

Sibs

For brothers and sisters
of disabled children and adults



Coping with managing care

A guide for adult siblings of people with lifelong disabilities

- Do siblings have to provide or manage care?
- What to do if you're burnt out from care giving
- Tips and advice on working with care providers

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 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.

More guides from Sibs

Other guides in this series include:

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

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

More support from Sibs

You're not alone! Did you know there are over 1.7 million adult siblings 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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My mum can't manage sorting out my sister's care anymore. I want to take this on, but I don't know where to start.

It can feel overwhelming when you're starting to think about providing more support as a sibling.

Here are some suggestions of what to do next:

- Start by talking to your mum and sister, and gathering key contacts that they have for professionals that might be regularly involved in your sister's care
- If your sister has already been assessed by adult social care, there should be a care plan detailing what her needs are and how the local authority will meet these. Get in touch with Adult Social Care in the area where your sister lives and let them know that you are now the main carer so that they liaise with you directly
- Contact your sister's GP and let them know that you are now the main carer, and ask this to be recorded on your sister's file
- Start seeking support as a carer. Join a sibling support group at www.sibs.org.uk/groups or find groups via your local carers centre. Ask the local authority for a carer's assessment (which is an assessment of your needs, not your sister's). You're not alone as a sibling carer and it's important that you start seeking out that support now to help you as you navigate through these first steps

Find out more

- Sibs guide - *Getting a care needs assessment*
<https://www.sibs.org.uk/guides>
- Join a sibling support group
<https://www.sibs.org.uk/groups>
- Carers UK – Having a carer's assessment
<https://www.carersuk.org/help-and-advice/practical-support/carers-assessment/>
- Carers Trust – Carer services near you
<https://carers.org/help-for-carers/carers-services-near-you>

There's no one else to look out for my disabled brother, so it's down to me. I really resent this situation and I don't want to do it. But if I walk away, I know I'd feel guilty.

You're not alone - many siblings in this situation experience resentment or guilt. It can feel like being between a rock and a hard place where neither choice feels like a good one. Some siblings feel torn, and angry that this is the life they have been given and that they have had no say about being in this situation.

A sibling might feel that it is automatically their legal responsibility as next of kin, to take on a carer's role once parents die. This is not the case. Siblings do not have any legal duties to care for their disabled brother or sister. It is your choice whether to become involved in your brother's care or not, and lots of siblings choose not to.

If you choose to be involved, it is up to you how much involvement you have. What tasks a sibling can and can't do needs to be a discussion between the sibling, their disabled brother or sister, and Adult Social Care. It's OK to have your own life.

Try and find a way that works for you without resentment. Do what you can. Don't feel guilty for saying no to tasks that you don't want to do, because in doing so you are taking care of yourself. In the long run, this is a much better decision for both you and your brother.

I want to keep overseeing my disabled sister's care, but I'm exhausted, and I need more support.

Sometimes a sibling becomes gradually more involved with their disabled brother or sister's care over time, taking on a few more tasks each year. The cumulative effect of this can take its toll and can be hard to spot at first. It is good that you have noticed this happening and that you're seeking support before things get more difficult.

As the saying goes, 'you must put your own oxygen mask on first before helping others with theirs'. You'll be unable to look after yourself, or anyone else, if you become burnt out and ill. Here are some suggestions:

1. **Make time for yourself.** Put things you enjoy on your calendar. Protect these times like you would a dentist appointment. Even if it is just 30 minutes reading a book – these breaks matter and the benefits add up over time. Don't cancel on yourself.

2. **Set boundaries** around care time. When you are the main carer for your brother or sister, it can feel like care tasks seep into every area of your life. Put boundaries around the time and the energy that you spend on care time. For example, allocate yourself a set number of hours per week towards care tasks or set a target of no care tasks after 7pm. This won't always work out, because emergencies happen. But if you keep aiming for it, you'll still have more time to yourself than you would have done.
3. **Keep relationships** going and have care-talk-free time with friends and family members, including your disabled brother or sister. This will help to give you a mental break from caring and will help to maintain your usual relationships. Be explicit and ask for support with this if you need to e.g. 'Let's talk about the hospital appointment for 15 minutes, then let's talk about...'
4. **Meet others sibling carers.** Join a [sibling support group](#) or [Facebook group](#), go to your local carers centre or contact a charity specific to your brother or sister's disability. Don't be isolated – the emotional support can really build your resilience and help to sustain you.
5. **Get more information** online. Health and social care topics can be complex and lengthy - search for a 'plain English guide' or an 'easy read guide' to find something more straightforward about a topic you've been looking for information on. Call advice lines (such as [Disability Rights UK](#)) if you have specific questions. Don't be afraid to ask, ask, and ask again. You won't be the first person to have asked the question and you won't be the last.
6. **Tell your GP** that you are a carer and ask them to record this on your file. Some GP surgeries will offer specific support groups or information events for carers. Others will allow you and your disabled brother or sister to book appointments together so that you don't have to make two separate trips to the surgery. Talk to your GP about any stress you are experiencing as a carer.
7. **Get a carers' assessment.** This is an assessment of *your* needs (not your disabled brother or sister's needs) from the local authority. They should look at what you need as a carer and what they can do to support you. Remember to provide specific examples of every aspect of care you provide and what you need support with. The support provided to you could include things like respite care for your brother or sister, so that you can have a break from caring.
8. **Get practical support.** Ask friends and family for help with specific tasks e.g. alternate the school run with a friend, freeing up your time to make an appointment for your brother or sister. Some people use support brokerage services to 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.

9. **Build a circle of support.** This is a group of people who meet regularly to help your brother or sister achieve their goals. Members of the circle could include family, friends, and people in the local community. People in the circle have a genuine interest in your brother or sister's wellbeing and are not paid to be there.
10. **Use technology** wherever possible. Keep a notes app and a calendar on your phone to help organise appointments and phone calls. Look into assistive technology that may help your brother or sister e.g. electronic reminders to take medication. *Jointly* is an app from Carers UK that can help a group of people to keep in touch, share information (e.g. list of allergies) and delegate tasks to manage a person's care. Research other solutions to care issues to see what is available.

I'm having a breakdown. I feel so guilty, but I just can't be a carer for my disabled brother anymore. Where do I go from here?

If your mental health is at risk, you must seek support from your GP as soon as possible. It's both common and unwarranted for siblings to feel guilt around their brother or sister's care – you're not alone but right now, your priority needs to be you. If you need space to talk, consider finding a counsellor too.

You should also contact Adult Social Care in your brother's local authority. Tell them that you are at breaking point and that you are no longer able to keep going in the caring role. Be specific about the caring tasks that you were doing and what support your brother will need now that you are unable to do this. They have a duty to assess this situation, so ask for an urgent reassessment of your brother's care needs as your situation as a carer has changed.

Find out more

- How to find a counsellor

<https://www.sibs.org.uk/findacounsellor>

My brother has autism and lives 180 miles away in supported accommodation. I keep telling the social worker that my brother needs more help, but I just get ignored. I'm so angry and frustrated. What can I say to get them to listen?

It's not surprising that you feel angry and frustrated, as this sounds like a relentless and exhausting situation. Siblings often feel that they must battle for the right care for their disabled brother or sister. Many siblings are supporting their disabled brother or sister over a distance and juggle repeated phone calls and emails with their own day-to-day lives – you're not alone. Here are some suggestions for tackling this:

1. **Be specific** about what help your brother needs. For example, don't say 'My brother needs someone to check in on him', say 'My brother needs reminding to brush his teeth and take his medication every day'. Read our guide [Getting a care needs assessment](#) for more advice.
2. **Make a complaint in writing** and be clear about the outcome you would like for your brother. Keep a record of your complaint and consider taking your complaint further if your complaint is not resolved. Read our guide [Making a complaint](#) for more advice.
3. **Don't let somebody tell you that you are not allowed to give your opinion as a sibling.** As a close family member with an active interest in your brother's wellbeing, your opinions on his care should be heard.
4. **Get support for yourself.** The phone calls and letters can feel endless at times – make sure you take some time out for yourself too and that you have your own life. You must look after yourself first to be able to also look after your brother.

Find out more

- Sibs guide - *Getting a care needs assessment*
<https://www.sibs.org.uk/guides>
- Sibs guide - *Making a complaint*
<https://www.sibs.org.uk/guides>
- Join a sibling support group
<https://www.sibs.org.uk/groups>

My sister's behaviour is challenging, and we have a high turnover of personal assistants (PAs) that we employ ourselves through direct payments. Where can I advertise and find more PAs?

Employing personal assistants for your sister through direct payments is a big task. There is a lack of PAs with the combination of skills, experience and qualifications to meet certain needs and it can be really tough to find the right person.

Skills for Care have produced a toolkit to help people to advertise, recruit and employ their own PAs, which includes letter templates and application forms that you can use. There is also an online hub for both individual employers and PAs to use. Disability Rights UK have information on employing PAs, including recommendations of websites to advertise on and your responsibilities as an employer.

Your local authority may have a direct payments advisor or a direct payments team. They may be able to advise on local places to recruit or have a local register of PAs. If there is a disability organisation or charity specific to your area, they may also have a list or register of PAs.

Some siblings use support brokerage services to help them recruit personal assistants. A support broker has experience of the health and social care system and can carry out tasks on your behalf, such as care staff recruitment and helping you find other local support services. People may use a support broker on a one-off or continuous basis.

Find out more

- A guide to support brokerage
<https://www.disabilityrightsuk.org/short-guide-brokerage-and-role-brokers-relation-social-care>
- A hub for people who employ PAs and people who are PAs
<https://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Information-hub.aspx>
- Advice on employing PAs from Disability Rights UK
<https://www.disabilityrightsuk.org/being-control-getting-personal-assistants-pas>

My brother lives in a residential home and the care can be inconsistent because there are so many staff – as well as agency staff over the bank holidays. I feel like I'm repeating myself all the time. How can I change this?

It can be really frustrating to have to micro-manage your brother or sister's care, and to repeat information to several members of staff because messages aren't getting passed on. Many siblings struggle with public holidays, when the usual carers aren't available, and they worry that some of their brother or sister's support needs will be missed or handled poorly. Here are some suggestions for handling this:

1. Focus on building a positive relationship with one or two members of the regular care team (it doesn't have to be the manager). It can really help to have someone who knows the family well and who is committed to passing on messages to other staff.
2. Put stickers or signs in prominent places around your brother's room that will help agency staff who don't know him as well as regular staff e.g. 'Tom needs encouragement to use his walking stick'.
3. If you call with a message that you would like all staff to know, ask this to be written in your brother's care folder.
4. If your brother has difficulty communicating, make a communication book that can be laminated and kept nearby, to help new or infrequent staff get to know him quickly. Make several copies of this, in case it gets lost.
5. If there is another friend or family member, ask them to drop in on your brother on a bank holiday for a social visit and to check that he is getting the care that he should.

If communication continues to be an issue in the residential home, arrange to speak to a manager about this and provide clear examples of times when it has impacted on your brother's care. Read our guide *Making a complaint* if you need to take this further.

Find out more

- Communication passport – example and template
<http://www.mycommpass.com/>
- Sibs guide - *Making a complaint*
<https://www.sibs.org.uk/guides>

My sister has frequent stays in hospital because of her epilepsy. I have to talk to hospital staff regularly and I'm tired of them using so much jargon.

It's exhausting to have to deal with so much jargon on a regular basis. *The Care and Support Jargon Buster* is an online plain English guide to the most frequently used health and social care words. You can search for a word or phrase and find out what it means. The definitions are in plain English rather than legal.

Health and social care staff sometimes forget that the words they are using are jargon – it's OK to remind them. Ask them to explain what they mean, and don't be afraid to ask several times if their descriptions are still not clear.

Find out more

- The Care and Support Jargon Buster

<https://www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/>

I am having difficulty with my brother's care home – I don't think they are taking my views seriously. What can I do?

Remember that as a sibling you have a lifetime of knowledge and experience that can be vital in supporting your brother or sister in their home. Sometimes it can feel challenging to get your views across. Here are some suggestions:

1. **Be confident.** You do have the knowledge, you do have the expertise and you have built up years of experience on your brother or sister's medical, behavioural, communication and personal needs.
2. **Build relationships** with the people who acknowledge and support you in your role as an advocate or carer for your brother or sister e.g. a strong relationship with an epilepsy nurse will be helpful if care home staff struggle to recognise seizures.
4. **Communicate clearly with managers** who are ultimately accountable for your brother or sister's care. If things go wrong, a good manager will take responsibility and work with you to make changes. Be assertive, not aggressive – this will get you better results.
5. **Be kind to support workers** as they have a difficult job and often receive little recognition for their role. Thank them when they go the extra mile. They will be more likely to do it again in future and build a positive relationship with your brother or sister.

6. Know the difference between a personal mistake and a poor culture. Mistakes will happen – we are all human. It's important to recognise the difference between a personal mistake that someone takes responsibility for, and an organisational culture of poor care, neglect or abuse. If the latter is in effect, take action and make a formal complaint and report safeguarding concerns.

7. There are ways you can be more assertive. You may find that it's difficult to put your point across when you're face-to-face with people. Send an email in advance or jot down relevant points to take with you. Take a friend and ask them to remind you of the points you want to make. Just having someone with you can boost your confidence to communicate your views. They can also help by taking notes of what was said in the meeting.

8. Know that you can change providers if the organisation does not meet your brother or sister's needs. Even if you have been told there are few providers in your area, it's important to tell adult social care that your brother or sister's needs are not being met by the current care provider.

Find out more

Taking action on safeguarding concerns

<https://www.sibs.org.uk/safeguardingadults>

Carers UK

<https://www.carersuk.org>

Carers Trust

<https://www.carers.org>

Jointly – an app from Carers UK

<https://www.jointlyapp.com>

Disability Law Service

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

Disability Rights UK

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

A guide to support brokerage

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

A hub for people who employ PAs and people who are PAs

<https://www.skillsforcare.org.uk/Employing-your-own-care-and-support/Information-hub.aspx>

Advice on employing PAs from Disability Rights UK

<https://www.disabilityrightsuk.org/being-control-getting-personal-assistants-pas>

Communication passport – example and template

<http://www.mycompass.com/>

Communities for sibling carers

Meet other siblings at a Sibs support group

<https://www.sibs.org.uk/groups>

Join #Sibliffe, Sibs private Facebook community for siblings

<https://www.sibs.org.uk/sibliffe>

Choice forum - the place to discuss issues affecting the lives of people with learning disabilities in the UK. Not specific to carers. Includes the PMLD network, events, resources and a vacancies board.

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

Mencap's Online Community – a place for family carers of someone with a learning disability to share experiences, advice and support. Includes a thread specifically for siblings to connect.

<https://www.mencap.org.uk/onlinecommunity>

Carers UK Carers Connect – an online community for all carers

<https://www.carersuk.org/get-involved/join-us/our-forum/>

Look for other online forums or Facebook groups e.g. ones specific to your brother or sister's diagnosis or for carers in your local area.

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

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](#).