



Thinking about the future

A brief guide to **thinking about the future** 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
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Contents

What's in this guide about thinking about the future?	3
I'm worried about my sister's future care but my dad refuses to discuss it. How do I get a conversation started?	4
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.	5
When my parents die, will I have to look after my brother?	6
I don't know whether to have children of my own	6
Further reading on thinking about the future	8
Next steps in supporting yourself and your disabled brother or sister.....	9
Further support	9
About Sibs	9

What's in this guide about thinking about the future?

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 their future – which are some of the most frequent we receive.

You might be worried about your own future or your brother or sister's future. These worries may have been in the back of your mind for a long time or may have appeared fairly recently. Sometimes there is a change in the family – such as a parent becoming ill – that triggers siblings to think more about the future.

You might have a lot of different questions about the future and it can feel overwhelming at times. 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.

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 year.
2. **Come back to it at a later date.** 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 people take action in their lives for different reasons. 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 isn't able to engage this you on 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 have to give yourself space to think about it. Talk to a trusted friend, do research online or seek counselling – ask your GP to refer you. When the time comes, hopefully you will be able to share this with your dad.

Some siblings may find *Thinking Ahead: A planning guide for families* helpful when thinking about their brother or sister's future care. Visit the links at the end of this document to download the guide. There are also further guides for adult siblings on topics around future planning (e.g. wills and trusts) on Sibs website.

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 will choose or which university they would like to study at – siblings may be worried about who will help their mum to brush their brother's teeth every night. 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.

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 isn't able to keep in touch by phone, email or Skype – send something in the post that you know he will enjoy, such as a photo or a bar of 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.

When my parents die, will I have to look after my brother?

No. You have no legal responsibility to care for your brother. It is your decision whether you become involved in his care or not. The local authority has a duty to assess your brother's care needs, and to put support in place if he is eligible to receive it. They will only assess his finances – not yours. Your brother'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, in order 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 brother if you don't wish to.

I don't know whether to have children of my own.

Adult siblings are often concerned about the genetic implications of their brother or sister's condition. Siblings also know first-hand how challenging parenting a disabled child is and many feel that they would not cope. It is also because they know that the current level of support for disabled adults in our society is not good enough. Adult siblings who explore this issue do not undervalue the lives of disabled people.

Genetic counselling

If you have any concerns at all about your brother or sister's condition being genetic, you can visit a genetic counsellor. This is a trained medical professional with knowledge of genetics. They will help you find out about any genetic basis for the condition, and signpost you to support about any related emotional or ethical issues. The decisions you make as a result are yours (and your partner's); you will not be told what decisions to make, but be given information to help you make decisions that are right for you. Visit your GP and ask to be referred for genetic counselling.

Talking to partners about children

Many adult siblings say that they need to make sure that their partner is fully aware of the implications of disability for having their own children. Have open and honest discussions about your feelings and views. This will help you find out if you have shared values about having children and about disability. Here are some suggestions for topics to cover in your discussions about having children together:

- Share openly any concerns or fears you may have about having children due to your family history.
- Talk about the decisions you would make about having pre-natal testing and what action you might take if the testing identified disability or serious illness.
- Talk about your values in relation to disability so you can learn what values you share and those that you don't.
- Discuss how you would deal with things or cope if you had a disabled child – it is important to remember that for many conditions your risk will be the same as for everyone else in the population and that disability can be acquired in childhood.
- Share the positive things you have learned from growing up in your family that will give you a head start as a parent – such as understanding behaviour and communication, being able to cope in a crisis and being able to keep things in perspective.
- Discuss all the other options to becoming a parent, including adoption and fostering; parenting children who may have come along with your partner; assisted reproduction e.g. egg donation.

Give your partner time to ask questions, time to think about the things you have discussed, and respect their way of seeing things. For some partners there may be a lot of new information to take in and they may need time to reflect on it before making any decisions.

Spend time thinking about it by yourself

Ask yourself these questions:

- What would having children of my own give me in life?
- What feelings and experiences would I expect to have through being a parent?
- What other things could I do in my life to bring me some of these same feelings and experiences?

We acknowledge that there are no easy answers here for siblings on this issue, however talking about it to partners and to other adult siblings can really help overcome the sense of isolation often felt by siblings about this.

Further reading on thinking about the future

Thinking Ahead: A planning guide for families

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

Adult sibling support groups

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

Further guides for adult siblings

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

Directory of private counsellors and therapists

<https://www.bacp.co.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.