

Sibs

For brothers and sisters
of disabled children and adults



Future planning

A guide for adult siblings of people with lifelong disabilities

- Do you have a legal responsibility to care for your brother/sister?
- How can you plan for an emergency?
- What resources are available to help with future planning?

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 available in this series include:

- Behaviours that challenge
- Coping with managing care
- Decision-making
- 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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When my parents die, will I have to look after my sister?

Some siblings feel that after their parents die, they become 'next of kin' and have parental or caring responsibilities for their disabled brother or sister. This isn't the case. Siblings have no legal responsibility to provide care and support. It is your decision whether you become involved in her care or not.

The local authority has a duty to assess your sister's care needs, and to put support in place if she is eligible to receive it. They will only assess her finances – not yours. Your sister's benefits can be managed by the local authority and care arranged by a social worker.

Some siblings feel that the role of keeping an eye on their brother or sister is automatically left to them, upon the death of parents. Siblings may find themselves changing jobs or moving house, to live closer to their brother or sister. It's important to know that you do have a choice in the level of involvement that you have. Some siblings may choose to become very involved with their brother or sister's care, and others may choose not to – and there are many different levels of involvement in between. You have no obligation to have any contact with your sister if you don't wish to.

I want to leave home for university – but I'm afraid of leaving my mum to care for my disabled brother and my two younger sisters on her own.

Leaving the family home for the first time is a mixed experience for anyone. It can be even harder for a sibling, who may have additional worries about the care and support of their brother or sister. Whilst others may be worried about what course they'll choose or which university they would like to study at, siblings may be worried about who will help do the things they would normally do at home. It's common for siblings to worry about this – you are not alone.

It's important to remember that you need to make the best decision for you. If your brother needs more care and support, this needs to be assessed by the local authority. You have no legal responsibility to care for your brother. Staying at home to care for your brother – at the expense of leaving home to follow your own interests – may result in you feeling resentful towards him or your mum. If you choose to go to university, remember that:

1. **You can come back and visit.** When you do, you will be more likely to spend positive time with your brother and you will have new experiences to share with him.

2. **You can keep in touch.** If your brother can't keep in touch by phone, email, or video call – send something in the post that you know he will enjoy, such as a photo of you in your new accommodation, a postcard of the city or some treats, like chocolate.
3. **You can find support.** Connect with other siblings at your university, set up a support group and make new friends. You are not alone in feeling this way.

My sister has Down's Syndrome and lives with our parents. I think she could live on her own and I want to help her move out and be more independent. Where do I start?

Siblings often grow up alongside each other. When you hit certain milestones (such as leaving home), it's natural to want this for your brother or sister too. In a family, it's often a sibling who notices this and advocates for this first, as siblings sometimes have a different perspective to parents, grandparents and other relatives on their brother or sister's abilities. Here are some suggestions of where to start:

1. **Talk to your parents and your sister.** This might be together, or separately. What are their thoughts and feelings about this? What would your sister like to do?
2. **Moving out is about much more than housing.** Use a planning guide (see below) to help you all think about the other aspects of your sister's life, such as finances, healthcare and social support too.
3. **Contact Adult Social Care and ask for an assessment of your sister's needs,** explaining that you are working towards her moving out of the family home. Read our guide *Getting a care needs assessment* for more information on this.

Find out more

- Together matters *Thinking Ahead: A planning guide for families*
<http://www.togethermatters.org.uk/planning-the-future/>
- Sibs guide - *Getting a care needs assessment*
<https://www.sibs.org.uk/guides>

I'm worried about my sister's future care, but my dad refuses to discuss it. How do I get a conversation started?

It is very common for siblings to have significant and continued worries for their disabled brother or sister's future care – such as where they will live, who will look after them and how they will manage financially. When you raise these worries with parents it can be painful to have them ignored. It leaves you with practical questions unanswered and an emotional burden unshared. It often heightens and prolongs the worry – which may be at the forefront of your mind or quietly eating away at you in the background.

If your sister is still living with your dad – and always has done – it may be very difficult for him to imagine a time when she will not be there. The transition of moving from the family home to another setting is incredibly emotive. Talking about it forces parents to consider their own ageing process and their own mortality. This may be too difficult for your dad to consider at the moment and may be why he avoids the subject. Approaches you can try are:

1. **Little and often.** There is a lot to consider with future care so break it down into small chunks. For example, ask your dad one question per week. Take care over the time, place, and way that you bring up the topic. Change takes time. Try this over the course of a month or two.
2. **Come back to it later.** If you feel the little and often strategy isn't working, wait a while before raising the topic again. This may feel counter-intuitive and exactly the situation you are trying to avoid - but your dad may be thinking about what you've said and just needs time to work out what he feels before talking to you about it. It may be easier to engage your dad in a discussion when there has been a change in the situation e.g. your sister's needs have changed, or your dad's ability to cope or provide care has changed.
3. **Identify someone else who can raise the issue.** There may be someone else who can start the conversation with your dad - another sibling, another relative or a trusted professional. They may be able to raise the topic whilst you are with your dad, or they may be able to persuade your dad to talk to you about it.

Even if your dad can't engage with this topic, it doesn't mean you should bury your questions and worries. Write down all your concerns and all your wishes. What would you like for your sister in the future? How much involvement would you like in her life and in what ways would you like to have this? You don't have to have definite answers – you just need to give yourself space to think about it. Talk to a trusted friend, do research online or seek counselling. When the time comes, hopefully you will be able to share this with your dad.

My Mum and I look after my autistic brother, but I'm worried about what we would do in an emergency, as we don't have anyone else who can help us.

You're not alone in worrying about this, as many siblings (and their parents) have no one else to turn to in an emergency situation. It can be frightening to think about and you may be especially worried about how your autistic brother would react to such a situation. It's good that you've thought about this now. There are some practical measures you can put into place now that will give you peace of mind. Creating an emergency plan with your mum is a really good way of considering all the potential options you might face. These could be:

- What would be an emergency for your caring situation?
- What can you do to prevent these things happening?
- What needs to happen if you can't?

Some options for next steps are:

- If you and your mum are employed or in education, tell your employer/place of education that you're both carers for your brother. You're entitled to time off from work in a caring emergency. Letting your employer/place of education know now that you have these responsibilities could make the conversation about emergency care easier and less stressful if and when it happens
- Contact your local authority and ask for a Carer's assessment. Tell them specifically that you'd like to look at emergency planning too, as some local authorities have specific services to provide care in emergencies. This gives you the opportunity to discuss whether these would be right for your brother in an emergency situation

You can also start writing down an emergency plan of your own. Your plan doesn't have to be very complicated, in fact, the clearer the better so that whoever needs it can get to the most important information quickly.

Some basic information to include in your plan:

- Name and contact details for you, your mum and brother (include any work or college/university contact details too)
- Are there any friends or neighbours that have a key to your home? List them here. An alternative to a friend or neighbour holding a key, is to install a keysafe outside your home. This is a small box that holds a key and is unlocked with a 4 digit code. In an emergency,

you could give the code to someone so that they can access your home. You can change the code afterwards

- Your brother's health information (including any medication), key professionals involved in his care, any day services/places of work or volunteering and any communication needs. You could consider using a communication passport (see examples at <https://mycommpass.com/>). If you or your mum have deputyship or power of attorney for your brother, list this here too

Keep your plan somewhere that's easy to access in your house, such as in the kitchen. The Lions Club has a free scheme called 'Message in a Bottle' which is a method of recording emergency information inside a plastic container (which could then state that a more detailed plan is available and where that is kept), that is kept in the fridge with an accompanying green sticker for the front of the fridge. Emergency services know to look for this.

Other useful tools in an emergency:

- Most smart phones have a feature for you to add two or three emergency contacts and your own medical information. These can usually be accessed without unlocking the phone. If you don't have a smartphone, store the number as 'ICE' (In Case of Emergency) followed by the person's name, as emergency services know to scroll and look for this
- The free app 'What Three Words' can pin-point your location within 3 metres, and allocate a three-word code to this location. This is useful if you live or regularly visit rural areas. If you urgently need to call an ambulance but can't describe your location, open the app and read the three words to the call handler

You could also use a planning guide to help you write your emergency plan (see link below). It may seem like a daunting task, but going through this process in advance will make dealing with an emergency easier and may even prevent one from happening.

Find out more

- Together matters *Making a plan for emergencies*
<https://www.togethermatters.org.uk/making-a-plan-for-emergencies-rewritable-version-pdf/>
- How to make and use a communication passport
<https://mycommpass.com>
- Lions Clubs – message in a bottle scheme
<https://lionsclubs.co/Public/>
- What Three Words app
<https://what3words.com/>
- Carers UK – carer’s assessment
<https://www.carersuk.org/help-and-advice/practical-support/carers-assessment/>
- Carers UK – time off work in urgent situations
<https://www.carersuk.org/help-and-advice/work-and-career/your-rights-in-work/taking-time-off-when-needed/>

My parents have died and there's only me looking out for my sister who has profound and multiple learning disabilities. I'm worried about what will happen to her when I die.

You're not alone. This is a huge fear shared by many siblings in similar situations and it can be really difficult to face. Here are some suggestions for managing this:

1. Make a list of all your worries. Don't censor yourself, let everything come out.
2. For each worry, circle the ones that you *can* control.
3. For each worry that you can control, think about what you can put in place *now* that might help you to feel a little more reassured about your sister's future. Use the planning guide below to help you.
4. Recognise that there will be things on your list that you can't control – much as you desperately want to! You just want your sister to live a safe and happy life and that's not a lot to ask. If you find yourself [worrying excessively](#), please [find a counsellor](#) and seek help with this.
5. Consider joining a sibling support group or sharing your worries on our private Facebook community, #Siblife. There are many siblings out there in your situation – and they 'get it'.

Find out more

- Together matters *Thinking Ahead: A planning guide for families*
<http://www.togethertatters.org.uk/planning-the-future/>
- Coping with feelings
<https://www.sibs.org.uk/copingwithfeelings>
- Find a counsellor
<https://www.sibs.org.uk/findacounsellor>
- Join a support group
<https://www.sibs.org.uk/groups>
- Join Sibs private Facebook community, #Siblife
<https://www.sibs.org.uk/siblife>

Find out more

Together matters *Thinking Ahead: A planning guide for families*

<http://www.togethermatters.org.uk/planning-the-future/>

Together matters *I'm Thinking Ahead: A planning guide for people with learning disabilities*

<http://www.togethermatters.org.uk/planning-the-future/>

Together matters *Making a plan for emergencies*

<https://www.togethermatters.org.uk/making-a-plan-for-emergencies-rewritable-version-pdf/>

Challenging Behaviour Foundation *8 ways to get a house*

<https://www.challengingbehaviour.org.uk/information-and-guidance/housing-education-leisure/8-ways-to-get-a-house/>

Taking action on safeguarding concerns

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

How to find a counsellor

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

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.

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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](#).