



Getting a care needs assessment

A guide for adult siblings of people with lifelong disabilities

- What makes your brother or sister eligible for support?
- How can you make sure they get the right support to meet their needs?
- Will they have to pay for their support?

Contents

Welcome.....	3
Can my brother have an assessment of his care needs?	4
What makes my sister eligible for support?	4
How can I help my brother to prepare for an assessment?	4
What happens at a care needs assessment?.....	6
What happens after an assessment?.....	6
Will my brother have to pay for his care?.....	7
What kind of support could my sister receive?.....	8
What if I'm not happy with a decision made by the local authority?.....	8
My sister isn't eligible for any support. What can I do?.....	9
Next steps.....	12
About Sibs	12

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 and/or who is autistic 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. 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.

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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/sibliffe
- 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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Can my brother have an assessment of his care needs?

If your brother needs care and support because of his disability, then the local authority has a duty to carry out an assessment to identify what his needs are. From this, they should provide the services or support that can help meet these needs and prevent or delay further needs from developing.

Contact the adult social care department where your brother lives and request an assessment. The local authority can't refuse to carry out an assessment just because they don't think your brother or sister will be eligible for support following an assessment or because they have a particular diagnosis. They also can't refuse an assessment on the basis that family are already providing care.

There may be a waiting list for an assessment, so don't delay in making this request, especially if there is a change in your circumstances which will affect arrangements currently in place to help care for your brother or sister.

What makes my sister eligible for support?

Many aspects of care and support provided to your brother or sister are based on legislation. The laws that underpin what is considered an eligible need and what support can be provided to meet those needs, are different in England, Wales, Scotland and Northern Ireland.

Additional eligibility criteria can also be used by the local authority where your sister lives. When you request an assessment, ask for a copy of the eligibility criteria that your sister will be assessed against.

If you are currently providing care and support for your sister, that should not be a factor in deciding whether she meets the eligibility criteria. At the time of assessment, be clear about what you can and can't do for your sister – it is your choice whether to be involved or not in her care.

How can I help my brother to prepare for an assessment?

Write down all the things that someone must do for your brother that they wouldn't do for another adult. When you're a carer you get used to multi-tasking and it's easy to overlook things you might be doing to support your brother. In advance of the assessment, all those helping to care for your brother could keep a journal for a week noting every single task. This may help to focus on what your brother's physical, mental and emotional needs are and how others help to

meet them. It's also important to think about how a fluctuating health condition may mean that some days are different from others and that may affect the level of need.

- 1. Think broadly about the help that is needed.** For example, you talk to your brother in a calm voice whilst feeding him because you know that it eases his anxiety. These are two tasks meeting two different needs. Good questions to ask yourself are 'would I do this for another adult?' and 'if I wasn't here, would this happen?'
- 2. Be specific and state what the task is in terms of frequency.** Instead of 'my brother needs someone to check in on him' write 'my brother needs to be reminded to brush his teeth and take his medication on a daily basis'. If a task needs two people, make sure this is noted.
- 3. State how long it takes** for someone to support your brother with a specific task. Saying 'he needs help to brush his teeth and take his medication' will not describe the support needs adequately if each task takes half an hour to complete with supervision.
- 4. Make a note of the consequences.** Think about what would happen if your brother didn't have the support that he needs, especially in terms of his safety, health, dignity, and overall wellbeing. For example, 'if I didn't call my brother to remind him to take his medication every day, he could become seriously ill.'
- 5. Cover every area of your brother's life.**
 - Eating and drinking (e.g. may choke when eating – needs supervision).
 - Personal hygiene (e.g. finds hair washing extremely distressing – needs two people to support).
 - Using the toilet (e.g. will not say when he needs wiping – needs to be checked and helped to be clean after using the toilet).
 - Getting dressed (e.g. does not understand how to dress warmly in cold weather).
 - Home safety (e.g. no sense of danger or fire safety, cannot use hob or kettle).
 - Home cleaning and maintenance (e.g. unable to manage money or pay bills).
 - Social activities and relationships (e.g. buys rounds of drinks for people to make friends - vulnerable to being taken advantage of; needs support to build appropriate friendships).
 - Education, work or training (e.g. would like to volunteer at a train station, will need support at each visit).
 - Accessing the community (e.g. becomes distressed in public spaces, needs two people to support; cannot use public transport independently).
 - Caring responsibilities (e.g. helps elderly mum with washing up and laundry but struggling to do so and needs more support).

It might feel uncomfortable and negative to point out all the things your brother *can't* do and it's natural to want to balance this by highlighting his abilities. It's easy to say 'he's fine with eating' whilst forgetting that it's you who made the sandwich and left it in the fridge for him. Preparing these notes fully in advance helps to make sure that nothing is missed in the assessment and that his needs are clearly understood by the assessor.

What happens at a care needs assessment?

The assessment should be carried out face-to-face by a social worker or assessor from adult social care in a private space (usually where your brother or sister lives). They may be offered a telephone or online assessment, but if this isn't the right method for your brother or sister you can request a face-to-face assessment instead.

If your brother or sister would like support at the assessment, yourself and other family members or carers can attend and we strongly recommend that you do. Together you will discuss with the assessor all the things that someone else must support your brother or sister with. Be absolutely clear about what would happen if your brother or sister did not get that support, especially the impact on their safety, health and wellbeing.

Make sure that all your brother or sister's needs are discussed – even if a family member currently supports them with these needs. Use the journal and notes you have made in advance and bring any relevant supporting information, such as a list of medication or details of any current services in place. Remember that you have a choice over what support you provide so it is important to state clearly what you can and can't do.

If specific health needs are identified at the assessment, the assessor may arrange for your brother or sister to have a health needs assessment or a referral to another statutory service such as a mental health service. The assessor can also discuss a provisional support plan with you if they feel that the need for support is likely to be met by the local authority.

What happens after an assessment?

The assessor will present your brother or sister's assessment and proposed support plan to an assessment panel. The panel will decide whether your brother or sister has needs that are eligible for support and approve funding to meet these needs.

If your brother or sister does have eligible needs, a care and support plan must be written giving full details of the needs that meet the criteria, how and when their needs will be met and the amount of money available to arrange their care and support. As your brother or sister's needs will probably change over time, the care plan should be regularly reviewed and the care plan should state when that will be. A copy should be sent to your brother or sister or to you if they don't have the ability to understand this. If you are not happy with any aspects of the support plan, such as if there are unmet needs, request a further meeting with the social worker to discuss it.

Will my brother have to pay for his care?

There's no charge for a needs assessment, but care and support from the local authority may be means-tested depending on local criteria, meaning that your brother will have a financial assessment to see what he can afford to contribute towards the services to meet his needs. This will depend on his income, capital (such as savings and property) and which of the UK nations and local authority that he lives in. Only the person receiving the care is financially assessed, this does not include you or other family members, even if you are providing care and support for your brother. Make sure you ask for the eligibility criteria when the financial assessment is undertaken so that you know what is and isn't included.

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.

What kind of support could my sister receive?

The support your sister can receive and the charges that can be made for them will depend on which of the UK countries she lives in, the area she lives in, and what her eligible needs are. Some local authorities fund voluntary and community organisations to provide services on their behalf and these may be free of charge. Your sister may also be offered a direct payment to enable her to choose and buy services directly rather than have them arranged on her behalf by the local authority. Some examples of the type of support that people receive are:

- Help with cleaning, laundry and shopping
- A place at a day centre
- Home adaptations or equipment
- A care worker to assist with personal care at home
- Respite care
- Meal delivery
- Option to move out of family home to supported living or residential accommodation
- Support with or funding to take part in leisure or social activities
- Assistance with travel

What if I'm not happy with a decision made by the local authority?

In the last few years, many local authorities have made cuts to people's care budgets and the support available to them. This is a huge worry and strain for many siblings who are supporting their disabled brother or sister. As a result, some siblings have received a care and support plan following an assessment that does not fully meet their brother or sister's needs.

If you or your brother or sister are not happy with either the way the assessment was carried out, the detail in the support plan or the outcome of the assessment, try to discuss this with the local authority assessor first and clearly state why you are unhappy. Return to the list you made previously about your brother or sister's needs for support. Provide specific examples of their needs and the impact on their wellbeing if these needs go unmet and ask to see the criteria that your brother or sister is being judged against. Ask the local authority to put their decision in writing – this may be enough for them to review their actions and any decisions that were made.

If this does not resolve the issue, you can make a formal complaint in writing. Ask to see a copy of the local authority's formal complaints procedure – they have a duty to respond in line with this, for example, within a certain number of days. Read more about what the law says in your area about the local authorities' duty to provide care needs assessments and support for eligible adults.

If you are unhappy with the response following the formal complaint, you can take the issue to the local government ombudsman. An ombudsman is an impartial organisation that can investigate the complaints of individuals against organisations such as local authorities. If the local government has acted unlawfully, you may be able to take them to court for a Judicial Review, but you will need legal advice about this as there are specific time limits and processes involved.

Concerns or complaints about the care and support provided by a service that is not part of the local authority will need to be directed to the specific provider themselves, for example the home care agency or local charity. Ask for a copy of their complaint's procedure.

My sister isn't eligible for any support. What can I do?

Even if your sister is not eligible for support, the local authority should still provide you with further information on local charities and other organisations that can help your sister. These may well be free, so it is worth finding out what other local services are available.

You can also request a carer's assessment which will help to identify your needs as a carer. Even if your sister is not eligible for support, you may be. The support provided to you could include things like respite care for your sister, so that you can have a break from caring or a direct payment to spend on something of your choice.

If your sister has difficulty creating social networks, building a circle of support may be another way to help her. A circle of support is a group of people who meet regularly to help your sister achieve her goals. Members of the circle could include family, friends and people in your sister's local community. People in the circle have a genuine interest in your sister's wellbeing and are not paid to offer this support.

Some siblings use support brokerage services to help them outsource certain care tasks. A support broker has experience of the health and social care system and can carry out tasks on your behalf, such as making phone calls or writing letters. People may use a support broker on a one-off or continuous basis.

It's also worth bearing in mind that if your sister's needs change – for example due to ill health or aging – her eligibility for support may also change. You can then request a reassessment of her needs.

Find out more

Carers Trust

<https://www.carers.org/>

Carers UK

<https://www.carersuk.org/>

Disability Law Service

<http://dls.org.uk/>

Disability Rights UK

<https://www.disabilityrightsuk.org/>

Information on setting up a circle of support

<https://www.learningdisabilities.org.uk/learning-disabilities/our-work/family-friends-community/circles-of-support>

A guide to support brokerage

<https://www.disabilityrightsuk.org/short-guide-brokerage-and-role-brokers-relation-social-care>

England

Care Act 2014

<http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

Health and Care Act 2022

<https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted>

Local Government & Social Care Ombudsman – for complaints about local councils

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

Scotland

Public Bodies (Joint Working) Act 2014

<http://www.legislation.gov.uk/asp/2014/9/contents/enacted>

Carers (Scotland) Act 2016

<http://www.legislation.gov.uk/asp/2016/9/contents>

Scottish Public Service Ombudsman

<https://www.spsso.org.uk/>

Care information Scotland

<http://www.careinfoscotland.scot/>

Wales

Social Services and Wellbeing Act 2014

<http://www.legislation.gov.uk/anaw/2014/4/contents>

Public Services Ombudsman for Wales – for complaints about public services and independent care providers

<https://www.ombudsman.wales/>

Northern Ireland

More information on the several laws that underpin community care in Northern Ireland

<http://www.lawcentreni.org>

Department of Health NI

<http://health-ni.gov.uk/articles/community-care>

Northern Ireland Ombudsman

<https://nipso.org.uk/>

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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Email info@sibs.org.uk

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Tel 01535 645453

LinkedIn [company/sibs_2](#)

Mailing list sibs.org.uk/subscribe

Instagram [SibsCharity_uk](#)

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