given to people with certain ongoing health conditions and it means your sister would receive her NHS prescriptions for free.

It’s also worth checking if your sister is entitled to an [NHS tax credit exemption certificate](#). Some people on a low income and in receipt of certain benefits may be eligible for this certificate. It entitles the person to free prescriptions, dental treatment, sight tests and the cost of travel to receive NHS treatment. If your sister isn’t eligible for this, try the [NHS low income scheme](#), which will help with these costs.

A final alternative, if your sister is not eligible for any of the above, would be to consider using a [Prescription Prepayment Certificate \(PPC\)](#). You pay a set amount upfront for 3 or 12 months, and receive the certificate. The certificate then covers the cost of your medications in that time. It’s cost effective if your sister has 2 or more regular prescriptions.

Find out more

- NHS Medical exemption certificates
www.nhsbsa.nhs.uk/exemption-certificates/medical-exemption-certificates
- NHS tax credit exemption certificates
www.nhsbsa.nhs.uk/exemption-certificates/nhs-tax-credit-exemption-certificates
- NHS low income scheme
www.nhsbsa.nhs.uk/nhs-low-income-scheme
- Prescription pre-payment certificates
www.nhsbsa.nhs.uk/help-nhs-prescription-costs/prescription-prepayment-certificates

My sister lives in a residential service and I'm worried because she doesn't seem to have much spending money.

It might be that your sister has very little spending money, despite being in receipt of all benefits she is entitled to. Living in a residential home changes the way a person receives their benefits. Some benefits they receive may go directly to the residential home, in part or in full, to pay for their care. What they may be left with is called their Personal Expenses Allowance. The process of receiving benefits while in residential care can be complicated and can vary between different local authorities. You need to contact the local authority where your sister lives for more information.

There is a way that you can support her with managing what spending money she does have – you can become an appointee. An appointee is someone who manages a person's benefits on their behalf.

Find out more

- Become an appointee
www.gov.uk/become-appointee-for-someone-claiming-benefits

My sister's health has worsened and she's finding it hard to travel. What support might be available to her?

If your sister's physical abilities have deteriorated significantly, it would be helpful to have her needs re-assessed by the local authority as this may change what personal budget is available to her. Contact the local authority to request a re-assessment of her needs - explain specifically what has changed and how it now affects your sister on a day-to-day basis.

Find out more

By car

- The Motability scheme leases cars, scooters or powered wheelchairs to people with disabilities who are in receipt of certain benefits
www.motability.co.uk
- You may be eligible for a reduction or an exemption from vehicle tax – it is dependent on the level of disability and circumstances
www.gov.uk/financial-help-disabled/vehicles-and-transport
- Blue Badge parking scheme - Displaying the blue badge in your car windscreen shows that the driver or a passenger has a disability. It allows you to park in disabled parking spaces, which are closer to shops and facilities. You do not need to be a wheelchair user.
England and Wales www.gov.uk/blue-badge-scheme-information-council
Scotland www.mygov.scot/apply-blue-badge/
Northern Ireland www.nidirect.gov.uk/information-and-services/motoring-and-transport/blue-badge-scheme

By bus

- Some local authorities offer concessionary bus travel. Some offer alternative schemes to people who may have difficulty accessing a bus or train, such as 'dial-a-ride' - an accessible, pre-booked community minibus.
England www.gov.uk/apply-for-disabled-bus-pass
Scotland www.mygov.scot/disabled-bus-pass/
Wales <https://portal.tfw.wales/en>
Northern Ireland www.nidirect.gov.uk/information-and-services/bus-and-coach-travel/free-bus-travel-and-concessions

By train

- Concessionary rail travel across the UK
www.disabledpersons-railcard.co.uk/

- Passenger Assist is a service you can book, to help you at stations and on the train. This might be with carrying bags, finding your seat or finding your way to the platform. Support is dependent on the area and often needs to be booked 24 hours in advance
<https://www.nationalrail.co.uk/help-and-assistance/passenger-assist/>

Other discounts that may be available to your disabled brother or sister

Council tax and rates

Some local authorities offer a reduction to people with disabilities

England and Wales www.gov.uk/council-tax/discounts-for-disabled-people

Scotland www.mygov.scot/council-tax/discounts-exemptions-and-reductions/

Northern Ireland www.nidirect.gov.uk/disabled-persons-allowance

TV licence

If your brother or sister is registered blind or severely sight impaired, then they can claim 50% off the household TV licence.

www.gov.uk/financial-help-disabled/television-licence-discount

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

X [Sibs_uk](#)

Email info@sibs.org.uk

Facebook [SibsCharity](#)

Tel [01535 645453](tel:01535645453)

LinkedIn [company/sibs_2](#)

Mailing list sibs.org.uk/subscribe

Instagram [SibsCharity_uk](#)

Sibs relies on donations and grants to support siblings. If this guide has helped you, please consider [making a donation](#) or become a [Friend of Sibs](#).