



# Coping with managing your disabled brother or sister's care

A brief guide to **coping as a carer and managing care packages** for adult siblings of people with a lifelong learning disability and/or autism

Sibs is the UK charity for brothers and sisters of disabled children and adults  
Registered charity number 1145200. Limited company number 7834303.

# Contents

What's in this guide about managing care?.....	4
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.	4
I want to keep overseeing my disabled sister's care, but I'm exhausted and I need more support. I don't want to get to breaking point - what can I do? .....	4
I'm having a breakdown. I feel so guilty but I just can't be a carer for my disabled brother any more. Where do I go from here?.....	5
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? .....	5
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? .....	6
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?.....	7
My sister has repeated 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 – what do these words mean? .....	8
Top 10 tips for sibling carers .....	9
Further reading on managing care .....	11
Next steps in supporting yourself and your disabled brother or sister .....	13
Further support .....	13
About Sibs .....	13

## What's in this guide about managing care?

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 being a carer and managing care packages.

When we say a sibling is a 'carer', we mean that a sibling is doing tasks for their disabled brother or sister that they wouldn't do if there was no disability. Those care tasks might include liaising with adult social care, employing personal assistants (PAs), picking up meals, attending meetings or daily checks by phone. Some sibling carers live with or near to their brother or sister, others live further away.

You may also find it helpful to read our other 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 getting a care needs assessment.

Being a sibling can be a complex and challenging experience. You are not alone – visit [www.sibs.org.uk](http://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.

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.

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

It is your choice whether to become involved in your brother's care or not. If you chose to be involved, it is your choice how much involvement you have. What tasks a sibling can and cannot 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.

I want to keep overseeing my disabled sister's care, but I'm exhausted and I need more support. I don't want to get to breaking point - what can I do?

The health and social care system in the UK is complicated and very difficult to find your way around. It is also very underfunded at present and many siblings are experiencing a loss of services or less funding for their brother or sister's support. It can leave you feeling completely lost, exhausted and frustrated. The tasks involved in overseeing care can feel never ending – when one thing is sorted, another crops up. You are not alone.

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 effective

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 are seeking support before things get more difficult.

You might feel that you *have to* do certain caring tasks. But what you have to do is 'put your own oxygen mask on first'. You will be unable to care for your sister if you become burnt out and ill. Read our top ten tips for adult sibling carers (p. xx) and take action.

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

Go straight to your GP. Your own mental health is suffering and you need support and treatment. It's both common and unwarranted for siblings to feel guilt around their brother or sister's care – you're not alone. Right now, your priority needs to be you.

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 in your absence. They have a duty to assess this situation. Ask for a re-assessment of your brother's care needs as your situation as a carer has changed.

## 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 – this sounds like a relentless and exhausting situation. Siblings often feel that they have to 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 "*My disabled brother/sister needs support: 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 "*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 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 in order to look after your brother.

## 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. Go to the end of this document for direct links to these guides.

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

## 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 important information to several members of staff because messages aren't getting passed down. 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 or communication book.
4. If your brother has difficulty communicating, make a communication book (see link at the end of this document for template and example) that can be laminated and kept nearby, to help new or infrequent staff get to know him quickly.
5. Ask a friend or family member 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 "*Top tips for adult siblings on working with care providers*" and "*Care provider statement of intent to involve siblings*" for further advice with this issue. See 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*" if you need to take this further.

## My sister has repeated 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 – what do these words mean?

It's exhausting to have to deal with so much jargon on a regular basis. It can feel like an entirely separate language that you need a university degree just to understand, let alone speak.

*The Care and Support Jargon Buster* is an online plain English guide to the most commonly 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. Go to the end of this document for a direct link to the guide.

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.



## Top 10 tips for sibling carers

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 amount of hours per week towards care tasks or set a target of no care tasks after 7pm.
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, 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. If you can't meet people in person, look for others online – see the links at the end of this document.
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. Call advice lines (e.g. 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.

## Further reading on managing care

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 getting a care needs assessment.

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

Carers UK

[www.carersuk.org](http://www.carersuk.org)

Carers Trust

[www.carers.org](http://www.carers.org)

Jointly – an app from Carers UK

[www.jointlyapp.com](http://www.jointlyapp.com)

The Care and Support Jargon Buster

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

Disability Law Service

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

Disability Rights UK

<https://www.disabilityrightsuk.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/>

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>

A toolkit to help you employ your own PAs

<http://www.employingpersonalassistants.co.uk>

Advice on employing PAs from Disability Rights UK

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

Communication passport – example and template created by a sibling

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

### Online support

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 Family Hub – 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://community.mencap.org.uk/>

Carers UK forum – an online community for all carers (not specific to learning disabilities and/or autism).

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

SibNet – a closed Facebook group for adult siblings across the world to come together.

<https://www.facebook.com/groups/SibNet/>

*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 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](http://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](http://www.sibs.org.uk) Email [info@sibs.org.uk](mailto: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.