



Looking after money: when your disabled brother or sister needs support to manage their benefits and funding

A brief guide to **managing finances** for adult siblings of people with a lifelong learning disability and/or autism

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

What's in this guide about managing finances?	4
I want to help manage my sister's finances. Do I need special permissions from the court to do this?	5
My sister who has autism lives at home with our elderly parents. They are struggling financially and I'm not sure they are claiming all the benefits that they could – what might be available to them?	8
I am the main carer for my brother - what financial support can I get?	10
I've heard about personal budgets. What are they?	11
My sister lives in England and has a heart condition, epilepsy, autism, cerebral palsy and a learning disability. She has been in and out of hospital this year and now needs more carers at home. Is there any extra funding available to her?.....	12
My brother has learning disabilities and cerebral palsy. He is getting older and I think he needs some adaptations to his house. What support might be available for this?.....	13
My sister with a learning disability has recently come to live with me and this has put some extra pressure on my family finances. My sister does get benefits and I am receiving Carer's Allowance, but these are swallowed up with everyday expenses. I would like to buy some extra items to keep her entertained, like a bigger TV and some sensory equipment to help her relax more. Is there somewhere I can get a grant for this?	14
My sister receives direct payments to pay for her support workers. Will this affect her benefits?	14
My mum receives direct payments to support my sister with a learning disability get out and about locally. My mum is getting increasingly forgetful and is struggling to keep up with the paperwork – last week she forgot to organise for the personal assistant that works with my sister to get paid. Is there another way we can organise this?	15
My brother has learning disabilities. Can he have his own bank account?.....	16
My brother has Down syndrome and lives independently with some support in his local community. I think he is being pressured to hand over money to a neighbour who seems to be taking advantage of my brother's vulnerability but I'm worried about how to address this.	16

My sister who has Rett syndrome is finding it increasingly difficult to travel, as she is getting older. What support might be available to her?	17
My sister takes long-term medication to manage her epilepsy, when I went to the chemist recently to pick up the prescription with Mum I noticed that she paid for the tablets – shouldn't my sister get these for free?.....	19
My brother has savings. Will this affect what benefits and funding he can receive?	20
My sister lives in a residential service and I am worried that she is not getting all the money she is supposed to receive. There never seems to be enough for days out, or buying a cup of tea in town when she goes shopping	21
Other discounts that may be available to your disabled brother or sister	22
Next steps in supporting yourself and your disabled brother or sister	23
Further support	23
About Sibs	23

What's in this guide about managing finances?

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 financial support for their disabled brother or sister. It is designed as a starting point for information, and does not replace independent legal or financial advice.

This guide assumes that your disabled brother or sister is over the age of 18 – financial support is different for those under 18. There are many different decisions involved in managing money. It may be that your brother or sister is able to make some decisions (such as how to spend small amounts of money) but needs support with others (such as signing a tenancy agreement). Your brother or sister's ability to make these decisions is referred to as their mental capacity.

Read our guide "*Decision-making and the law: when your brother or sister can't make a decision, who does?*" before continuing with this guide on finances. You cannot legally manage someone's finances if they have the capacity to do it for themselves.

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.

I want to help manage my sister's finances. Do I need special permissions from the court to do this?

It depends on what financial decisions are being made and whether your sister has the mental capacity to make those decisions or not. Read our guide "*Decision-making and the law: when your brother or sister can't make a decision, who does?*" before continuing.

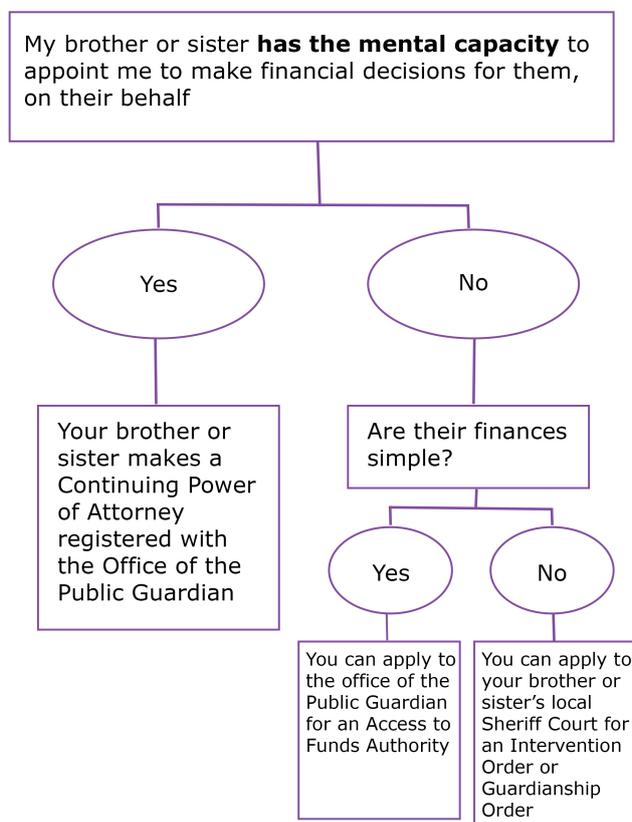
Benefits

To manage your sister's benefits, you need to become her appointee. An appointee can be an individual or can be an organisation, such as a solicitors or a care home. You apply to become an appointee by contacting the Department of Work and Pensions.

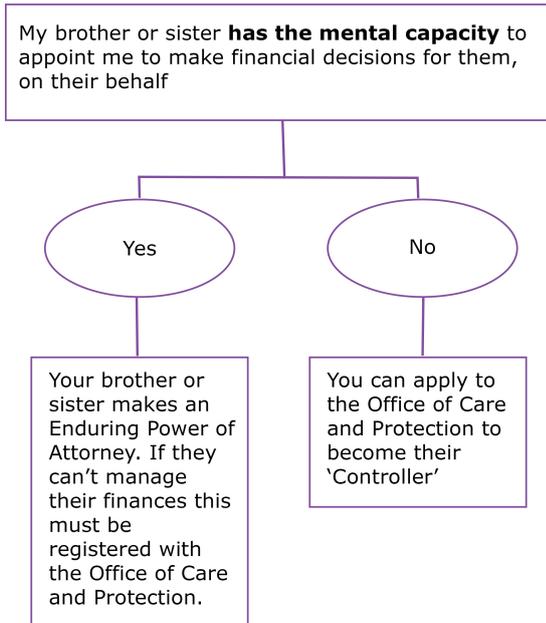
Other financial decisions

For more complex decisions, for example signing a tenancy agreement, you will need special permission. The exact details depend on the circumstances and country. Different laws in the UK countries govern this and different fees will apply.

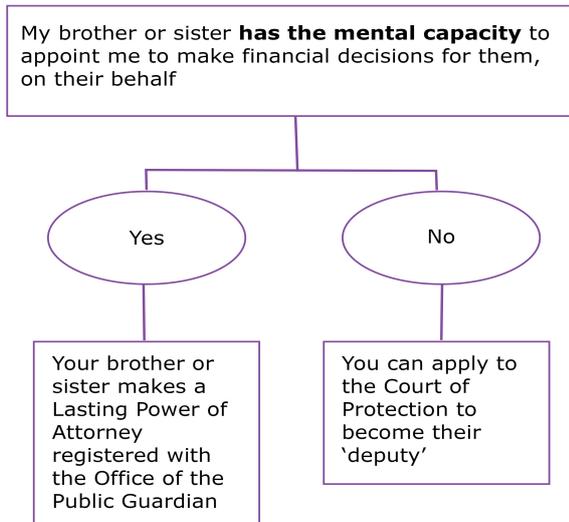
Scotland



Northern Ireland



England and Wales



Further reading on special permissions

Mental capacity

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

<https://www.sibs.org.uk/guides-adult-siblings-people-lifelong-learning-disability-autism>

Special permissions

Appointee <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>

England and Wales

Lasting power of attorney and deputyship

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

Guidance for people wanting to manage a bank account for someone else

<https://www.bsa.org.uk/BSA/files/0f/0f3b146d-d669-4ad7-bcd5-ba1d13988ca2.pdf>

Scotland

Power of attorney

<http://www.publicguardian-scotland.gov.uk/power-of-attorney>

Financial guardianship

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

Northern Ireland

Power of Attorney

<https://www.nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney>

Controller

<https://www.justice-ni.gov.uk/articles/how-apply-become-controller>

My sister who has autism lives at home with our elderly parents. They are struggling financially and I'm not sure they are claiming all the benefits that they could – what might be available to them?

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. Benefits calculators are available online to help you gauge what your sister may be able to claim.

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. It was introduced in April 2013 to replace Disability Living Allowance (DLA) for adults (aged 16-64), and many people have been phased from DLA to PIP.

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 was introduced in October 2013. It 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. Universal credit is being introduced in phases across the UK. It will replace several benefits, including:

- Employment and Support Allowance (ESA) – provides ill or disabled people with financial support if they are unable to work. People who may have previously been claiming Income Support or Incapacity Benefit may have been transferred to ESA.
- Housing Benefit – provides people on a low income with financial support to pay all or part of their rent.

Your sister may still be in receipt of ESA and Housing Benefit. The Department of Work and Pensions states that you do not need to do anything to actively transfer to Universal Credit – you will be contacted about when the transfer will take place.

Further reading on benefits

Personal Independence Payment (PIP) which has replaced Disability Living Allowance (DLA) in a phased approach

<https://www.gov.uk/pip>

Attendance Allowance

<https://www.gov.uk/attendance-allowance>

Universal Credit that is replacing a range of benefits in stages, including Employment Support Allowance (ESA) and Housing Benefit

<https://www.gov.uk/universal-credit>

Employment Support Allowance (ESA) – to be replaced by Universal Credit

<https://www.gov.uk/employment-support-allowance>

Housing benefit – to be replaced by Universal Credit

<https://www.gov.uk/housing-benefit>

Benefits calculator

<https://www.turn2us.org.uk/Find-Benefits-Grants>

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.

Carer's Allowance is a payment of around £60 per week and is eligible to people who spend 35 hours a week or more caring for somebody who is also in receipt of certain benefits. If you receive Carer's Allowance, you will automatically receive National Insurance credits. You don't have to live with your brother whom you are caring for. There are other conditions and limitations to Carer's Allowance (such as the amount of hours you can work) and it could affect other benefits you or your disabled brother receive.

You may also be eligible for Universal Credit, depending on your income. Use a benefits calculator online to obtain a guide of what and how much you may be able to claim.

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 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.

Further reading on support for carers

Carer's Allowance

England, Wales and Scotland - <https://www.gov.uk/carers-allowance>

Northern Ireland - <https://www.nidirect.gov.uk/information-and-services/money-matters/carers-allowance>

Carer's Credit

<https://www.gov.uk/carers-credit>

Carers' assessment

<https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment>

Support and information for carers on a wide range of topics

www.caresuk.org

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

A personal budget is an amount of money that is provided by your local authority to meet your disabled brother or sister's needs. 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).

Main ways that your brother or sister's personal budget is 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 Scotland and Northern Ireland, a personal budget is referred to as self-directed support. 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.

Further reading on personal budgets and self-directed support

Personal budgets

<https://www.disabilityrightsuk.org/personal-budgetsthe-right-social-care-support>

Northern Ireland – Self-directed support

<http://www.hscboard.hscni.net/sds/>

Scotland – Self-directed support

<http://www.selfdirectedsupportscotland.org.uk/>

England only – Personal Health Budgets

<https://www.england.nhs.uk/personal-health-budgets/>

My sister lives in England and has a heart condition, epilepsy, autism, cerebral palsy and a learning disability. She has been in and out of hospital this year and now needs more carers at home. Is there any extra funding available to her?

Your sister may be eligible for continuing healthcare funding from the NHS. This funding is available to people who require care outside of hospital and who have certain ongoing needs (e.g. needs help to reposition in bed so they do not develop pressure sores). 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. 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

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. NHS continuing healthcare funding may also be available to people living in Northern Ireland and Wales, but is not available in Scotland.

Further reading on NHS continuing healthcare funding

NHS continuing healthcare

<https://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/nhs-continuing-care.aspx>

Continuing healthcare checklist

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

My brother has learning disabilities and cerebral palsy. He is getting older and I think he needs some adaptations 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.

Further reading on grants for home adaptations

More information on different housing grants available across the UK

<https://www.disabilityrightsuk.org/housing-grants>

My sister with a learning disability has recently come to live with me and this has put some extra pressure on my family finances. My sister does get benefits and I am receiving Carer's Allowance, but these are swallowed up with everyday expenses. I would like to buy some extra items to keep her entertained, like a bigger TV and some sensory equipment to help her relax more. 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 use the Turn2Us website to search for grants for additional equipment for her.

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 cannot 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.

Further reading on grants for additional equipment

Search for grants

<https://www.turn2us.org.uk/Find-Benefits-Grants>

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). Receipts must be submitted to the local authority to show how the money has been spent.

My mum receives direct payments to support my sister with a learning disability get out and about locally. My mum is getting increasingly forgetful and is struggling to keep up with the paperwork – last week she forgot to organise for the personal assistant that works with my sister to get paid. Is there another way we can organise this?

Your mum is currently an employer and 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.

Your options are:

- 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 she gets older we would not 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 will need to discuss what is best for your sister versus how manageable each option is for you and your mum.

Further reading on direct payments

Information on direct payments from Carers UK

https://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/direct-payments?gclid=CjwKCAiA693RBRAwEiwALCc3uzgJe15qDnn7PcJisHQnW64gZ6CkWP0ZdaY89ndAT7jq7PUr8mMitBoCX74QAvD_BwE

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.

My brother has Down syndrome and lives independently with some support in his local community. I think he is being pressured to hand over money to a neighbour who seems to be taking advantage of my brother's vulnerability but I'm worried about how to address this.

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.

Further reading on financial abuse

Taking action on safeguarding concerns

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

My sister who has Rett syndrome is finding it increasingly difficult to travel, as she is getting older. 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.

You may also find the following information on transport helpful.

Further reading on transport

Car, scooter and powered wheelchair lease schemes

The Motability scheme leases cars, scooters or powered wheelchairs to people with disabilities who are in receipt of certain benefits.

<https://www.motability.co.uk/>

Financial support from Motability

<https://www.motability.org.uk/charitable-grants/>

Vehicle tax exemption

You may be eligible for a reduction or an exemption from vehicle tax – it is dependent on the level of disability and circumstances <https://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 - <https://www.gov.uk/blue-badge-scheme-information-council>

Scotland - <https://www.mygov.scot/apply-blue-badge/>

Northern Ireland - <https://www.nidirect.gov.uk/information-and-services/motoring-and-transport/blue-badge-scheme>

Concessionary bus travel

Your local authority will be able to provide further information about concessionary bus travel. Some local authorities 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 - <https://www.gov.uk/apply-for-disabled-bus-pass>

Scotland - <https://www.mygov.scot/disabled-bus-pass/>

Wales - <https://beta.gov.wales/concessionary-bus-travel-guidance-local-authorities>

Northern Ireland - <https://www.nidirect.gov.uk/information-and-services/bus-and-coach-travel/free-bus-travel-and-concessions>

Disabled persons rail card

Concessionary rail travel across the UK

<https://www.disabledpersons-railcard.co.uk/>

Passenger Assist

You can book help at stations and on the train, for example 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.

National rail – information for disabled passengers

http://www.nationalrail.co.uk/stations_destinations/44971.aspx

My sister takes long-term medication to manage her epilepsy, when I went to the chemist recently to pick up the prescription with Mum I noticed that she paid for the tablets – shouldn't my sister get these for free?

Potentially yes, your sister should receive these for free. It depends upon the type of epilepsy she has and the medication she is taking for it. Talk to your Mum and sister and see if your sister is eligible for a medical exemption certificate or NHS tax credit exemption certificate.

Further reading on NHS prescription charges

NHS tax credit exemption certificates – 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.

<https://www.nhsbsa.nhs.uk/exemption-certificates/nhs-tax-credit-exemption-certificates>

Medical exemption certificate - Free NHS prescriptions for people with certain ongoing medical conditions

<https://www.nhsbsa.nhs.uk/exemption-certificates/medical-exemption-certificates>

NHS low income scheme - If your brother or sister is not eligible for a certificate (above) they may be eligible for the NHS low income scheme

<https://www.nhsbsa.nhs.uk/nhs-low-income-scheme>

Prescription pre-payment certificates - If your brother or sister is not eligible for the above schemes, and they have more than one prescription per month, they may benefit from buying a pre-payment certificate

<https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/prescription-prepayment-certificates>

My brother has savings. Will this affect what benefits and funding he can receive?

It may do, yes, it depends on where he 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 the benefit calculator listed below 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 evidence to believe that the person was deliberately depriving themselves in order to avoid paying for their care (e.g. by transferring their savings to another person).

England - If a person has more than £23,250 in capital they will have to fund the full cost of their care.

If they have less than £14,250 in capital they will not have to contribute towards the cost of their care from their savings. However, they will have to contribute from their income. This will be assessed, and used towards their care (apart from a weekly Personal Expenses Allowance that is intended to cover the cost of personal items like toiletries, magazines or haircuts).

People with between £14,250 and £23,250 in capital will undergo a financial assessment by the local authority and will be charged for part of their care.

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.

Further reading on how savings can affect benefits and funding

Benefits calculator

<https://www.turn2us.org.uk/Find-Benefits-Grants>

Paying towards the cost of your care and support at home

<https://www.disabilityrightsuk.org/charging-community-care>

My sister lives in a residential service and I am worried that she is not getting all the money she is supposed to receive. There never seems to be enough for days out, or buying a cup of tea in town when she goes shopping.

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 with learning disabilities and/or autism 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; this is currently £24.90 in England and Northern Ireland, £25.80 in Scotland and £26.50 in Wales. The process of receiving benefits while in residential care can be complicated and can vary between different local authorities. Contact the local authority where your sister lives for more information.

There is a way that you can support her with managing what money she does have – you can become an appointee. An appointee is someone who manages a person's benefits on their behalf. You apply to become an appointee by contacting the Department of Work and Pensions.

Further reading on receiving benefits whilst living in a residential service

Becoming an appointee

<https://www.gov.uk/become-appointee-for-someone-claiming-benefits>

Personal expenses allowance (PEA)

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 learning disabilities.

England and Wales - <https://www.gov.uk/apply-for-council-tax-discount>

Scotland - <https://www.mygov.scot/council-tax-info/discounts-exemptions-and-reductions/>

Northern Ireland - <https://www.nidirect.gov.uk/campaigns/a-guide-to-rates>

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

<https://www.gov.uk/financial-help-disabled/television-licence-discount>

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.

Website www.sibs.org.uk Email info@sibs.org.uk Tel 01535 645453

Twitter [Sibs_uk](#) Facebook [SibsCharity](#)

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