



When your disabled brother or sister needs support: How to get a care needs assessment

A brief guide to **getting a care needs assessment** for adult siblings of people with lifelong learning disability and/or autism

Sibs is the UK charity for brothers and sisters of disabled children and adults
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What's in this guide about getting a care needs assessment?

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 how their brother or sister's needs are assessed.

This guide assumes that your disabled brother or sister is over the age of 18 as the assessment process is different for people under the age of 18.

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 – November 2018

Can my brother have an assessment of his care needs?

If your brother needs care and support because of his learning disability and/or autism, then the local authority has a duty to carry out an assessment.

Contact the adult social care department where your brother lives and request an assessment.

The local authority cannot refuse to carry out an assessment just because they don't think your brother or sister will be eligible for support or because they have a particular diagnosis.

What makes my sister eligible for support?

There are different laws in England, Wales, Scotland and Northern Ireland that underpin what support can be provided and what specific eligibility criteria are used. When you request an assessment, you can request a copy of the eligibility criteria that your sister will be assessed against.

Some local authorities may not provide support if they feel that the need is already being met by a family carer. At the time of assessment, be clear about what you can and cannot 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 has to do for your brother that they wouldn't do for another adult. If your brother is living in the family home and your parent is the main carer – ask them to keep a journal for one week noting every single task.

When you make this list, make sure that you:

- 1. Think broadly about tasks.** 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. For example, you talk to your brother in a calm voice whilst feeding him because you know that it eases his anxiety. This is two tasks meeting two different needs. Think about your brother's needs physically, mentally and emotionally. 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** - state exactly what the task is. 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 the time it takes** for someone to support your brother with a specific task. Saying 'he needs help to brush his teeth' will not describe the support needs adequately if this task takes half an hour to complete with supervision.
- 4. Make a note of the consequences** – what would happen if your brother didn't have the support that he needs? Think about this in terms of his safety, health, dignity and overall wellbeing. E.g. 'If I didn't call my brother to remind him to take his medication, 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 to dress warm 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)
 - Relationships (e.g. needs support to build friendships. Buys rounds of drinks for people openly - vulnerable to being taken advantage of)
 - Work (e.g. would like to volunteer at train station, needs support at each visit)
 - Accessing the community (e.g. becomes distressed in public spaces, needs two people to support)
 - Caring responsibilities (e.g. helps elderly mum with washing up and laundry but struggling to do so and needs more support)

It might feel unfair and highly negative to point out all the things your brother *can't* do – it's natural to want to balance this by highlighting his abilities. But this is exactly the point of the assessment – to identify what he can't do in order to look at the support he needs. 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.

What happens at a care needs assessment?

The assessment should be carried out face-to-face by a social worker from adult social care in a private space – usually your brother or sister’s home. Your brother or sister may be offered a telephone or online assessment. If they have difficulty communicating you can request a face-to-face assessment instead - an online or telephone assessment may not reflect the extent of their needs.

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 social worker all the things that someone else has to support your brother or sister with. Be absolutely clear about what would happen if your brother or sister did not get that support - 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. Remember that you have a choice over what support you provide - state clearly what you can and cannot do.

The social worker can also discuss a provisional support plan with you if they feel that the needs for support are likely to be met by the local authority.

If specific health needs are identified at the assessment, the social worker may arrange for your brother or sister to have a health needs assessment also.

What happens after an assessment?

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

If your brother or sister has eligible needs a care and support plan will be written, and a copy should be sent to your brother or sister or to you if they do not have capacity to understand this. This should reflect what was discussed in the assessment. It should list all of your brother or sister’s needs and how those needs are to be met. If you are not happy with any aspects of the support plan request a further meeting with the social worker to discuss it.

Will my brother have to pay for his care?

Care and support from the local authority is means-tested. Your brother will be assessed to see what he can afford to pay. What he will pay will depend on his income, capital (such as savings and property) and where he lives.

England - If a person has less than £14,250 in capital they will not have to contribute towards the cost of their care. If they have over £23,250 they will be required to pay for their care. If they have between £14,250 and £23,250 the local authority will carry out a financial assessment and they 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.

What kind of support could my sister receive?

Some examples of the type of support that people receive are:

- A place at a day centre
- Home adaptations or equipment
- A support worker to assist with personal care
- Respite care
- Meals delivered
- Option to move out of family home to supported living or residential accommodation
- Funding to do leisure or social activities

The support your sister can receive will depend on which of the UK countries she lives in, the area she lives in, and what her eligible needs are.

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.

Discuss the decision with the local authority 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. 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 change their mind.

If this does not resolve the issue, 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 country about the local authorities' duty to provide care needs assessments and provide support.

If you are unhappy with the response following the formal complaint, you can take the issue to an ombudsman. An ombudsman is an impartial organisation that can investigate the complaints of individuals against organisations such as local authorities. Read our guide "*What to do if your disabled brother or sister doesn't receive the care that they should: A brief guide to making a complaint*" for further advice.

My sister isn't eligible for any support – but we're still providing care for her as a family. What can I do?

Even if your sister is not eligible for support, the local authority should still provide you with further information on charities and local organisations that can help your sister.

You can also request an assessment of your needs as a carer from your local authority – remember to provide specific examples of every aspect of care you provide, how many hours of care per week you provide and what you need to support you 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.

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. Visit the links at the end of this document for more information on circles of support and support brokerage.

If your family has a special trust fund in place for your sister use some of this money to buy in support with care.

Remember 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 re-assessment of her needs.

Further reading on getting a care needs assessment

Further Sibs guides for adult siblings of someone with a lifelong learning disability and/or autism that cover topics such as mental capacity, finances, wills and trusts, challenging behaviour, making a complaint and managing care packages.

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

Disability Law Service

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

Disability Rights UK

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

Carers UK

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

Information on setting up a circle of support

<https://www.mentalhealth.org.uk/learning-disabilities/a-to-z/c/circles-support-and-circles-friends>

A guide to support brokerage

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

National brokerage network

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

England

Care Act 2014

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

Local Government Ombudsman

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

Scotland

Public Bodies (Joint Working) Act 2014

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

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

<http://www.ombudsman-wales.org.uk/>

Northern Ireland

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

<http://www.lawcentreni.org/EoR/community-care/introduction-to-community-care.html#Framework>

Northern Ireland Ombudsman

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

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.