

# Sibs

For brothers and sisters  
of disabled children and adults

# Self-care for siblings

An eBook for adult siblings in the UK  
who have grown up with a disabled  
brother or sister

- Recognise your sibling experiences
  - Take care of yourself
- Have a choice in the role you play in your brother or sister's life

# Contents

Acknowledgements .....	2
Welcome.....	4
Being a sibling .....	7
Your feelings .....	11
Your mental health.....	32
Childhood experiences .....	40
Thinking about the future.....	51
Your relationship with your parent(s) .....	56
Your relationship with your disabled brother or sister(s) .....	62
Having your own children.....	68
Your own family life.....	71
Being a sibling carer.....	76
Siblings and work .....	85
Bereavement.....	88
How to find a counsellor .....	95
About Sibs .....	98

## Disclaimer

We have made every effort to ensure that the information in this eBook 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 eBook.

## Copyright notice

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without the prior permission of the copyright owner. All text and graphics © Sibs 2020. Version 1.

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

# Acknowledgements

This eBook was written by siblings, for siblings. Sibs would like to thank all the siblings who generously shared their personal experiences and advice, all those who completed our online consultation survey and everyone who lent a keen eye during the review process. Without you, this eBook would not have been possible.

## A note from Clare Kassa

At Sibs we have long recognised that adult siblings struggle to put themselves first and take care of their own needs and wellbeing. Adult siblings who have grown up with a disabled brother or sister have a wealth of strengths and skills – resilience, adaptability and problem solving to name but a few. However, many adult siblings struggle to get their own needs for support and care met as they navigate the complex emotional journey of siblinghood. I hope this book will be a companion to you and a resource you will revisit often as a sibling health check.

I am deeply grateful to Frances Danylec who has written and co-ordinated this book with such care and understanding. We hope that you will find comfort and support in its pages alongside lots of practical advice.

Chief Executive, Sibs

# Welcome

*"My whole world has always revolved around my brother and what he needs. I think I forget that I even have needs sometimes" – Sibling*

## Who is this eBook for?

This eBook is for adult siblings who have grown up with a disabled brother or sister.

Being a sibling can be a complex and challenging experience – you are not alone. There are an estimated 1.7 million adult siblings in the UK, some who will have two or more disabled brothers and sisters.

*"Siblings are a lost group. We are accustomed to existing in the shadows of someone we love who has more urgent needs." – Sibling*

Your experience as a sibling isn't limited to your childhood – it will affect you across your lifespan. Many siblings have positive experiences and develop a range of skills and qualities as a result. Many siblings have also experienced significant challenges and these may have affected their wellbeing and life choices. That's why we've written this eBook.

## How can this eBook help me?

We hope this eBook helps you to:

1. Recognise that you're not alone. There are millions of other siblings who have similar experiences to you.
2. Make time for yourself and look after yourself. We want to give you self-care ideas that might be especially important for you as a sibling.
3. Take things further if you need to. This eBook is just a starting point. If you need more support – whether that's counselling, a carers assessment from adult social care or an appointment with your GP – we hope that this encourages you to get the help you need.

We don't expect that you'll find every section relevant to your personal circumstances, as siblings vary so much. We hope that this helps you to realise that you are valued as a sibling and that you matter.

## What is "self-care"?

"Self-care" means looking after yourself. It means things you can do - often by yourself - that will have a positive impact on your mental or physical health.

Examples of adult sibling self-care might include:

- Turning your phone off for 20 minutes while you read a magazine that you enjoy, so that you won't be interrupted by your sister calling to ask you something
- Booking yourself that GP appointment to talk about the neck pain you have been putting off for weeks, despite the fact that you have booked your brother a GP appointment
- Asking your parents to phone you once a week, rather than every day, because you find listening to their worries about your sister's care distressing

"As a child, I got very little sleep. My autistic brother was up and down in the night, banging his head, hitting things... As an adult, my sleep is really important to me and I make sure I get as much as I need, no matter what!" -

Sibling

We've included self-care tips throughout this eBook. Not all will apply to all siblings - pick the ones that feel relevant to you.

## Why is self-care important for me as a sibling?

It's likely that you have experienced a lifetime of your needs coming second (or third, or fourth) to other people's. Or your needs may not have been met at all in some situations. For this reason, it can be particularly hard for siblings to meet their own needs (such as to get enough rest, to do something they enjoy, to say no when they need to). But self-care is not a self-indulgent luxury. It is an absolute necessity:

- You need and deserve to put yourself first, because you matter and you are important in your own right
- If it helps you to have a second reason, remember that you also need to put yourself first so that you can be there for others

What happens if you don't look after yourself? Here are some common examples:

- You don't turn your phone off while you're trying to read a magazine. You snap at your sister when she calls because you are frustrated and you're not getting

enough time to yourself (*self-care – she can wait 20 minutes. You know that in this period of time, she is still safe*)

- You don't book yourself a GP appointment for the neck pain you've been having, but you book all of your brother's instantly without fail. You're upset that you miss your child's play because you're in too much pain to go (*self-care – if you would do it for your brother, do it for you too. Make sure you get the healthcare you need*)
- You don't feel able to ask your parents not to call you everyday, so you go to bed most nights full of their worries about your sister. You're repeatedly late for work because you haven't slept well. You feel like you're letting your colleagues down (*self-care – you deserve mental time and space to yourself. It's OK to say 'No' to your parents*)

Self-care is a starting point. If you need further support – such as counselling, a carer's assessment from adult social care, or an appointment with your GP – make sure you get this.

## We know it is harder than it looks

All of the tips, advice and suggestions in this eBook are given with the best of intentions. We do not give them flippantly, expect them to be easy or expect that they will be immediately available to everyone. We acknowledge that self-care and accessing further support can be hard.

## What's not in this eBook?

This book is about you and your experiences. It is not about the care and support of your disabled brother or sister. This is why it doesn't cover practical topics about their care, such as mental capacity, managing finances and getting a care needs assessment. If you need information on these topics, have a look our [guides for adult siblings](#).

You must 'put your own oxygen mask on first'. Self-care is not an optional luxury, it is an absolute necessity. You will be unable to care for your brother or sister if you become burnt out and ill.

# Being a sibling

*"When you meet another sibling, there's so much you don't have to explain about your life." – Sibling*

Like many experiences, being a sibling to someone with a disability will have shaped who you are. You'll have grown up with different day-to-day experiences to your peers, and this will affect the way you see the world today. You might have thoughts, worries or plans for the future that include your disabled brother or sister. Siblings' experiences will vary a lot, and you might identify with none, some or all of what is listed below. What's important is that you recognise and acknowledge your *own* experiences. Why? It can be helpful to recognise your sibling experience because:

- It's probably formed part of your identity as a person, so it's good to acknowledge all of who you are
- It may help you to feel less alone knowing others have experienced similar things
- Feeling less alone might help you to feel more resilient when facing challenges ahead
- It feels good to celebrate and smile over the successes and happy moments
- It can help you to come to terms with unresolved issues

"I thought, there were absolutely no positives to being a sibling, it's all been an overwhelmingly negative experience. But when I thought about it a bit more, I had to admit that it has probably made me a 'better' person in some ways; I am more empathic, more open minded and accepting, and more aware that other people have hidden problems too, than I would have been otherwise." – Sibling

Read some of these experiences and see what feels like 'you'.

## Unique positive experiences

Many siblings recognise that having a disabled brother or sister has brought them unique positive experiences not shared with their peers. Some examples include:

- Having a strong and meaningful bond with your brother or sister that others can't relate to
- Being the one who 'just knows' your brother or sister best, and who is able to communicate with them like no one else can
- Becoming closer with other family members as a result of the challenges you've faced and how you've overcome them together
- Sharing humour with your family about some of your unusual experiences together
- Having a deep insight into the lives of disabled people and using this to campaign and influence service provision
- Having a deep insight into the human condition and empathy with others

## Sibling strengths

What strengths have you developed as a result of being a sibling in adulthood? What skills did you learn at an early age, years before your peers? Here are a few common examples:

"Being a sibling has shaped my career, shaped me as a parent and shaped me as a person." – Sibling

- Having developed skills and knowledge through your sibling experiences in areas such as psychology, social care, teaching, communication, assertiveness and campaigning
- Bringing the above skills to your work life and providing an excellent and compassionate service as a result
- Working directly in health and social care, special needs education or the voluntary sector and having excellent insight into the needs of family carers and the reality of disability within that role
- Being a passionate advocate for disabled people
- Having strong skills in parenting and behaviour management
- Appreciating your own health and opportunities and making the most of them
- Having quite a mature attitude at a young age
- Taking a practical approach to most tasks and finding it easy to 'get on with things'
- Having a very wide perspective on the ups and downs of life – your version of a 'bad day' might be quite different from a friend's and you might be unfazed by most common life challenges
- Being able to listen empathetically and support others emotionally



## Significant challenges

A lot of siblings will have faced some really tough times growing up and will continue to do so as adults. You might find it easy to put your finger on these, or you might find them hard to talk about.

You might have experienced challenges such as:

- Difficult feelings - resentment about the impact of disability on childhood and life choices; guilt for feeling anger or resentment; feeling unworthy of getting attention in your own right (read more in 'Your feelings' p.11)
- Unresolved childhood issues – traumatic experiences relating to brother/sister; parts of childhood lost to giving care; home life being different from peers (read more in 'Childhood experiences' p.40)
- Worry about the future – where will your brother/sister live, who will support them, what will your role be (read more in 'Thinking about the future' p.51)
- Relationship with your parent(s) - feeling that your brother or sister still comes first all the time, even in conversation; providing ongoing emotional support for parent(s); anger towards your parent(s) that you have not been able to express (read more in 'Your relationship with your parent(s)' p.56)
- Relationship with your brother/sister(s) - struggles with challenging behaviour; time spent together is only on care-giving; feeling like the relationship is one-sided – (read more in 'Your relationship with your disabled brother or sister(s)' p.62)
- Deciding whether to have your own children – considering whether genetic conditions may be passed on; worrying about the possibility of having a disabled child and parenting them (see more in 'Having your own children' p.68)
- Your own family life – balancing time with your brother/sister and time with your own family; partners and friends not understanding life as a sibling (see more in 'Your own family life' p.71)

"I'm one of five siblings, I have a brother with Down syndrome and a sister with Autism. Growing up in a big noisy household, there was always a lot going on. It's definitely shaped who I am. I find that I still need a lot of noise! I like chaos!!" – Sibling

"Write a list of all the things that are positive for you, no matter how small. Keep it somewhere you can see and look back at this when things are tough. It can be easy to forget the good things when things aren't going well." - Sibling

- Being a carer – wanting to make sure your brother/sister is safe and has a good quality of life; challenges of liaising with adult social care; carer stress (see more in 'Being a sibling carer' p.76)
- Work – telling your employer about caring responsibilities; juggling work and sibling life (see more in 'Siblings and work' p.85)
- Bereavement – loss of brother/sister in childhood or adulthood; having to support parents through the loss too (see more in 'Bereavement' p.88)

"I don't wish that he didn't have a disability. I wish that we'd had more support" – Sibling

"My parents never talked about my sister's future, never talked about her challenging behaviour, never talked about how we were feeling. We all just put our heads down and got on with day-to-day life. I thought that other families must be dealing with this better and that ours was weird. But when I read about other siblings, I realised we weren't alone in how we were coping with it and actually...that made me feel so much better" - Sibling

# Your feelings

*"I was always the one that was 'fine' and I became numb to most of my feelings" - Sibling*

Feelings are a natural way of our mind and body telling us that we need something. Feeling irritable might be a sign that we need more sleep, feeling stressed might help us to re-assess our priorities and laughing with a friend tells us we need human connection. It makes sense to acknowledge, listen to and respond to our feelings in the right way for us.

Feelings aren't always straightforward, and sometimes what you *know* and what you *feel* might be two different things. For example, you might *feel* hurt because your brother doesn't ask how you are, even though you *know* that he doesn't ask how anyone is. Feelings can also be very mixed and layered. For example, you might then feel guilty for feeling hurt and for expecting your brother to ask how you are! All of this is normal as a sibling.

Adult siblings might have difficulty acknowledging the full range of their feelings, because of experiences in childhood that influenced this. For example:

- Feelings were overlooked by parent(s) whose focus and attention was on the disabled child
- Some feelings were rejected by parent(s) (such as expressing anger or dislike towards disabled brother or sister)
- Some feelings were accepted by parent(s) and encouraged (such as looking happy, being able to cope)

*"I was expected to get on with things and not to show any emotion or upset; I was expected to excel at school and not be any trouble." – Sibling*

When a parent directly (such as 'You can't say you hate your sister!') or indirectly (such as looking relieved when you smile and say that you're 'fine') accepts or rejects your feelings as a child, you learn from this and may carry it into adulthood.

Adult siblings might also find it difficult to express feelings because:

- Sibling experiences are not understood in wider society
- Complex and mixed feelings can be difficult to explain or express such as grief following the death of your brother mixed with relief that you will not have to provide care for him in future

Your feelings as a sibling matter. It is important to acknowledge your feelings because they will not disappear if you ignore them. Having a full range of feelings - even ones that you might not like or find difficult - is part of being human and is not a personal fault.

Adult siblings - like anyone - will experience a full range of feelings. Some however, are particularly common:

- Guilt
- Worry or anxiety
- Anger
- Resentment
- Ongoing grief
- Strong connection and love
- Disconnection
- Loneliness
- Mixed feelings
- Shame

## Guilt

Guilt is the feeling that you have done something wrong. For siblings, this is often something they think they should do or feel about their brother or sister. Feelings of guilt may have come from what they believe their parents and other adults have expected of them during childhood.

Siblings may feel guilty that they don't have the disabling condition but their brother or sister has; that they have uncaring thoughts about their brother or sister; that they haven't spent much time with their brother or sister; that they have resented the impact

"Try to accept all your feelings without judgement. It's understandable to feel angry, proud, resentful, joyful, jealous, loving, hating - anything. Feeling something doesn't make you a 'bad' or a 'good' person. No feelings are 'off limits' - remember this." -  
Sibling

of disability on their lives; or that they have not helped parents as much as they feel they ought to. These are all normal feelings for siblings to have.

Sometimes siblings try and numb feelings of guilt with food, alcohol, shopping or being excessively busy. If this is you, tune in to when and why you are doing it and try out the suggestions below instead.

## Ways of dealing with guilt

1. Acknowledge the feeling for what it is:
  - a) Have you really done something wrong? Is this really a justifiable feeling or is it something like you used to feel as a child?
  - b) Acknowledge that certain things that have happened are not your fault. For example *'I feel guilty that my sister grew up in an institution. I was not involved in that decision as I was a young child. It is not my fault that she had a hard time there.'*
2. Do something about it:
  - a) The feeling of guilt may be telling you that there is something you need to take some action on. What you do will depend on the circumstances. For example, you may feel better if you simply make a decision to visit your sister twice a month, rather than feeling that you should go every week but don't actually do it. Put the dates in your diary.
  - b) Is there something you have been putting off and just need to go and do? For example *'I have been intending to find a befriender for my brother for the past year and I've done nothing about it except feel guilty that he has no friends. I will spend 30 minutes on the internet on Wednesday night getting contact numbers for local services.'*
3. Practise saying no. People may feel guilty because they have always felt that way whenever they have not done something for someone. This can be especially the case if a parent asks a sibling to support their brother or sister in some way and the sibling is not able to or doesn't want to do it. Learn how to say no to requests from other people for small things first. When you practise this, you will find that the world does not come to an end and people will respect your position. It is

"There were certain emotions I was experiencing that I thought were abnormal. But being in a room filled with other siblings at a support group and having a judgement-free open space to talk about things has made me realise that my feelings are entirely normal." - Sibling

likely to make it easier for you to feel comfortable about saying no to parents or to your disabled brother or sister's demands.

4. Reframe how you view things.
  - a) Recognise that other people's expectations of how you should behave as a sibling are simply that – their expectations. How do *you* want to be as a sibling? What is realistic for you given the other commitments you have?
  - b) How can you think about an experience in a positive way rather than in a guilty way? For example *'I used to feel guilty about being able to go away for the weekend. Now I go and enjoy it and know that when I come back I will feel refreshed and energised and that my good mood will be good for people who are around me, including my disabled sister. Taking time to do things I enjoy will be better for everyone.'*
  - c) Forgive yourself for things that are in the past and accept those things that simply can't be changed. Just let go of things that you really don't have any ability to change. *'I used to pretend that I didn't have a brother and never mentioned him at school. I felt bad about this for years. That's what I needed to do as a child. I don't need to do it anymore. I don't need to feel guilty about this. It's just a way for a child to cope.'*
5. Have a rule about not feeling guilty.
  - a) Learn how to do things that are just for you and when you do, fully enjoy them and say that you will not feel guilty during this period of time.
  - b) You have a life that is about other people and other experiences that are not to do with your brother or sister. Allow yourself to see that these things are really important too, and it is OK to do things like give priority to your partner or your own children.
  - c) If you find guilty thoughts creeping in, write them down so you can get on with what you are doing, and then have a set time each day when you read them and deal with them in one of the above ways.
  - d) If you find that guilty thoughts are a major problem in your life you may need help from a counsellor with this – talk to your GP.

"I have a lifetime of guilt! All the things I can do that my sister can't do... I feel like I have to live life to the fullest, for the both of us." - Sibling

"Finding out that 'sibling issues' was a known concept and that there were resources around to help me (and others) was a great relief but it took over 40 years for me to access them." - Sibling

## Worry

Adult siblings can worry about a whole host of things such as the future, being able to cope with care tasks, genetic issues, their parent's health, and the wellbeing of their disabled brother or sister. Worry may also have become a habitual way of thinking for some people. If we think of worry as a prompt to do something, this can help us to deal with it, rather than be overwhelmed by it. Many siblings find that all their worries merge into one large impossible mass of anxiety. If worry takes over and you feel anxious most of the time, speak to your GP.

Ignoring worry doesn't make it go away. Give yourself the time and space you deserve to work through your worries using the strategies below.

## Ways of dealing with worry

1. Write all your worries down using the grid on the next page.
2. Put each worry into one of the following categories:
  - a) Things that are never going to happen or are very unlikely to happen – for example, a meteorite falling on your house, thinking that you will get the same condition as your brother or sister.
  - b) Things you don't like but you cannot change and other people cannot change either like the weather, your brother or sister's disability, your own parent getting older.
  - c) Things that can be sorted out by other people or organisations – such as asking a psychologist to check on your brother or sister's mental health, getting your parent to go for a check-up.
  - d) Things that you can sort out for yourself, for example, making a phone call to a professional to ask for a re-assessment of need.
3. Acknowledge what can't be changed. With the things you can do nothing about, simply acknowledge that fact and let yourself know that there is nothing you can do about them. Be kind to yourself – it is hard to let go of what you cannot change. Give it time. Remember you are not alone – many other siblings will have had the same worries.
4. Do something about those you can change. Start with the easiest one first and write down *when* you will do something about the other worries and *what* you plan to do. Doing something at all will help alleviate the worry.

5. Other things that may help:

- a) Exercise – such as going for a walk or run.
- b) Focus – start thinking about things that are pleasant for you, such as a night out you have enjoyed.
- c) Keeping your mind occupied – such as getting involved in a hobby.
- d) Sharing the worry – such as talking to other people who understand the issues.

## Worry worksheet

Things that are very unlikely to happen	Things you don't like but you cannot change
Things that can be sorted out by other people or organisations	Things that you can sort out for yourself



## Anger

Anger is a natural response to feeling threatened in some way. Siblings can struggle with feelings of anger and resentment about their situation and have unresolved feelings of anger from childhood. Often siblings talk about not being able to discuss issues they feel strongly about with their parents or having to hide their true feelings. Anger can become a problem for adult siblings who have not been

allowed to express anger in the past. Feeling angry can help us deal with situations but it can also be scary. Sometimes the feelings of anger get out of control and cause problems for ourselves or those around us.

"Sometimes I get annoyed with my brother not because of his disability or mental health needs, but because his behaviour is a lot like my Dads!"- Sibling

Many people find that there are triggers (such as someone's tone of voice) that make them feel angry and that the anger is way out of proportion to the situation. Someone may become very angry in response to a minor irritation and for some people this excessive anger can become a habit. For others the anger is proportionate to the situation. Many adult siblings experience not being listened to by service providers. The feelings of being dismissed or undermined can lead to strong feelings of anger especially when they are worried that their brother or sister's safety is at risk or if they themselves are at risk of losing income as they are having to provide care.

Excessive anger can lead you to communicate poorly about situations that really matter to you. Don't let excessive anger hold you back like this.

## Ways of dealing with anger

1. Write your feelings down. This can help you understand what is causing your anger. When something makes you feel angry it might be helpful to note down:
  - a) What happened just before you became angry in the situation?
  - b) What happened at the time?
  - c) What happened straight afterwards – how did you feel?
2. Assertiveness. Working on being more assertive in expressing your feelings may help you to have more positive experiences of dealing with anger.

3. Relaxation. Practising relaxation techniques can help you manage your feelings more easily. Look for a local yoga class or try an app like [Calm](#) to help you learn these skills.
4. Meditation. There are lots of different ways to meditate, but most focus on having a quiet few minutes in the day just to give your mind some space. It might not sound like much, but it can make all the difference. Have a look at an app like [Headspace](#) to try this out.
5. Expert help. Sometimes in order to deal with anger you may need some additional outside help. Some adult siblings have found counselling or Cognitive Behaviour Therapy helpful. Anger Management courses or workshops might also be beneficial. Ask your GP about what is available in your area.

If self-help does not change things for you or if you have anxiety or depression that does not go away after a few weeks, talk to your GP about getting further help.

## Ongoing grief

Grief is often associated with the term 'death', but it can be helpful to associate it with the term 'loss'. Siblings can experience an ongoing and chronic grief for the loss of the things they haven't been able to have in life, as a result of their brother or sister's disability. Siblings who acknowledge these losses do not undermine the qualities, life and skills of their brother or sister. Acknowledging losses also does not undermine the positive aspects of a sibling's relationship with their brother or sister either.

It's common for adult siblings to grieve:

- For the sibling relationship, activities and shared experiences they have missed out on, because their brother or sister isn't able to do certain things or be a certain way (*'My brother wasn't happy for me when I got engaged – he didn't understand'*) or because the opportunities weren't there (*'There was no support in our local area, so my sister was sent to a residential school miles away'*)
- For the parts of their childhood they have missed out on, because they have been so involved with their brother or sister's care (*'I spent my weekends as a teenager changing my older sister's nappies. I couldn't have friends round'*)
- For the parental relationship they don't have (*'I became self-sufficient very early on because my Mum just didn't have time for me'*)

This grief in a sibling's life can be ongoing. As a sibling reaches another milestone – a new job, a birthday, the birth of a child – they may be reminded of how these events are different for them to their peers.

There is no way around grief – you have to go through it. Acknowledge your feelings of sorrow and loss if and when you feel them.

## Do I have ongoing grief?

Start at the beginning. Think about how sadness, loss and grief was processed when you were growing up and read the examples below.

1. Some families recognise the loss as it happens and are able to process it at the time. For example, when a sibling child is sad that they can't share certain things with their brother, a parent might say *"I can see that it's really hard for you to see Jack and Chris running, laughing and mucking about together as brothers. You'd like to be able to do that with your brother too and you feel sad that you can't"*. This opens up the conversation and lets the sibling child know that it's OK to talk about parts of their childhood that they can't share with their brother, and that being sad about it is an acceptable way to feel.
2. Some families struggle to acknowledge grief and dismiss it. For example, a parent might say *"Well you can't run about with your brother, there's no point dwelling on it, don't be so negative."* This shuts down the conversation for the sibling child and tells them that it's not OK to be sad about something and talk about it. When in fact, talking a bit might have helped come up with some 'answers' such as celebrating what they can share with their brother, as well as acknowledging what they can't.
3. If you think your grief might have been dismissed growing up, it would be a good idea to see a counsellor to talk about it.

"I thought my parents might help out more when my first child was born, but they weren't able to because they were looking after my brother"  
– Sibling

"When I graduated, I was so proud of myself but I had to minimise the celebrations so that my sister didn't get jealous and angry" – Sibling

Whilst you can't change the past, you can change how you feel about the past. Feelings from childhood don't go away – they just get buried, and then they pop up in the wrong places.

For example, an adult sibling might feel extremely sad seeing their own two young children playing together. The feeling of sadness they felt at the loss of what they couldn't have with their own brother in childhood, is displaced onto this moment in adulthood. This can be a really confusing experience for an adult sibling who isn't able to recognise where the feeling came from. They might say to themselves '*Shouldn't I feel happy to see my two children playing together?*'. If you find yourself having displaced or disproportionate feelings, make sure you get the support you need. You deserve to have your feelings heard, whether they are about the past or about the present.

"I was on holiday recently with my boyfriend's young niece and nephew, and seeing them running around and playing outdoors with each other, in such a relaxed and easy way, made me feel so sad for both my brother and me, and the experiences and the relationship we've missed out on." – Sibling

## Resentment

Resentment is a feeling of anger towards a situation that you feel forced into or that feels unfair. Whereas parents usually make a choice about having a child, siblings do not have that same choice with having a brother or sister. It's normal for siblings to have feelings of resentment and it doesn't mean it's personal to their brother or sister – it's often about the circumstances.

"My brother's problems were very rarely spoken about openly, and I pictured them as a big black cloud floating just above my head."- Sibling

For example, adult siblings might feel resentful of:

- Receiving less attention from parents
- Having different rules to their brother or sister growing up
- Doing caring tasks
- Making difficult choices between their own needs and their brother or sister's needs

## Resentment about assumptions

Sometimes, an adult sibling might feel resentful of assumptions that are made about them and what role(s) they will take on in their brother or sister's care. It's hurtful when an off-hand comment is made without proper discussion about your own feelings and choices.

For example:

- Your Mum has never asked you to look after your brother after she passes away, but she comments that you'll need a two bedroom house to make sure there is space for him
- A social worker tells you what time to drop off/collect your sister from the new day centre, assuming that you will do it and not offering to provide transport
- Your step-Dad books a holiday and tells you that your brother will need looking after, not asking whether you are able to or would like to
- A physiotherapist at the hospital invites your parents to a meeting but not you, as they assume you don't want to be involved

These situations can leave you feeling ignored and angry. This is an appropriate response – your needs have been passed over when they should have been considered. Of course you would feel resentful of this. It can be very hard to challenge other people's expectations, whether they are unsaid or not, and siblings have to deal with this more often than most people.

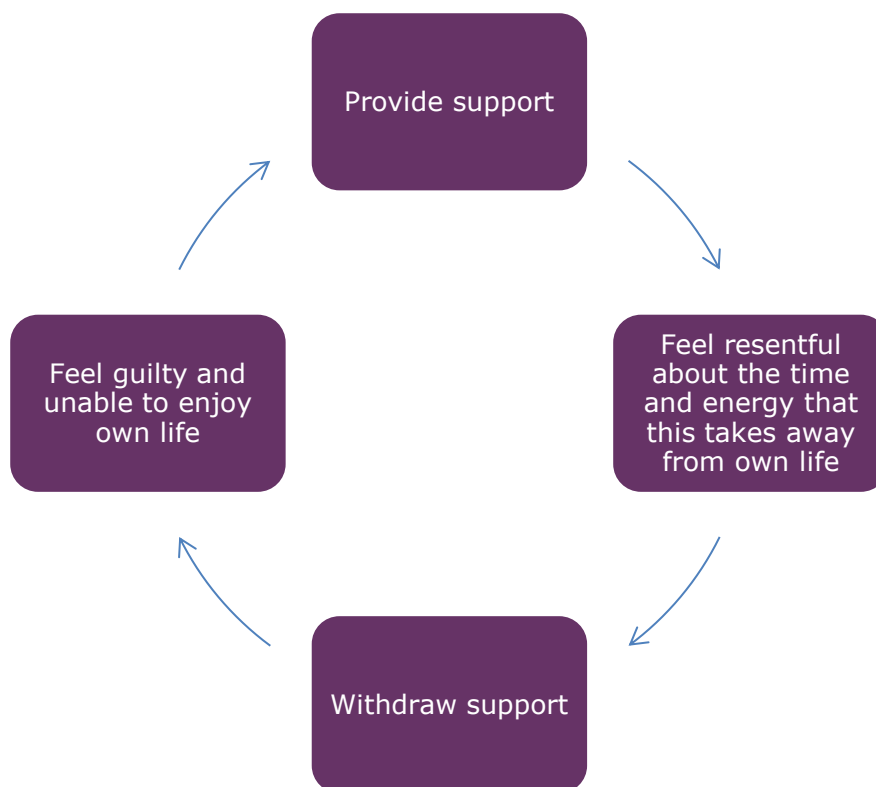
## Resentment about tough choices

**Adult siblings have no legal responsibility to provide care for their disabled brother or sister** – it's their choice whether to become involved or not. But *knowing* this is one thing, and *feeling* it is another.

Many siblings feel that they are left with a very difficult choice in adulthood:

- a) Be involved in their brother or sister's care and support – and feel resentful at the expense of their own life
- b) Don't be involved in their brother or sister's care and support – and feel so guilty about having their own life, that they struggle to enjoy it

This can feel like a cycle:



Adult siblings may look at their peers and feel resentful that they don't have the same tough choices. No one asks for tough choices like this, and no one wants them. It's understandable at times to feel angry and resentful of the life you have been given and to ask 'Why me?'. And it's important that you don't let resentment take over your life. Resentment is a useful sign that you're not living in line with what's important to *you* and that you need to find more balance. We know that this is much easier said than done and that it is not straightforward.

## Feeling resentful is normal

Feeling resentment doesn't mean that you have a negative opinion towards disability. You're not 'blaming' anyone for the situation and you don't love your brother or sister any less. Resentment is a normal response. It's not selfish. You're a person in your own right with needs and wishes that deserve to be considered.

## Ways of dealing with resentment

1. You need to get really clear on what you feel resentful about and why. Make a list, be specific and honest. No one else has to see your list, it's for you. Try the resentment worksheet on the next page.
2. Circle all the times you have used the words '*I have to*' or '*I should*'. These are an indication of the times when you're meeting other people's expectations and not your own (said or unsaid). This is helpful to be aware of.
3. For each time that you have written '*I have to...*', write the same sentence with '*I chose to...*'. Notice how that does (or doesn't) change the sentence and how you feel about that.
4. For each thing that you resent, ask yourself if it is something you can change or something that you can't change.
5. Look at the things you can change, and make a plan. Start small. Don't try and change everything at once.
6. Look at the things you can't change, and acknowledge how you feel about them. If you need to say '*I just wish I'd had a different life!*' then let yourself say that. It's OK. Find a counsellor if you need to explore this further.

"Be realistic about what you can offer your family and use technology. It's OK to join a meeting by Skype if it means you can go to your child's play.

Send a regular postcard if phone calls are challenging or visiting is hard to fit in. You can only do what you can." –

Sibling

Changing things will feel odd, uncomfortable and scary at first. That's understandable – you are trying something new and it's out of your comfort zone. You might not change things too - you may find that because you have had the option of changing them that they feel differently anyway. Do what feels right for you.

# Resentment worksheet

I resent....	Because...	Can I change this...? If so, how?



## Strong connection and love

Siblings can feel a strong connection with their disabled brother or sister that they don't feel with anyone else. It might feel a bit like the love a parent has for a child – a sense that you would do anything for them, above all else. A fiercely protective feeling.

But it's a bit different from parent-love because a sibling will have grown up with this feeling, whereas parents don't. It might have developed in childhood and you might feel more strongly connected with your disabled brother or sister than with your typically developing brothers or sisters if you have them. It might come down to the fact that you know that society might treat your typically developing brother or sister differently to your disabled brother or sister. Your disabled brother or sister might not be able to advocate for themselves or get the support they need. It might also be because you went through a lot together in childhood. Traumatic events and circumstances can bring people much closer.

Sometimes wider society doesn't understand this love. Sometimes your own partner might not understand this love. People might ask you why you don't take more time off as a carer for your brother or why you got so angry after a phone call to adult social care. It's this strong connection and love that drives that. It can be hard for others to understand this if they haven't experienced it themselves.

## Disconnection

Siblings can feel disconnected from their disabled brother or sister. They might dislike their brother or sister, feel ambivalent towards them, or feel like there is not much relationship at all. This can be a very lonely feeling in itself because wider society often promotes the idea that family should come first, for its own sake.

Siblings may have had little opportunity or support to spend quality time with their brother or sister growing up. Their brother or sister may actually not have been around

“Even though we are not parents, that unconditional love and care is just as strong.” – Sibling

“I love my brother more than life itself and he is the greatest person in my life. It's hard to say whether our relationship would be different if he was not autistic, but I'd like to think we would still have our Disney obsession.” – Sibling

“I find it really hard to connect with my autistic sister. If I died, she wouldn't be sad about it. We don't have a reciprocal relationship” – Sibling

that much if they were in residential care or were in and out of hospital a lot. No one may have shown you how to communicate with your brother or sister in a meaningful way.

Challenging behaviour can be a factor too. Your brother or sister may have hurt you, and you may not have had the opportunity to repair that relationship. It may also be very difficult to have a loving connection with someone who is unable to reciprocate that because of their disability. This is not your fault.

“We get along, but we don’t really have a brother-sister relationship. I know I should try harder, but he is quite difficult to be with. He is grumpy or angry a lot of the time.” – Sibling

Also, it is worth remembering that many siblings don’t get along. Disability or no disability, you may not have been close anyway. You are different people, with different interests, values and life-paths. It’s natural for people to move in different directions sometimes.

If you’re feeling disconnected from your brother or sister, and you would like to try and connect, have a look at the chapter ‘Your relationship with your disabled brother or sister(s)’ on page 62 and consider some of the suggestions for spending time together. But do this because you want to and not because you feel you have to. There is no ‘have to’. Your relationship with your brother or sister is between the two of you, and no one else.

You don’t have to spend time with your brother or sister if you don’t want to. You don’t have to feel love towards them either. It doesn’t make you a ‘bad’ person.

## Loneliness

Loneliness isn’t about being in a room full of people or being by yourself. It’s about feeling connected. For example, you might feel connected to a friend who has the same sense of humour – you might feel that you just ‘get’ each other. You might go to a favourite coffee shop and not feel lonely even if there is no one else there. Because it is

familiar to you, it's warm, it connects you to yourself and to something you know. It's about connection. Everyone experiences loneliness sometimes. Siblings might experience it more than others. Here are some examples:

- Feeling lonely around your parents, who have never really got to know 'you'
- Feeling lonely around your disabled sister, because she isn't able to empathise with you and listen to your feelings
- Feeling lonely in the place you grew up with your brother because it just doesn't feel like 'you' and it never has. Your brother was the focus of attention there
- Feeling lonely with your partner because they just don't 'get' the love you have for your sister and why you put her first sometimes
- Feeling lonely around your friends because they seem to have a whole other set of worries and life issues that seem trivial to you in comparison to the life you have known
- Feeling lonely because you don't love your brother and never have and you don't feel able to tell anyone out of fear of being judged
- Feeling lonely as a family. Disability can be isolating when things you would usually do as a family aren't accessible for your brother or sister
- Feeling lonely with childhood memories – when you think back to a funny noise your sister used to make or the ways that you used to try and make her laugh, no one else quite 'gets' this and can share it with you

"Before I started going to a sibling group, I felt completely alone and felt that no one understood what I was going through. After meeting like-minded people it really lifted me, and encouraged me as I had been feeling very down and isolated." - Sibling

Many siblings didn't realise that others have had similar experiences to them growing up. They didn't know that there were shared experiences, common feelings and themes that come out of this set of life circumstances – but there are. There are 1.7 million adult siblings in the UK – and many of them will be saying, thinking and feeling similar things about their sibling experiences to you. You are not alone!

If you are feeling lonely as a sibling, connect in a way that works for you. This might be reading books about sibling experiences (see p31), writing about them and reading it back to yourself, or through talking with other siblings. Meeting other siblings face-to-face can make a big difference – but it's not the be all and end all. Just knowing that there are others out there is a really good start.

## Mixed feelings

It is very common for siblings to have mixed feelings. These can be hard for siblings to work out because they seem to conflict with each other. This can feel frustrating and you might feel really torn.

Here are some examples of conflicting feelings:

- Relieved when your brother left for a residential school because his behaviour was so hard to cope with AND missing him at the same time
- Resentful that your parents weren't able to spend more time with you as a child AND also understanding why they didn't

It might seem like these feelings are at opposite ends of the same scale. You might feel like you need to be at one end or the other end, to make sense of it all. Can you feel relieved someone is gone and also miss them at the same time? The answer is yes – because it's not one scale – it's lots of different parts. You have to look more closely at what, specifically, you are feeling to help make sense of it.

You might find that one feeling brings on another feeling and they start to layer up. Here are some examples of layered feelings:

- Feeling guilty about taking time off from caring for your sister AND THEN feeling angry towards society and the lack of appropriate social care that you feel guilty about it
- Feeling anxious about having a conversation with your parents about your brother's care AND THEN feeling sad that you feel so anxious when you're talking to your parents

Layered feelings can be exhausting and feel very heavy. You already have one thing to process and suddenly there's another to work through.

Mixed feelings are very common and they aren't specific to siblings. But siblings might have a harder time understanding or expressing them, because there aren't common examples of them in society. Many non-siblings don't fully understand what life as a sibling is like and how it feels.

Conflicting feelings and layered feelings are very common. Accept that there will always be different parts of you feeling and wanting different things. This is part of being human.

## How mixed feelings can look

**Conflicting feelings** can sometimes feel like a confusing scale:

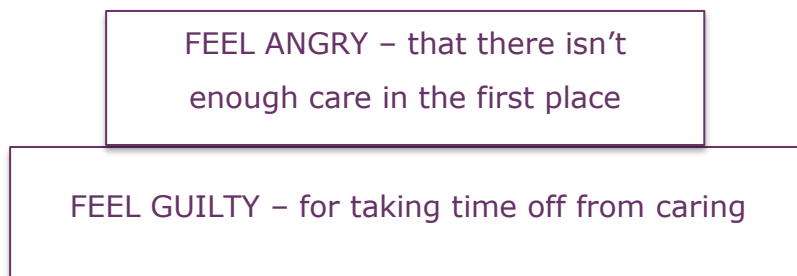
I don't miss you                      I miss you a bit                      I miss you a lot  
0      1      2      3      4      5      6      7      8      9      10

And it can be hard to know where to place yourself.

But it's more nuanced than that – it's not a scale, it's lots of different parts. These parts don't deny each other and they can exist alongside each other. It's OK to have all of these feelings.



**Layered feelings**, can build up like this:



They can seem exhausting and heavy.

## Shame

Shame is the feeling that you're a 'bad person'. It's the feeling that you've thought, said or done something you consider to be so bad that other people wouldn't want anything to do with you. Everyone experiences shame during their life and it can be incredibly painful. It's the feeling that you might have most difficulty recognising or dealing with.

Shame is different from guilt. As shame researcher Brené Brown says:

*"The difference between shame and guilt is best understood as the differences between "I am bad" (shame) and "I did something bad" (guilt). Shame is about who we are and guilt is about our behaviours"*

From page 13 of "I Thought it Was Just Me (But it Isn't): Telling the Truth About Perfectionism, Inadequacy and Power" by Brené Brown.

The sorts of things that siblings might feel shame about are:

- Having thoughts about wishing their brother or sister had never been born or was dead
- Saying things to their brother or sister in the middle of an argument, like *"You've ruined my life, I hate you!"*
- Others may have done things to their brother or sister that they regret, like hitting or kicking back when their brother or sister's behaviour is challenging them

And the sorts of things siblings sometimes say to themselves are:

- *"I can't believe you just wished your brother dead! You are terrible!"*
- *"You can't tell your sister she has ruined your life, it's not her fault she is the way she is!"*
- *"You just kicked your disabled brother, what sort of person are you?!"*

These are all very difficult things to grapple with. You might say to yourself *"This isn't who I am, I don't want to think/say/do these things"*. You might keep them to yourself, because you worry that if you tell people they will disown you.

The reality is – you are not that special or different! Most of the things you have thought, felt, said or done will have been experienced by other siblings too. You're not the first person in the world to say these things and you will not be the last. You are a human being, not a robot and not an angel. Human beings have a very wide range of

thoughts and feelings. Some of them we will hate and we'll give ourselves a hard time for.

The best way to combat shame is to reach out – to talk to someone else who *will* understand and give you a compassionate response. That might be a sibling friend, a sibling support group, an online facebook group, it might even be in a letter to yourself. You might worry about 'letting yourself off the hook' or 'condoning the behaviour'. Acknowledging and sharing shame doesn't condone whatever has happened – but it helps you to recognise the shared humanity in it. Beating yourself up doesn't help you to move on and learn from experiences. Being compassionate towards yourself does.

"Reading books about other siblings has really helped to validate my own experiences. I feel much stronger" – Sibling

## Books and films for adult siblings

- 'Special Siblings: Growing Up with Someone with a Disability' by Mary McHugh (2003) Brookes Publishing Co
- 'Siblings: Brothers and sisters of children with disability' by Kate Strohm (2014) Wakefield Press
- 'The Ride Together: A Brother and Sister's Memoir of Autism in the Family' by Paul Karasik & Judy Karasik (2003) James Bennett Pty Ltd
- 'Riding the Bus with My Sister: A True Life Journey' by Rachel Simon (2003) Plume Books
- 'What About Me?: Growing Up with a Developmentally Disabled Sibling' by Bryna Siegel & Stuart Silverstein (2001) Da Capo Press
- 'The Music Room' by William Fiennes (2009) Picador
- 'The Sound of Turquoise' by Gill Gregory (2009) KUPress
- 'Boy Alone: A Brother's Memoir' by Karl Taro Greenfield (2009) Harper
- 'Hamlet's Dresser' by Bob Smith (2003) Simon and Schuster
- Fiction - 'My Sister's Keeper' by Jodi Picoult (2004) Hodder

### Films

- What's Eating Gilbert Grape (1993)
- The Black Balloon (2008)
- Mission to Lars (2012)
- Wonder (2017)

# Your mental health

*"I realised the affect growing up with my sister had on my mind." – Sibling*

Everybody has mental health just like they have physical health. Your mental health is about your psychological, emotional and social well-being. It's about how you feel, think and act. In the same way that you might (or might not) go to the gym and eat healthily to take care of your physical health, you need to take care of your mental health too. Pause for a moment and think about how you currently do this. What helps you stay mentally health day-to-day?

Things I do to take care of my mental health every day:



Mental health problems can happen for a number of reasons. Some siblings will have mental health problems as a direct result of growing up with their brother or sister, or caring for them. Some siblings:

- May have developed depression as a child due to the impact of the home environment
- May have coped with ongoing stress, which has arisen from the strain of being a carer
- May have developed Post-Traumatic Stress Disorder (PTSD) arising from challenging behaviour or life-threatening circumstances
- May have experienced suicidal feelings at the thought of a future with or without their brother or sister

Some siblings have trouble acknowledging their mental health:

- May not have realised they have experienced mental health problems, because their outlook of health is much wider than the general population (*"My brother is constantly at death's door. His illness is so severe. I don't notice any minor ailments I have"*)
- May have realised they have experienced mental health problems, but dismissed them because they are *"not as bad as my sisters"* and not sought treatment. Siblings might compare their health to their disabled brother or sister's
- May have realised they have experienced mental health problems, but not sought treatment for them because they don't feel they deserve a happy and healthy life (*"Anytime I start to feel happy and enjoy my life, I just feel too guilty that my brother can't do the same with his. I think this is why I haven't sought much help with my depression"*)
- May have experienced mental health problems for so long that they have become the norm (*"I'm constantly on edge around my sister because of her violent behaviour, I'm constantly anxious, I don't remember a time when I wasn't. I don't know what it would feel like not to be so anxious and on edge"*)
- May have not even considered the possibility of mental health problems because they have a view that they *"have to get on with things"* or *"don't have the option of not coping"*

Many mental health problems are treatable or manageable. Siblings may need more encouragement to seek and accept the right support or treatment, as some may not see their problems as "bad enough". Siblings, like everyone, deserve a happy and healthy life.

## Depression

Depression is a low mood that lasts for more than a couple of weeks. It affects your everyday life and can range from mild to severe. You might find things are more effort than usual or find that things seem pointless. Things you used to enjoy might now feel grey and lifeless. As well as feeling low, you might notice that you feel tired, irritable, restless and you have difficulty concentrating. You might notice changes in how much you eat and how much sleep you are getting.

*More from Mind.org.uk – take a closer look at the [symptoms](#) of depression, ideas for [self-care](#) and available [treatments](#).*

“We had no other support at that time. I was sleeping on my sister’s floor, just to make sure she was safe. I sunk further and further into depression” – Sibling

“I had a mental breakdown and have not worked for over 2 years due to anxiety and depression. Much of this was caused/exacerbated by worries about my sister who has learning disabilities and difficult interactions with my Mum because of disagreements/worries about my sister's care” – Sibling

## Anxiety

Anxiety is a tense and uneasy feeling, usually about something with an uncertain outcome. It might feel quite frightening. It can be experienced as a feeling, a thought or as physical sensations (like a faster heartbeat or breathing). Lots of siblings worry about things (have a look back at page 15), but if you find that all your worries merge into one impossible mass of anxiety then it’s time to speak to your GP about whether this is becoming a mental health problem.

Anxiety might start affecting how you are able to live your life. The anxiety might feel very intense, or it might last for long periods of time. You might find that your fears are disproportionate to the situation or that you can’t get on top of them.

*More from Mind.org.uk – take a closer look at the [symptoms](#) of anxiety, ideas for [self-care](#) and available [treatments](#).*

"I have struggled with anxiety and depression since I was in my teens and have had 3 separate experiences of counselling/psychotherapy. The most recent experience has been very positive: the therapist has really tried to see things from my point of view and is also able to help me untangle and verbalise some of the complex feelings I have about my family and my brother. She is able to see that I am quite close to my brother and always acknowledges that, while also helping me to realise that it's ok to also have negative thoughts and feelings towards him: I'm gradually learning that having negative feelings doesn't automatically make me a bad person. The experience has been very validating and has really helped me to begin to get on top of the depression and anxiety which I've been experiencing." - Sibling

"I find myself worried about everything. Has she had her breakfast, will the carers arrive on time, what do people think of how I'm doing, am I good enough...the list goes on. It's like my brain just needs something to worry about and if it's not one thing, it's another. I feel like I will never be worry-free." – Sibling

## Obsessive-compulsive disorder (OCD)

Obsessions are unwelcome or anxious thoughts that appear over and over again (for example, worrying that you are contaminated with germs). Compulsions are repeated actions that reduce the anxiety caused by the obsession (for example, repeatedly washing your hands). The compulsions provide only temporary relief to the obsessions. Sometimes the obsession and the compulsion don't logically match up.

Sometimes the obsession can be difficult for another person to 'see' such as silently counting to yourself. Many people experience minor or obsessions and compulsions, but it's when these persistently interfere with how you live your life that you need to seek further support

*More from [Mind.org.uk](http://Mind.org.uk) – take a closer look at the [symptoms](#) of OCD, ideas for [self-care](#) and available [treatments](#). You can also visit [OCD-UK](#) – the national charity run by and for people with lived experience of OCD.*

“When I was caring for my brother, I had to check everything three times. Check his hair, check his clothes, check all of the plug sockets in the house before we left...the list went on. I believed that if I didn’t complete the checks, something would happen to him, and I would be directly responsible for that. It was more than just being ‘caring’ or being ‘careful’ – it was all consuming” – Sibling

## Post-traumatic Stress Disorder (PTSD)

PTSD is a type of anxiety disorder that may occur after a person has been involved in or witnessed a distressing or traumatic event. This could also have been an ongoing period of events. People often associate PTSD with having [flashbacks](#) and nightmares.

Other symptoms include not being able to remember anything from the event, being constantly alert or on edge (known as [hypervigilance](#)) and disturbed sleep. Some siblings will have experienced severe and repeated traumatic events throughout their childhood (read more about childhood trauma on page 49), but may not have considered those events to be traumatic because they became the norm for the family.

Some siblings experience PTSD soon after the event (or series of events); others will develop PTSD much later in life. Some siblings will live with mild or moderate PTSD for many years before realising that they have it, because they have become so accustomed to the symptoms (for example, hypervigilance – being on ‘high-alert’). Siblings whose disabled brother or sister has experienced a particular traumatic event (for example, being abused in care) may experience [secondary trauma](#) as a result.

*More from [Mind.org.uk](#) – take a closer look at the [symptoms](#) of PTSD, ideas for [self-care](#) and available [treatments](#). You can also visit [PTSD-UK](#) – the only charity in the UK dedicated to raising awareness of post-traumatic stress disorder, no matter the trauma that caused it.*

“My sister’s violent outbursts left me constantly on edge. I was always living in fear.”  
– Sibling

“He was in and out of hospital so much. As a family we were always on ‘high-alert’ and every visit was touch and go; life or death. The constant anxiety was exhausting”  
– Sibling

“She was abused in care, and I felt so guilty for being affected by it – because it didn’t happen *to me* – but I definitely was. But once I acknowledged that I was, and I got the help I needed, things did get better. I still have to be careful with the news and social media – stories about other care home abuse really trigger me” – Sibling

## Addiction

Many people associate addiction with alcoholism, drug misuse or gambling. People also have addictions to shopping, sex, work and the internet. Some people can become addicted to ‘being busy’. Addiction is different from just doing or taking a lot of something. Addiction happens when you no longer have control. It’s when you find that you *need* to do or take something to feel a certain way, and when this thing is becoming harmful to you.

Some siblings have had traumatic experiences or shouldered a great deal of stress in their lives (and continue to do so). They may become addicted to something in order to feel a certain way (e.g. to experience the high of drugs) or to avoid feeling another way (e.g. shopping temporarily helps me forget my sadness). Everybody does this to a certain extent, but it’s when it takes over your life and starts to create serious problems that you need to get more help.

Read NHS advice about [addiction here](#)

[Action On Addiction](#) – the only UK addictions charity that works across all the areas of treatment, research, family support and professional education

## Suicidal feelings

Feeling suicidal might mean feeling that the world would be better off without you or it might mean making plans to end your life. For some siblings, it feels less about wanting to die and more about wanting the pain they are feeling – or the circumstances they are

going through - to stop. Some siblings do not see a positive future for themselves and their disabled brother or sister, and they feel hopeless and lost.

Suicidal feelings can be frightening and overwhelming. Some siblings might have a fear of telling others about their feelings, for fear of judgement. Many siblings have experienced a lifetime of being told they must "*be grateful for their health*" and "*make the most of the opportunities*" that their disabled brother or sister does not have. So on top of feeling suicidal, they may also feel extremely ashamed or guilty for feeling suicidal. It's important to remember that many people have suicidal feelings at some point in their life.

*More from Mind.org.uk – read about [suicidal feelings](#), how to help yourself [now](#) and in the [long-term](#), and the types of [support and treatments available](#). There's also advice on [supporting someone else who feels suicidal](#).*

**You deserve support and you are not alone.**

Phone Samaritans on 116 123 at any time

"I felt suicidal as a teenager when I was living with my brother. His behaviour was non-stop – banging, screaming, breaking things. I had no privacy. I thought there was no end. I started going running, and it saved me. I'd run out my frustrations. It got me out of the house" – Sibling

"I had a wife, two wonderful children, and a great job. When I started having suicidal feelings, I just pushed them away. I felt incredibly guilty because my brother (who has cerebral palsy) can't have any of the things I have. What did I have to feel suicidal about? I broke down one day and told my wife. Saw my GP and got some help. It doesn't have to be this way. Just reach out" – Sibling

"No matter how desperate things feel now, it will get better" - Sibling

## Look after your mental health

The mental health conditions described above are not an exhaustive list. Poor mental health is not an inevitable part of life as a sibling or as a carer and you do not have to live with it. Many conditions are treatable or manageable. You deserve to be healthy and happy. **If you have identified with some of the experiences above and you think you might be experiencing a mental health problem, you must see your GP.**

## Further support

### Phone lines

- [Samaritans](#) confidential listening service. Call 116 123 anytime
- Samaritans Welsh Language line. Call 0808 164 0123 anytime
- [Breathing Space Scotland](#) – confidential phone line for anyone in Scotland feeling low, anxious or depressed. Call 0800 83 85 87 (Monday-Thursday 6pm to 2am and weekends: Friday 6pm-Monday 6am)
- [Lifeline](#) – Northern Ireland crisis response helpline. Call 0808 808 8000 anytime
- [Campaign Against Living Miserably \(CALM\)](#) - leading a movement against suicide, the single biggest killer of men under 45 in the UK. Call 0800 58 58 58 between 5pm – midnight everyday; or use their [webchat service](#).

### Self-care

- Didn't write much back in the box on page 32? Have a look at the NHS [Every Mind Matters](#) website for ideas on taking good day-to-day care of your mental health from
- Podcasts and videos more your thing? Have a look at this list from the [Mental Health Foundation](#)
- The mental health charity Mind have a range of advice on living with mental health problems and [coping with the impact on everyday life](#)
- Try [Calm](#) – the app to help with sleep problems and stress levels

# Childhood experiences

*"Your whole life orbits around one other person. You don't know any different." – Sibling*

Everyone has certain experiences that shape their childhood. It might be growing up in a particular country, growing up with little (or lots) of money, growing up with divorced parents. Growing up with a brother or sister who has a disability will have shaped your childhood too.

"I'm gradually learning that having negative feelings doesn't automatically make me a bad person" – Sibling

## Home life

Your home life might have been quite different from your peers when you were growing up, in both positive and challenging ways. You might have noticed some of these differences as a child when you went to friends' houses. Or you might not have noticed these until adulthood, and only thought about it when something else nudged you to – such as having your own family or meeting your partner's family.

Common experiences for siblings:

- Family life was centred around 'what kept your sister happy' – if she was calm and happy, your parent was too
- Your family may have been unable to live together under one roof – your brother was in residential care; you were at home
- There was a very set routine in the home, and everything had to be done at a certain time, because it fitted around your brother's needs

"Me and my sister always, always, always sang along to every song on her favourite album, together. I still know all the words today and it still makes me smile" – Sibling



- Home life may have been very unpredictable and chaotic, depending on your sister's behaviour
- There was one set of rules for your sister, and a different set of rules for you. For example, if she screamed, she was given what she wanted, but if you screamed, you were told off
- You were allowed the same rules as your brother, even if these were unconventional, because they fitted around his needs – such as being allowed to make a lot of noise or draw on the walls
- Meal times were focused on what your sister needed and liked to eat, and may have been limited to certain foods
- Trips in the car or on public transport may have been particularly significant (*'My brother loved buses!'; 'We had to bribe my sister into the car'*)
- Your sister had a favourite song or TV programme that was always playing (even when everyone else was tired of it)
- You spent a lot of weekends going to visit your brother in residential care
- The activities you chose to do as a family centred around your sister's needs, what she enjoyed and what she could do

"I never realised that being a sibling was a 'thing' - that there was a word for it and that there were others out there like me." – Sibling

"I felt painfully isolated for almost my entire childhood and adolescence." - Sibling

Acknowledge your experiences – whatever they have been. What memories do you have of growing up with your brother or sister? How was your home life similar or different to your peers? What advice would you give to your younger self or to young siblings today? Use some of the prompts on the next page.

## My home life as a young sibling...

My strongest family memory is...

I wish we could have had...

I really appreciate that we had...

It was difficult when...

The thing I enjoyed most was...

I had the following experiences that my peers didn't...

The advice I would give to my younger self is...

## Things not discussed

Families don't always talk about things openly. Your parent may not have known how to bring up a topic like your brother's health, how to answer your questions about your sister's behaviour or how to help you understand a life-limiting genetic condition. They may not have known what was age-appropriate, and may have given you too little (or sometimes, too much) information.

The decade that you were born in will have had an impact – there is more information and there are more resources for parents in 2020 than there were in 1960. How your grandparent brought up your parent, will have had an impact on how they raised you. Culture and religion will also play a part in how much is shared between adults and children, and how topics are addressed (or not).

When a small child isn't given enough information about something that is worrying them, there is a risk that their mind will 'fill in' the other information. Common examples of this in young siblings include:

- Your brother was in residential care. No one explained why he was 'sent away' and you feared you would be next
- Your sister had a seizure after the two of you had an argument. You worry that you cause all seizures in future, but when you bring it up with a parent they do not answer you
- You ask a parent why your brother is disabled, and they don't want to talk about it. You feel guilty and assume it was because you must have hugged your mum too tightly when she was pregnant with him. You feel responsible for his disability for a long time
- Your sister is recovering well from a routine operation. You ask to go and see her in hospital, but your parent says they don't want you to see her like that. You feel incredibly anxious and think that your sister must be dying
- Your brother hits you on the back of your head, to get your attention and because he likes spending time with you. You assume he is doing this maliciously and that

"My twin severely autistic brothers were institutionalised at the age of 7. I was 6 and our younger brother was 5 at the time. This was in 1962. I do not remember our parents explaining to us what was happening, nor why our family was being broken up." - Sibling

"I was the only one in school that had a brother and a sister who both had learning disabilities. Everyone else had siblings that were unlike mine. Ones where they went to the park together or family events/holidays together" - Sibling

he doesn't like you. You have no other support or information on how to communicate with him differently

- Your sister was never discussed outside of the family, and you felt like you had a secret that you had to hide from your friends
- Your two older brothers have a genetic condition and you didn't understand why you don't have it too. You think that it is something you will 'catch' or 'grow into' as you get older. For each day that you are healthy, you feel very guilty about this

Some young siblings will carry these ideas for a long time, until they realise they are not true. If this was you, you might have lived with substantial anxiety, fear or guilt for many years. If it still affects you today, make sure you get the help that you need – whether that's seeing your GP for counselling or talking to a close friend about it. Many young siblings had thoughts like the ones above – you're not alone.

Don't stop seeking information. Read up on your brother or sister's condition, look for new insights and research, and if you have new questions – don't let them go unanswered. You deserve to have the information you need.

## Lost childhood

Many adult siblings may have missed out on parts of a typical childhood. Some may not have had their basic needs met. Daily activities such as eating, sleeping, playing, going to school, meeting friends, having time with parents and doing homework may have been lost to other things. The limited opportunity to do these typically developing things may have had an impact on you.

"I think as a child, you just accept your own life as 'normal'. You don't know any different. But when I look back, I can see how our whole world was focused on my brother and his needs" –  
Sibling

Some siblings experience the following in childhood:

- Disrupted sleep due to brother's night time needs
- Being bullied at school for having a disabled brother or sister
- Having to only eat certain foods to fit in with your sister's routine and preferences
- Unable to go on holiday or have hobbies that you would like because they don't fit in with your brother's needs

- Feeling isolated as a family – unable to take part in usual activities other families would because they are not accessible for someone with a disability
- Spending lots of time doing practical care tasks
- Limited opportunity to spend time with parents
- Limited love and affection from parents, for example due to parent-carer exhaustion or stress, all time being spent with disabled child
- Unable to bring friends home from school
- Providing emotional support to distressed parents such as making them laugh
- Being ‘the good one’ – extremely well-behaved and working very hard at school (this may have been unconscious behaviour)
- Clothing, toys, furniture, windows etc repeatedly broken due to brother or sister’s challenging behaviour
- Growing up too quickly in an emotional way - having to face serious topics and difficult situations on a daily basis, often with little emotional support
- Growing up too quickly in a practical way - having to get themselves dressed and ready for school, sort out their own practical issues and problems as no one else can or will

It can be hard for some adult siblings to recognise the things they missed out on in childhood. It may feel as if they are placing blame. For example, a sibling might not feel comfortable saying that they didn’t have enough love or affection from their parents because they understand that their parents resources were very limited and that their brother or sister needed a lot of care during childhood.

But acknowledging this is not about placing blame. It’s about acknowledging the circumstances and really seeing what has happened. It is about recognising what you haven’t had, so that you can address it in adulthood, possibly through counselling. And recognising that you did not have your needs met in one area, does not mean you’re ungrateful for what you have had in another area.

You can’t have another childhood, but you can make up for lost time in small ways. Do the things you couldn’t do when you were younger. Eat the foods you weren’t allowed to, go camping where you couldn’t, let yourself ‘play’ a bit more. It all adds up and it does make a difference.

## Separated or divorced parents

Raising a disabled child can take extra energy, time and financial resources. It can be stressful and challenging for the whole family. Many siblings will have experienced their parents separating or divorcing as a result of the strain of raising a disabled child.

“When Dad left, I became the third parent to my brother” – Sibling

Some siblings may have had the opportunity to talk to both their parents at the time, and to process their thoughts and feelings about the separation. Others will not have had this opportunity, and much of the focus may have been on the disabled child. Siblings may have been left with unresolved anxieties or feelings of blame.

Some siblings feel that they are to blame for the separation, and that if they had ‘helped out more’ with their disabled brother or sister, then their parents would still be together. This is not the case. Going through difficult times makes a good relationship stronger, and shows the cracks in a bad relationship. Your parents’ relationship with each other is theirs alone. It is not, and was never, your responsibility to ‘save’ it.

Experiences of some siblings after their parents’ separation:

- May take on extra care tasks for disabled brother or sister
- May feel increased sense of responsibility and need to ‘look after’ the parent
- Changes in time/attention each parent can give sibling
- Changes in household income
- Challenging behaviour from disabled brother/sister

“My mother said that I was born independent – but is a child equipped to fend for herself, especially concerning her emotional growth – alone? Somehow I managed to reach the age of 62 more or less intact.” – Sibling

# Supporting a parent with a disability

## Mental health

Some siblings grow up supporting their disabled brother or sister and their parent who has a mental health problem. This may be an existing and long-standing condition that the parent has had since they were young - such as Bipolar Disorder, Borderline Personality Disorder or Schizophrenia. Or it may be a mental illness that has arisen out of the circumstances of raising a disabled child - such as stress, anxiety or depression. Some mental health problems have an impact on the physical health too - such as difficulty sleeping and a lack of energy.

“Mum left, Dad had depression, my brother had severe autism. I had no other siblings. I was the child who was parenting the whole family.” - Sibling

You may have noticed signs and symptoms of a particular mental health condition in your parent, but it may not have been diagnosed. Depending on the decade you grew up in, your parent may have not have sought support for fear that their children would be taken from them because of the stigma around mental health problems. There may also have been no support available.

Your parent may have had good days and bad days, meaning that the support you offered changed too. You may have felt like you were the only consistent source of support in the family, the only person holding all of you up. In particular, you may have struggled with your parent's ability to make decisions and provide emotional support and you may have felt very alone in some of the choices you had to make. You may have felt a great weight of responsibility at a very young age as you made decisions for the family.

## Physical health

Your parent's physical health may have impacted on the family. You may have carried out extra practical care tasks for your parent themselves, or helped out more with your disabled brother or sister. There may have been good days and bad days. Having a family with two (or more) physically disabled people in it can be hard. Many things that other families take for granted - such as public transport, leisure facilities or local events - may not have been accessible to you.

“My Mum had chronic fatigue syndrome. On bad days, I had to do everything for my sister. There was no one else to” - Sibling

## Living on a low income

Growing up with a disabled brother or sister may have affected your income as a family. This could be due to:

- Effect of being a parent-carer on work (such as needing part-time or flexible work; not being able to work; one parent working; taking unpaid time off work to provide care)
- May be living in single-parent household and not receive enough financial support from the other parent
- Benefits and financial support available does not cover the full cost of raising a disabled child, or was not available at all at the time you were growing up

"My counsellor helped me to make a connection between having a disabled sister (and how that had impacted on me) and experiencing depression and anxiety later in life, particularly after becoming a parent. She helped me to understand my own behavioural traits better." -  
Sibling

It may also have affected how the money was spent. For example:

- Spent on the extra costs of raising a disabled child (such as more clothing due to regular incontinence, specialist equipment, aids or toys, cost of travel to regular hospital appointments, cost of travel to visit residential schools, cost of replacing items broken due to challenging behaviour)
- Savings (if any) going towards disabled child's future, because of these extra costs continuing into adulthood

As a sibling, it may have meant that there was less money available to be spent on you and this may have affected the opportunities that you had as a child and as a young adult.

As an adult, it may have affected your decisions about:

- Where and when to move out of the family home
- Whether to stay on in education or find a job
- What kind of job to get

If you grew up in a household on a low income, you are not alone. Many siblings were affected by the cost of disability while they were growing up, and it has shaped the choices and the opportunities that they have had in adulthood too.



## Childhood trauma

Some siblings may have experienced traumatic events in childhood, in relation to their brother or sister. It is important for siblings to recognise the impact these events may have had in order to move on from them and not let them affect their adult lives.

Types of trauma that siblings may have experienced:

- Direct violence - being repeatedly hit, smacked, kicked, punched, having hair pulled, spat on, bitten, having objects thrown at them by their brother/sister
- Seeing or hearing violence between disabled brother/sister and parent or other siblings
- Life-threatening situations due to behaviour (such as brother grabbing parent while they are driving and causing them to lose control of the car; sister setting fire to things in the home)
- Seeing brother or sister injuring themselves (such as eye gouging, hitting themselves, head-banging)
- Witnessing the impact and the effects of strong medications
- Psychological impact of repetitive noise – all day, every day (such as head-banging, hitting things, screaming, crying, wailing)
- Seeing their brother or sister endure repeated life-threatening events, such as choking, seizures, hospital admissions
- Emotional distress or secondary trauma after their brother or sister has been abused or mistreated
- Seeing sexualised behaviours such as masturbation
- Repeated emergency hospital trips, not knowing if their brother or sister will live or die
- Providing intimate personal care for their brother or sister
- Having to perform (or watch parents perform) CPR or carry out life-saving techniques on their brother or sister, such as administering emergency medication
- Parent repeatedly shouting at sibling child and neglecting their needs due to stress/lack of sleep taking care of disabled child

“The fallacy that children are resilient is repeated as a truth – but do children really have a choice when faced with hardships and challenges they have no control over? It’s what we make of our struggles that I find interesting in others, and now, as I become used to self-identifying as a sibling, in reflection upon my own life and how I have lived it.” –  
Sibling

After a traumatic event, it is normal to feel shaken up and to need time to recover. Some need to talk about things and others need quiet reflective time to themselves. Some need to make art or create things to make sense of what has happened. Others need to absorb themselves in sport – burning off excess adrenaline and stress. Sometimes, these things may not have been possible and a sibling may not have had the opportunity they need to work through the trauma.

“I remember as a teenager being left in charge of him whilst my parents went to a school event, and my brother had a Tonic Clonic seizure. In those days there were no mobile phones, I just had to wait for my parents to come back.” – Sibling

If you have experienced a traumatic event like the one(s) above, and you have not had the opportunity to recover as young person, you may still benefit from the time and space to do this as an adult. Speak to your GP about having counselling or find a private therapist who has a background in trauma therapy. Read more about siblings and Post-Traumatic Stress Disorder (PTSD) on page 36, and if you do feel that you have some of the symptoms of PTSD, you need to discuss this with your GP as well.

Writing or talking about the past doesn't change what has happened, but it can change how you feel about it and you cope in your adult life. Consider writing about your childhood experiences or seeking counselling if you have unresolved childhood issues.

# Thinking about the future

*"I never stop worrying about his future. It's always in the back of my mind." – Sibling*

Many adult siblings worry about the future. 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 and it can feel overwhelming at times.

*"It's just too much to think about sometimes...both my sisters have disabilities and need long-term care, what are we going to do?" – Sibling*

Common worries that adult siblings have about their brother or sister's future:

- Where will they live?
- Who will look after them?
- What support is available?
- How will they manage financially?
- If my parents died suddenly, I don't know even know where to start with getting my sister the support she would need...who would I call?
- Will I have to look after my brother?
- Will I have to pay towards their care?

Common things that adult siblings say about their own future:

- I don't want to look after my brother, but I feel guilty for saying 'no'
- I wish social care was better
- I want to look after my sister, she will come and live with me – I need to find a house big enough for us both

- I don't know what my role will be in my brother's future
- I see myself as helping out with overseeing my sister's care, but I don't want to do personal care
- Will I have to live nearby to my brother?
- Do I want to have children of my own?
- Any partner I have will need to understand that me and my sister come as a package!
- I only want work that is nearby to my sister
- I'm going to have no support from my parents during uni/work/buying a house because they use all their time and resources to support my brother

## Do I have to look after my brother or sister?

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.

"I always assumed that David would come and live with me. When I spoke to my sister about it, she had assumed he would come and live with her! It was odd, but we'd just never talked about it" – Sibling

### **You have no legal responsibility to care for**

**your brother or sister.** The local authority\*/local health and social care trust\*\* has a duty to assess your brother or sister's care needs, and to put support in place if they are eligible to receive it. They will only assess your brother or sister's finances – not yours. Your brother or sister's benefits can be managed by the local authority\*/local health and social care trust\*\* and care arranged by a social worker. 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. Thinking about what is right for you, will be better for you and your brother or sister in the long run.

\*England, Wales and Scotland \*\*Northern Ireland

Remind yourself that it's OK not to see your brother or sister. Siblings do sometimes dip in and out of each other's lives, they have periods of greater closeness too during times of crisis. All of this is natural.

## My parents don't want to talk about the future

When you raise your worries about the future 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.

Reasons why adult siblings want to discuss this issue:

- Worried that there is no emergency plan in place to care for their brother or sister who is usually cared for by a parent such as if a parent goes into hospital suddenly
- Want to look out for their brother or sister in future, but don't have the information they need
- Concerned that parents have assumed the sibling will want to look after their brother or sister in future, when actually the sibling doesn't want this
- Want the same for their brother or sister as they want for themselves - to move out of the family home, grow into adulthood and expand their own life

If your brother or sister is still living with a parent it may be very difficult for them to imagine a time when he or she will not be. Some strategies for dealing with this are:

### **Be direct**

Your parent may not have realised how much this worries you. Tell them that you would like to discuss your brother or sister's future care and agree a date and time to do this. Write a list of the things you would like to discuss and take it with you. You won't be able to resolve everything in one conversation - but it will help to start discussing things.

### **Little and often**

If a direct conversation is too much, break it down into small chunks and include it in your regular conversations with them. For example, if you're thinking about arranging your will, you could ask your parent where they had their will arranged.

### **Come back to it at a later date**

People change things in their lives for different reasons. It may be easier to talk to your parent when there has been a change in the family situation. This might be when your brother or sister's needs change, or your parent's ability to provide care changes.

## **Ask someone else to raise the issue**

It can be hard for parents to take advice from their adult sons and daughters. Ask another relative, a trusted professional, religious leader or family friend to raise the topic with your parent or persuade your parent to talk to you about it.

## **Look after your own needs**

Even if your parent isn't able to talk to you about this right now, don't bury your questions and worries. Write down all your concerns and wishes. What would *you* like for your brother or sister in the future? How much involvement would you like in their 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 your ideas with your parent.

Even if your parent 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 brother or sister in the future? Use the prompts on the next page as a guide

## **Further information**

Having information can help you to feel empowered. Some siblings find that exploring the practical topics around the care and support of their disabled brother or sister can help. This might include learning more about:

- Mental capacity and who can make decisions for your brother or sister
- Managing finances and thinking about wills and trusts
- Getting a care needs assessment and the right support

If you need information on these topics (and more), read our [guides for adult siblings](#).

## My thoughts about the future

*The life I would love my disabled brother or sister to have is... (list all your hopes)*

*I am worried about... (list all your concerns)*

*I see myself having no/some/lots of involvement in their care...*

*What can I control and what can't I control?*

*What would help ease my worry?*

You don't have to have definite answers – you just have to give yourself space to think about it. Share your list. Talk to a trusted friend, do research online or seek counselling.

# Your relationship with your parent(s)

*"All their time and energy was spent on my sister" – Sibling*

It's common for parents to focus on their disabled child more than their sibling child. While you were growing up, you may have had less attention, time, energy, love or affection from your parent(s). There may have been topics that were difficult to talk about as a family (such as your brother or sister's future care) or routines that developed that went unquestioned (such as you providing care for your brother or sister). Some parents find it hard to hear advice from or be questioned by their adult sons and daughters and conversations around care can feel too confrontational. These are difficult topics for siblings to address. Your relationship with your parent(s) as an adult sibling matters.

## Having a positive relationship with your parent(s)

Adult siblings often want to have time with their parent(s) that is focused on things other than care and support issues. However for many siblings the pattern from their childhood, of their parents' main focus being on their disabled son or daughter, does not change with adulthood. This can be very disappointing and an adult sibling can feel that they are missing out on sharing their adult lives with their parents.

*"Mum was there for me in a practical sense...but emotionally, she was just never 'there'. Her mind was always occupied by my sister. And it still is." – Sibling*

Some of the issues that arise are:

- Parent not being able to spend time with an adult sibling due to the pressures of care
- Parent only talking about their disabled son or daughter during conversations



- Parent not getting involved with grandchildren as their focus is still on their disabled son or daughter
- Parent not asking siblings about their own needs and lives
- Parent not relating to their sibling son or daughter as an adult, and still very much seeing their disabled son or daughter as a child

“My Mum cried when my brother opened a door, because he’d never done it before. But when I got a new job, she didn’t bat an eyelid. Nothing I do will ever live up to what he does!” – Sibling

Some strategies for dealing with this are:

### **Tell them what you need**

Communicate clearly to your parents about what you need from them:

- A regular meet up to talk about your stuff
- Going shopping/for a coffee together once a month
- Doing a joint fun activity together like going to the cinema
- To have your adulthood recognised and celebrated

### **Set limits on care talk**

- Say that you need to have chats about other things – not just about your brother or sister’s issues
- Set aside a day of the week for an update on your brother or sister. You and your parent can talk about care issues and keep the time for just that
- You can say *“Let’s talk about my sister first for about ten minutes and then let’s talk about my children; job-hunting; decorating...”*
- It is common for parents to offload issues to siblings late in the evening – have a cut off time of day for this so that you can go to bed without having care and support worries at the forefront of your mind
- Make it clear that certain dates such as a child’s birthday or graduation day, are not times for talking about your brother or sisters care issues
- Help your parent find support networks so they have others to talk to

“It can be so tiring having to act as a diplomat and interpreters between my parents’ generation and modern, care providers and their regulations” – Sibling

## Point out new priorities

Talk about the changing dynamics of the family as everyone gets older – partners, children, siblings with health needs of their own, parents needing care too. This is a normal part of all families changing over time. This change can be positive such as being involved as a grandparent or a partner's family helping with support logistics.

"A really big thing that has helped my sister has been talking through with the sibling support group about how to respond to my Mum when I feel she is bullying my sister. My responses used to make things worse for everyone but now I'm able to be more measured so that my sister doesn't become upset if I challenge my Mum but I don't feel that I'm condoning my Mum's behaviour. My responses are also more in line with me treating my sister with dignity rather than seeing her as a helpless victim which I'm sure is building her own self esteem." - Sibling

## Feeling excluded from your disabled brother or sister's life

Parents often worry about their sibling son or daughter taking on caring responsibilities for their disabled son or daughter, as they move into adulthood. This might lead a parent to exclude their sibling son or daughter from their disabled son or daughter's life, when in fact the sibling would like more involvement. Some parents exclude adult siblings from their brother or sister's life by:

- Not passing on important information, such as letting them know about a recent hospital visit
- Not supporting their disabled son or daughter to keep in touch such as helping with a video call
- Not letting other services know that a sibling son or daughter wants to be contacted, for example in emergencies
- Not allowing them to see or spend time with each other

Some adult siblings would like more involvement in their brother or sister's life and care, and some wouldn't. However, this is not the parent's decision to make. **You do not need your parent's permission to have a relationship with your disabled brother or sister who is over the age of 16.** You and your brother or sister are both adults and this is your choice to make about your own relationship.

"My brother's Dad just doesn't involve me and it really frustrates me." – Sibling

Reasons why adult siblings may want to be involved in their disabled brother or sister's life:

- They may love each other
- They have grown up with their brother or sister and share a connection
- They enjoy spending time together
- They care about their brother or sister and want them to have a good quality of life
- They understand their brother or sister's needs very well and gain a sense of satisfaction from helping with care tasks
- Advocating for their brother or sister forms a meaningful part of their life

Adult siblings who have a choice in the role they play in their disabled brother or sister's life, will try to balance this with their own lives, work and family. Being involved doesn't mean a sibling will have no life of their own.

Some strategies for dealing with this are:

### **Tell your parents how you feel**

Your parents may not know how you feel. Tell them how you feel, show them this eBook and help them understand why you want to be involved.

### **Share your views with health and social care professionals**

You can let professionals (such as a social worker, learning disability nurse, GP...) know that you would like to be involved in your brother or sister's care and to invite you to meetings, contact you in emergencies and copy you into letters.

Any decisions which are made in your brother or sister's best interests (for example by social workers), should be made whilst collaborating with those who know them well – including siblings.

### **Keep going**

Remember that your views are important. You have the lived experience of growing up with your brother or sister – others have not had the same experiences as you and therefore cannot offer insights in the same way.

## Feeling pressured to provide care for your disabled brother or sister

Many siblings tell us that a parent has always relied on their support. This makes it difficult for siblings to take a step back from caring for their disabled brother or sister when they want to take time for their own lives, work and family.

"No one has ever asked me what involvement I want in my brother's future – Sibling

Some of the issues that arise are:

- Parent assuming that sibling son or daughter will carry out care tasks for their disabled son or daughter, or putting pressure on them to do so
- Parent assumes that after their death, their sibling son or daughter will become next of kin for their disabled son or daughter and will need to care for them. This is not the case - you have no legal responsibility to care for your disabled brother or sister
- Relationship between sibling and their disabled brother or sister suffers (unable to spend regular brother-sister time together as all time is focused on care tasks; sibling may feel they have little choice in the caring role and may begin to feel resentful...)
- Other areas of a sibling's life are neglected such as their work, partner, own children

"My parents assume that I'll look after my sister every time they want a holiday. They book it and don't even ask me." – Sibling

Some adult siblings would like more involvement in their brother or sister's life and care, and some wouldn't. However, this is not the parent's decision to make. When a sibling has a choice in the role they play in their disabled brother or sister's life, they can balance this with their own work and family life.

**Your involvement in your disabled brother or sister's care, is a decision between the two of you. No one else.**

Some strategies for dealing with this are:

### **Think about what you want**

Spend time thinking about what *you* want to do and how you want your life to be balanced (such as between care tasks, work, own family life). If you don't want to do care tasks at all – that is OK too. If you are struggling with guilt around this issue, have a look at page 12 for some ideas on how to tackle this.

### **Tell your parent what you can and can't do**

Your parent should not assume or put pressure on you to provide support. It is your choice whether you become involved with your brother or sister's care or not. Make a list of caring tasks, and be clear with your parent about what you can and cannot do. When you have more choice and balance as a carer, the role will be more manageable in the long term and you will have a more positive relationship with your brother or sister.

### **Help your parent to find other sources of support**

The local authority\*/local health and social care trust\*\* have a duty to assess your brother or sister's care needs, and to put support in place if they are eligible to receive it. They will only assess your brother or sister's finances – not yours. Your parent can request a carer's assessment from the local authority\*/local health and social care trust\*\*, to support them in their role too. Read our [guides for adult siblings](#) for more information on topics like getting a care needs assessment.

\*England, Wales and Scotland \*\*Northern Ireland

### **Spend time with your brother or sister that isn't focused on care tasks**

Many siblings enjoy spending time with their brother or sister. You may have been doing the same things together for years and need a bit of encouragement to try some new activities together. Have a look at some of the ideas on page 64.

You can't change your parent's behaviour, but you can change your own. You don't have to keep going with the same patterns from your childhood - you can have a different relationship with your parents.

# Your relationship with your disabled brother or sister(s)

When you were growing up, your relationship with your brother or sister may have been affected by a number of things surrounding their disability. These things will have shaped your sibling relationship and may still do today. You might feel very little connection with your brother or sister, you might feel really close and you might be somewhere in between. You might not know how you feel. As with any sibling relationship, it may change over time. These are all normal feelings for siblings to have.

Common experiences of adult siblings:

“There were no local services that were right for my sister, so she went to a residential school miles away. I wasn’t able to see her often and our relationship suffered”

“I didn’t understand my sister’s challenging behaviour when I was a child – I had no information and no support. Our relationship has been very strained.”

“It makes me so angry when people assume my brother can’t achieve anything just because he has Down syndrome – he’s achieved a lot and I couldn’t be more proud of him.”

“It was very hard for my sister when I got married – because she thought she never would (she later did!). But we grew apart for a while.”

“My brother is autistic. He doesn’t say thank you, he doesn’t listen, he can’t reciprocate kind gestures... I care about him and I do things for him, but it’s hard not having this in return.”

“My brother and I went to the same secondary school, where he was bullied because of his learning disability. I was always very protective of him, and I think this brought us closer together.”

### **Accept your feelings**

Accept that it is normal to have mixed feelings about your brother or sister and the impact of their disability. Whatever you feel – know that it is OK. Go back to page 11 to read more about feelings. Remember that you are not alone – there are 1.7 million adult siblings in the UK. There will be others who have had similar experiences to you.

### **Do some research**

Find out more about your brother or sister’s condition(s) or disability. New research may be available and what you knew about it some time ago may have changed, or your brother or sister’s condition may have changed. Read books about other siblings and their relationships with their brother/sister too (see page 31).

### **Seek support**

Talk to close friends or your partner about how you feel – show them this eBook. Join your nearest [sibling support group](#) or [set up a group in your area](#). Seek counselling support if you are finding it hard to cope with your feelings, or are experiencing anxiety or depression.

If you haven’t had the relationship you wanted - don’t beat yourself up. Don’t make yourself feel guilty for things you have or haven’t done in the past. Relationships are complicated and difficult at the best of times. Move forward.

## Enjoying time with your brother or sister

Many siblings enjoy spending time with their brother or sister. You may have been doing the same things together for years and need a bit of encouragement to try some new activities together.

The type of things you can do together will depend on how close you live together, how well you get on (as with any sibling relationship), and your brother or sister's ability to participate in the sort of activities that you enjoy.

"I think I'm more intentional in trying to make sure I have good times when I see my sister and try hard to do things that will make us both laugh, which I think always continues to build a stronger bond between us." - Sibling

## Some ideas for sibling time together

### Visual activities

Going to the cinema; Visiting an outdoor sculpture park; Looking at family photo albums together; Bird watching; Playing on Wii; Going to the theatre; Going to a football or cricket match; Sending picture postcards; Watching funny videos on Youtube; Watching the sun rise or set.

### Touch and movement activities

Riding a bike together on a tandem or chair-bike; Going for a walk; Trampolining; Washing the car; Swimming; Painting; Sledging at a snow-dome; Dancing; Going for a ride on the bus; Getting a massage or a beauty treatment; Pet therapy; Going to a cat café; Jacuzzi; Weeding the garden

### Listening and sound activities

Listening to an audiobook; Downloading some music; Singing aloud together; Going to a music workshop together (such as drumming); Karaoke; Attending concerts and festivals; Identifying birds in the garden by their song; Recording a family member reminiscing about the past and listening together later; Getting free tickets to sit in on a radio or TV show recording; Making a best songs playlist

"It's hard sometimes combining the needs of my family with those of my brother who has a learning disability. One activity is a must though, every time we meet up, we take the car through the car wash – my brother and my daughter both love it and gets us all off to a good start with much hilarity about whether the brushes will come through the windscreen and will we all get wet! None of us ever tire of it!" - Sibling



### **Food activities**

Going out for a meal; Tasting ice-creams; Preparing food together; Going strawberry picking; Food and wine tasting; Visiting a restaurant with an ethnic food you haven't tried before; Making juices and smoothies; Buying at a speciality food shop together

### **Smelling activities**

Visiting a scented garden; Buying perfume together; Aromatherapy; Guided tour of a brewery or chocolate factory; Going to the sea; Lighting different scented candles at home; Choosing spices to cook with

## **Nurture other sibling relationships**

If you have other siblings, think about how your upbringing has shaped your relationship with them.

Common experiences for adult siblings:

"Me and my two sisters are really close. We've had to be. We've been through a lot together growing up and now all three of us are looking out for our brother. We're a team!"

"I do all the care for my half-sister who has learning disabilities and autism. My other sister does nothing. She has pretty much split off from the family."

"The four of us argue about our brother's care all the time...we can't agree on anything..."

"My oldest step-brother had left home by the time my youngest sister (who has cerebral palsy) was born – and he's never really been involved in her care. So it's always felt like it's been down to me and my other older brother"

Think about ways you can nurture your relationship with other siblings you have. It can be easy for time together to be focused on how to support your disabled brother or sister, or elderly parent. Or you may be in conflict about issues of fairness about who provides care or about the best way to manage things. It may not be possible to resolve these issues but it will be easier to work on things together if you are involved in each other's lives in a positive way. Take time to talk about the other things that matter to you both and to spend time just hanging out together.

"I feel like I have been on an emotional roller coaster with Frazer all of my life. I often feel he has been given a raw deal but he is happy and enjoys his life and never complains." - Sibling

## Being an 'only' sibling

You might not have any other siblings and you might wish that you did, as it may have felt quite lonely growing up as an 'only' sibling. Alternatively, you might not identify with that experience at all and you may feel very close to your disabled brother or sister. It really depends on the relationship you have with them.

Some people wish that they had another sibling for emotional reasons (to share the joys and stresses of sibling life) and for practical reasons (to share caring and decision-making responsibilities). But as you can see from some of the sibling experiences above, having more siblings in the family wouldn't necessarily have meant that you'd get along with them or that they would want to share caring responsibilities. Also, siblings of different ages and different birth order can have quite different experiences too – and may not necessarily have shared what you share.

"My Dad left when I was two, so it was just me, Mum and Michael growing up. Me and Mum were really close through looking after Michael"

"Growing up, I felt like an only child – but without the attention an only child gets"

“I think I’m closer to my disabled brother, because it has always been just the two of us. I feel like we’re in this together.”

## Having two or more disabled brothers or sisters

There are many siblings who have two or more disabled brothers or sisters. Sometimes this is due to a genetic condition, sometimes this is due to chance. Siblings who have two or more disabled brothers or sisters may experience all the things other siblings do, but on a more intense level. For example:

“My two sisters both have disabilities and I feel a lot of pressure to be the ‘achieving’ one” - Sibling

- Guilty for not having the disabilities their brothers or sisters do (particularly if they are the only other child)
- Extra pressure to achieve in life, for the sake of their parent
- Extra pressure to provide care, growing up and/or as an adult
- Increased anxiety and fear of the future care, particularly if their brothers or sisters have complex or high levels of need
- Difficulty balancing their brothers or sisters very different needs
- More lost experiences during childhood, as the time a parent had was even more limited
- Significant worries about having their own children with the same condition, particularly if it is genetic
- Increased difficulty accessing facilities, outings and services as a family (for example, places that have space for only one wheelchair not two; difficulty with transport; lack of support staff needed when out in the community)

Your relationship with your disabled brother or sister(s) is yours alone. It’s between the two of you. It’s not up to anyone else (society, your parents, other siblings...) – to determine your relationship. No one can tell you how you should or shouldn’t be.

# Having your own children

*"My friends just assume they'll have kids. For me, there's a lot to think about" – Sibling*

Adult siblings are often concerned about the genetic implications of their brother or sister's condition. This may be something that has concerned you since you were a young teenager, or it may have become a concern recently if you are thinking about having children of your own.

Due to siblings' increased knowledge about disability and health issues, it is possible that siblings think disability is more prevalent than it actually is.

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.

"I worked in the disability sector and having a disabled brother meant that I never saw lots of healthy babies born. Every baby scan I had when I was pregnant was nerve-wracking. My fears were unfounded when my daughter was born healthy" - Sibling

## Genetic counselling

It is important to get accurate information and make informed decisions about having your own children. We have spoken to many adult siblings who have chosen through fear alone not to have children. If you have any concerns at all about your brother or sister's condition being genetic or know that you or your partner have someone in the family with a genetic condition, you can see 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.

## 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 before having their own children. Have open and honest discussions about your feelings and views and this will help you find out if you have shared values about having children and about disability. It can sometimes help to have a fresh pair of eyes and ears, and you may want to get in touch with a relationship counsellor to help facilitate the discussion.

"I knew I always wanted children. I knew it would be hard for my brother as he likes to have all the attention on him. But this choice was about me and my life." - Sibling

Here are some suggested 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
- Arrange a meeting with a genetic counsellor to get information about the potential risks of having a child with the same condition as your brother or sister
- Discuss the pros and cons of either one of you having genetic screening prior to a pregnancy – a genetic counsellor can help you do this
- 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
- Discuss how you would deal with any negative comments about your suitability for having children, from members of your partner's family or friends
- 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

"When the midwife came to see me after the birth of my daughter, she was surprised I was up and about. I explained that after looking after my brother, caring for a baby was a doddle" - Sibling

- 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 parenting skills, understanding behaviour and communication, being able to cope in a crisis, patience, a good knowledge of first aid, and being able to keep things in perspective
- 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

## Look at all the options

There are other options that may be open to you and it is important to explore all of these if you want to be a parent including:

- Adoption and fostering
- Parenting children who have come along with your partner
- Assisted reproduction such as egg donation

## Useful questions to ask yourself

- What would having a child 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?

There are no easy answers here for siblings on this issue. Talking about it to partners and to other adult siblings can really help overcome the sense of isolation often felt by siblings about this.

The decision to have children is a personal one. Don't let fear or pressure make the decision for you. Take your time and work through it in a way that's right for you.

# Your own family life

*"Sometimes it's hard putting other people before my sister (she has always come first). But I'm learning that it's OK to"*

- Sibling

Your relationships with other people in your life are important. Many siblings find it hard to get the right balance of time with their disabled brother or sister, and time with partners and children.

## Partners

Siblings sometimes find that their relationships with their disabled brothers and sisters negatively affect their relationships with their partners. This might be because there are pressures placed on couples and families about the amount of time spent supporting the disabled person and/or ageing parents, or it might be because of unresolved issues from the past about their sibling role.

*"Any partner I have needs to know that me and my sister come as a package" - Sibling*

Sometimes partners feel resentful and angry at the dominance of the disabled brother or sister in a sibling's life. Sometimes the disabled brother or sister is jealous of his/her sibling having an independent life or has been used to a lot of sibling companionship, which then changes when the sibling is in a relationship. These may lead to the sibling feeling guilty about spending time with a partner.

*"My husband struggled with how much my brother dominated my life. He told me he 'hated' what pressure he put me under" - Sibling*

If you want your partner relationship to work you will need to nurture it and make choices about how you use your time.

## **Nurturing partner relationships**

- Spend regular time together doing things you both enjoy – a walk in the park, going to the cinema or a meal out – this can sustain relationships that are under pressure
- Express appreciation for your partner – acknowledge the small things that you admire and are fond of about your partner on a daily basis
- Communication is at the heart of all relationships – make time to talk things through regularly and to listen to each other
- Siblings may know all the small details about their disabled brothers and sisters lives and not know much about their partner's life – take time to learn about your partner's work, interests, views and feelings

“My girlfriend didn't have any experience of disability, but she didn't need to. Her attitude towards my brother said it all – she was just open to getting to know him” - Sibling

## **Balancing responsibilities**

- Set clear limits for your brother or sister. For example, if your disabled brother insists on ringing every night when you both get in from work, try to find alternatives – talk to care staff or other family members about what works better for you.
- Try not to let your relatives dominate both of your lives – make sure you spend time with your partner's family too. It might be that other relatives could take on some of the support or care or that more services are needed. Is what you are doing realistically manageable with your other responsibilities?
- Is there a role for your partner in supporting your brother or sister? Sometimes partners feel they have little to offer in supporting your brother or sister and don't know him or her like you do. They may have valuable skills they can use and want to be included, for example, managing finances, chairing family discussions about the future or interviewing personal support assistants.

“I found a partner who welcomed with open arms both my siblings (which was my first and most important requirement). She is now a major part of their life, as they are of hers.” - Sibling

## **Seeing things from the other's perspective**

- More often than not your partner has your best interests at heart. Arguments often arise out of worry and concern about how caring might be affecting your



health and wellbeing. Take a step back from time to time and consider what the situation might be like if your roles were reversed

- Equally it may help if your partner understands more about what being a sibling is like. Perhaps you could ask them to have a look at the Sibs website and this eBook

## Getting help

If you feel like your conversations are going around in circles – or they're not happening at all – give relationship counselling a try. It can really help to have a fresh perspective on the situation from someone who is viewing it from the outside. The charity [Relate](#) offers relationship and family counselling and can provide this to you individually or as a couple/family.

## Children

If you have children under 18 you have parental responsibilities for them that should be prioritised over and above the needs of your adult disabled brother or sister. As a sibling growing up you may have experienced the impact of having less attention or feeling less important than your brother or sister – so you will know how important it is for your own child to have your focus and involvement.

Siblings often feel that they can continue to spend a lot of time being with or supporting their brother or sister after they have a child. However the reality is that once siblings have children of their own, their priorities change and their available time and energy changes.

Make sure that your own children are your first priority and that you are spending more time with them than with your brother or sister.

## Friendships

Friends come in all shapes and sizes – some might be really easy to talk to and you might chat about your sibling situation a lot. Others might find it difficult to understand and you might not bring up the subject very much. It can help to have both sibling friends and non-sibling friends.

"I have a few sibling friends. I turn to them when I know no-one else would 'get it' or actually even believe what's just happened!" - Sibling

## Sibling friends

The benefits of having sibling friends:

- Understand what sibling life is like
- Share the joys and challenges
- Listening ear and mutual support
- A reminder that you are not alone
- Can be particularly helpful if you are an 'only' sibling or if you don't get along with your other typically developing siblings

Sibling friends can feel especially important if you don't have much support from your parents or wider family too. You may have shared some really difficult times with your sibling friends and become quite close, whilst not actually sharing much about other areas of your life. You may have sibling friends from all backgrounds – perhaps people you have not much else in common with. It can also be challenging having sibling friends at times – sometimes, you may just want a bit of time away from sibling issues and experiences and you may want to talk about other things.

“Unlike bereavement, financial worries, relationship issues, the usual family challenges, this is something I have never been able to discuss shared experiences with. Friends can be sympathetic and understanding but will not contribute to a conversation in the same way as another sibling.” - Sibling

## Non-sibling friends

The benefits of having non-sibling friends:

- Different conversations and time away from sibling life and issues
- Friendship based on another aspect of yourself and your identity (such as a shared hobby)
- Healthy opportunity to have your 'own' life that doesn't centre around your brother or sister. You are a sibling, but you are not *only* a sibling – you are much more

“My friend Karen says she was nervous about meeting my brother because she knew I wouldn't have any more to do with anyone who didn't get on with him. Thankfully they hit it off and are part of each other's lives” - Sibling

Non-sibling friends can also be a bit frustrating sometimes! It can be difficult to talk to them about sibling issues – they may not fully understand what it's like. It's also quite normal to feel resentful of your non-sibling peers. Their problems may seem insignificant compared to the wider perspective you have developed. It can be difficult to see your non-sibling peers with less responsibility than you have.

Your non-sibling friends may have good intentions and may want to understand a bit more about your sibling life. If this is the case, ask them read the Sibs website or this eBook. There are small ways that they can help you, that don't have to centre around sibling conversations. For example, if your non-sibling friend knows and understands that you came second a lot during childhood they may be happy to let you 'go first' in your friendship.

Make sure your successes are celebrated! Find support from those who care about the things that are important to you. Post it on Facebook, go to the cinema or have a drink with friends. Find ways to mark your important life steps.

# Being a sibling carer

*"I promised my Mum I would always look after him and I have" – Sibling*

As an adult sibling of someone with a disability you might provide advocacy and support for your brother or sister, but may not have thought of yourself as a carer.

## Caring tasks

Some adult siblings think of a 'carer' as an unpaid family member who lives with their brother or sister and helps with:

- Washing and dressing
- Making meals and drinks
- Cleaning and laundry

But the definition of a carer is actually much wider than this. Think about what you do for your brother or sister that you wouldn't do for an adult without a disability. This might include:

- Answering the phone to your brother five times a day when he calls for support or because he is lonely
- Reading through bills with your sister and helping her to understand them
- Advocating for your brother's needs at meeting with a social worker
- Phoning a hospital when your sister is admitted to let them know how she prefers to communicate

"I have been challenged by members of the sibling group to think about what I am choosing to help with in terms of supporting my sister. Instead of a burden I can see this as more of a privilege. Also we have talked in the group about circles of support and I can see that my sister has a lot more people who can support than just my Mum and me. This is a huge weight off my mind." - Sibling

You do not need to live with your brother or sister to think of yourself as their carer. Some siblings consider themselves 'distance carers'.

You might also find that you are providing emotional and practical support to your parent(s), who are supporting your brother or sister such as:

- Listening to them while they share their worries about your sister going to a new day centre
- Looking up information about relevant laws online so that they receive all the support they are entitled to
- Employing and paying for practical outside support, such as a cleaner
- Only telling them about the 'good things' going on in your life and not sharing your own worries/stresses because you feel that they have enough worries and stresses caring for your brother or sister
- Not asking for your own support that you might have done otherwise, for example asking your parents to babysit their grandchildren

"As an adult sibling carer to my disabled brother and sister, their health is a constant worry to me. I worry that paid carers won't fully understand how important it is to maintain their routine and eating habits – which have helped fend off seizures." - Sibling

## Recognising yourself as a sibling carer

Recognising the role that you play in your brother or sisters life can help you to access more support for yourself.

"Other relatives "help" but I have to drive everything." - Sibling

Benefits of recognising yourself as a sibling carer:

- Protection from discrimination under the [Equality Act 2010](#)\*
- Right to request flexible working hours and to have time off in [emergency situations](#)
- Recognition of your role within other services. Some [GP services](#) allow sibling carers and their disabled brother or sister to visit the surgery at the same time to avoid two trips
- Having a [carers assessment](#), to look at the support you need to continue your caring role
- May be entitled to [carers allowance](#), depending on the number of hours you provide care

\*England/Wales/Scotland. In Northern Ireland you are protected under the Human Rights Act and Section 75 of the Northern Ireland Act. This requires public bodies to promote equal opportunities for carers.

## Help others to recognise you as a sibling carer

It can be hard to cope with being a sibling carer, if your non-sibling friends, partner or colleagues don't fully understand what it is like for you. You might hear comments like "*take a step back*" (when there is no one else to 'step up') and "*Your brother will be fine*" (when you know that he won't). Another common response when you share day-to-day challenges might be "*but this isn't your responsibility!*".

"It frustrates me when people ask 'Why you?' when asking about my caring commitments. Because I love him! No one is forcing me!" – Sibling

People don't understand that you have grown up with your disabled brother or sister, and your life may have always revolved around their needs. You may have the longest standing relationship with them. You may be the only living relative your brother or sister now has, or you may be a sibling carer alongside other family carers.

Highlight the sections of this eBook that reflect your experiences as a sibling, and share them with the non-siblings in your life. Explain what your experiences have been like and what your hopes are for the future. You need the people around you on board.

## Look after yourself too

Many adult siblings provide support, advocacy and care for their brothers and sisters, at the same time as juggling support and care for their elderly parents, their own children, and their work.

"Sometimes we have had to accept we have done all we can and tried our best. It is exhausting." – Sibling

It's important to remember that **you do not have any legal responsibility to care for your disabled brother or sister** - it is your choice whether you become involved in their care or not.

"Caring for my brother is very isolating and the responsibility huge. After the support group, I had more energy and an idea of what to try next" – Sibling

If you are not able to continue with part or all of your caring role, contact adult social care in your brother or sister's local authority\*/local health and social care trust\*\*. Ask for an assessment of your brother or sister's needs – they have a duty to carry this out.

You might feel that you have to provide care for your disabled brother or sister. But what you have to do is 'put your own oxygen mask on first'. You will be unable to care for your brother or sister if you become burnt out and ill.

Read more about getting care needs assessments and coping as a carer in Sibs [guides for adult siblings](#).

\*England, Wales and Scotland \*\*Northern Ireland

You must 'put your own oxygen mask on first'. Self-care is not an optional luxury, it is an absolute necessity. You will be unable to care for your brother or sister if you become burnt out and ill.

## Stress

Stress can make you feel tense, exhausted and irritable. You may find that you have difficulty sleeping, feel anxious or tearful. It's the feeling that your demands are outweighing your resources – there is more on your plate than you have the time or energy to cope with. Sometimes, it can feel impossible to reduce the demands and you can feel like you are losing control.

"Many people assume the stress comes from your disabled siblings. I fiercely love my brothers and would (and do) do anything for them. The stress comes from the system that's broken and failing us all." – Sibling

Situations that cause some sibling carers stress include:

- Providing direct care to their disabled brother or sister, day in, day out, without enough breaks provided by the local authority
- Practical difficulties of caring from a distance and the strain of the travel
- Managing challenging behaviour from their brother or sister and receiving little support to do so
- Disagreements with parents over disabled brother or sisters care
- Large amounts of time spent on the additional life admin that comes with being a disabled person (liaising with carers, health appointments, certain travel arrangements, access requirements)
- Lengthy and complicated forms – for benefits, assessments, housing
- Making phone calls to organisations and local authorities – being passed from person to person, kept on hold, not receiving a response

- Having to drop everything for emergency situations on a regular basis – hospital admissions, carers not turning up for work, mental health or behavioural crisis
- Making complaints about inadequate services and care
- Attending meetings or appointments both with and about their disabled brother or sister
- Juggling multiple responsibilities – caring for disabled brother or sister alongside parenting, work, caring for elderly parents
- Being disregarded by professionals – not invited to meetings, included in decision-making, not given proper information, having their opinion ignored
- Finances – not being able to work, carers allowance not enough, extra costs of caring

The UK health and social care system is inadequate and difficult to use. The task of making sure that a disabled person has a safe, happy and healthy life can be an enormous one. Many people do not realise that the additional administration and organisation can take enough time, effort and skill that it could easily be considered a part or full-time job in its own right. All of this means that stress can be very common for sibling carers – but it should not be ignored.

## Coping with stress

### **In the moment...**

Accept that you cannot do everything. This is very hard for siblings who are used to being the person in the family who 'fixes things'. What you consider to be 'bare minimum' may be someone else's 'going above and beyond' – you may have very high expectations of yourself. Sometimes just acknowledging to yourself that you are human, not super-human, can begin to ease feelings of stress.

Experiment with mindfulness and meditation apps (like [Calm](#) or [Headspace](#)), breathing techniques, relaxation and yoga until you find something that helps you. It could be a five minute technique or a 30 minute session, but your body needs that respite from the feelings of tension, frustration and anxiety. It needs to wind down.

### **Every day...**

You must look after yourself and meet your basic needs. You wouldn't put diesel in a petrol car. You wouldn't let your children stay up until midnight and get a terrible night's sleep before school the next day. You need food, exercise, sleep and relaxation. We don't say this flippantly and we know there will be times when this is not possible. But



you must strive for it on a daily basis, because *you matter*. This can really help to combat day-to-day stress.

If you find yourself saying "*I don't have time to look after myself*" then you need to make some longer term changes (see below), so that you can. As a sibling carer, you will not be able to help your disabled brother or sister if you become burnt out and ill.

### **Longer term...**

Sometimes stress is short term – it's about a particular event or circumstance that will soon change. Sometimes stress is long-term - you may have gradually taken on more and more caring tasks for your brother or sister over time and it could be too much. Look at what you're spending time on in your life and what you want and need to change.

It might be that you need more help with the school run, a carer's assessment, to see your GP, more respite, a change in your brother or sister's care package or more practical help at home. Sorting these things out can add to your plate in the short term, but will make a difference in the long term. And if they improve your health – they are worth doing.

*More from Mind.org.uk – take a closer look at the [signs of stress](#), developing [resilience](#) and available [treatments](#).*

## **Carer compassion fatigue**

Siblings who experience compassion fatigue may notice feeling physically and emotionally exhausted. They may have the feeling that they 'just don't care anymore' and that their feelings of empathy and kindness towards their brother or sister have run out. Compassion fatigue is different from burnout. Burnout tends to build slowly over time, whereas compassion fatigue can come on more suddenly. Compassion fatigue tends to be the result of providing intense care for someone, especially through very difficult or traumatic circumstances.

Compassion fatigue is something many people experience – you are not alone. Any feelings of guilt or shame that you might have for feeling this way are unwarranted. You can reduce the risk of developing compassion fatigue by striving to look after yourself as a carer – taking care of your physical, mental and emotional health as much as you can. If you have already experienced compassion fatigue, you need to re-dress the balance to

include more time to care for yourself. You may also need to speak to your GP about accessing counselling.

## 5, 15, 50

We have all said 'I don't have time'. It's hard to prioritise one thing over another, and you cannot please everyone, all of the time. Here are some self-care ideas that you can do in 5, 15 and 50 minutes.

### Five minutes:

- It is essential to take breaks from caring. Write down in your diary or calendar when you will take your next break from caring
- List the positive – what is going well for you or for your brother or sister and their care right now? It can be all too easy to focus on what isn't going well
- Stop. Close the door. Sit. Set a timer on your phone for five minutes. And just pause and breathe. Sometimes we keep ourselves busy as a way of hiding from our feelings. Just take five minutes out, to sit and breathe

### Fifteen minutes:

- Stop. Close the door. Make a cup of tea. Sit down and drink the cup of tea and do nothing else. Do not look at your phone. Do not read an email. Sit and drink the tea
- Read one short article about your brother or sister's condition(s) or disability - new research may be available. It might help you to understand some of the reasons they are as they are such as that some behaviours may not be personal to you
- Do something that YOU enjoy, just for the sake of it – and keep it nearby so that you can dip in and out of it. Something that you can absorb yourself in will make a difference (such as ipod and headphones; favourite magazine; top three favourite Instagram accounts about nature; cryptic crosswords book). Small moments do add up, they give you a vital mental break and can improve your overall wellbeing

### Fifty minutes:

- Be listened to. Whether you go to a counselling appointment, call a good friend, spend time on an online group or forum, or just write down all your thoughts and feelings and read them back to yourself – it needs to be done.

As a sibling, you may well have had less time than others to have your thoughts and feelings heard and as a carer you need this the most

- Information is empowering. It can make you feel more confident. Our guides are written by siblings, for siblings and will help you to feel less alone too. Read our [guides for adult siblings](#) on the practical aspects of caring, supporting and advocating for your brother or sister. But make yourself a cup of tea first and sit down with it
- Send an email to a close friend and open up a little about your situation as a sibling. Ask them to read pages on the [Sibs](#) website or this eBook that you relate to, so they can understand the challenges you face as a sibling which are not yours alone

## 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 such as '*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.
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 (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\*/local health and social care trust\*\*. 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. Alternating the school run with a friend, could free up 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 such as 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 (such as list of allergies) and delegate tasks to manage a person's care. Research other solutions to care issues to see what is available.

\*England, Wales and Scotland \*\*Northern Ireland

Keep your head held high when you're talking with health and social care professionals and don't let anybody cut you out of meetings or ignore your views. 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.

# Siblings and work

*"I use so many of my sibling strengths at work" – Sibling*

Being a sibling can impact on your working life in a number of positive and challenging ways, such as:

- Being a carer for your brother has dictated what hours you can work (not at all, part-time, flexible hours...)
- Concerns about the future and who will look out for your brother or sister after your parents have died has dictated where you live and therefore, what options for work you have
- You bring enormous strengths to your work as a result of your sibling experiences such as being able to respond calmly in an emergency, being emotionally resilient and self-sufficient, being a naturally caring person, being good at problem solving
- You do paid or volunteer work in a field that directly relates to your experiences growing up with your brother or sister and you are naturally very good at it – such as special needs teacher, speech and language therapist, disability researcher

"I'm a special needs teacher. It's interesting how I just ended up in it, but being a sibling has made me better at my job. I have a better level of insight into the needs of people with disabilities." – Sibling

"I am the person I am because of my experiences. It is a unique view on the world that cannot be learnt. My levels of empathy and tolerance are part of that experience." - Sibling

As a sibling you will have some fantastic strengths that you can apply to paid or volunteer work. Think about what you have experienced that others haven't. What skills have you developed as a result? Make a list of these, celebrate the positives and importantly – make use of it at your next job interview!

## My sibling strengths

*Many siblings develop skills and knowledge through their sibling experiences in areas such as psychology, social care, parenting, teaching, communication, behaviour management, campaigning....*

What strengths have I gained as a sibling?

## Telling your employer and colleagues

It is up to you whether you tell your employer and your colleagues about the sibling-side of your life, and how much you tell them. You have no obligation to disclose anything you don't want to or don't feel comfortable with. You might be worried about how much people will understand your situation. Will they really 'get it'? It is understandable to feel this way, because adult siblings' needs and experiences are not fully understood in wider society.

If you are a sibling carer – and that includes caring from a distance and supporting your parents with providing care – it could help to let your employer know about your responsibilities. As a carer, you have a right to request time off for emergencies and flexible working, so it can be helpful to use that word even if you also see yourself as a sibling and a friend to your brother or sister mostly.

When colleagues ask about your weekend or what you're doing over the holidays, it might be easy and natural for you to talk about your brother or sister openly and it might be met with understanding. It might also be difficult for you because you face judgement, stigma and a lack of understanding from colleagues. Share what you feel comfortable to. You don't owe anyone an explanation and it is OK to say whatever you want to say.

“How much do I say about my sister? It depends who I'm talking to. I'll give more detail with close friends, but I'll tend not to say much at work. People would understand if she was in a wheelchair or had cancer, but she's autistic and she doesn't 'look' disabled so people don't really get it. It's exhausting having to explain to people why she doesn't work when people ask about her” – Sibling

“My brother has Down Syndrome and I'm so proud of what he has achieved. I'm always giving out flyers at work about his latest theatre performance or a sponsored walk that he's doing. My colleagues have been really supportive and it feels no different talking about him than my sisters. My boss knows I pick him up and take him swimming on a Thursday so I finish work early” – Sibling

# Bereavement

*"When people ask how many brothers I have, I always say two even though my disabled brother has died" – Sibling*

You may have experienced the loss of your disabled brother or sister, either during your childhood or as an adult. Whatever your age at the time, your loss is real and significant. Losing a brother or sister will have a profound effect on you and those around you. It has been said that: *'When a parent dies you lose the past. When a child dies you lose the future. When a sibling dies you lose the past and the future.'*

*"It wasn't until my sister died that I began to understand the impact she had on my whole life" - Sibling*

## Sibling bereavement in childhood

Parental grief:

- Your parent's own grief may have meant they were unable to support you with your own grief. You may not have had any support from either family or professionals
- Your parent(s) may not have talked to you about your brother or sister when you wanted to know more about their illness, their death, or to share memories

Guilt:

- You may have misunderstood the cause of death and felt guilty that you were in some way responsible for it
- You may have felt guilty about things that you did or didn't do with your brother or sister
- You may not have had an opportunity to say goodbye in the way you would have liked



Family life not the same again:

- You may feel that you also lost the family life you knew before your brother or sister's death. Some families become very dysfunctional after a child's death
- The relationship you had with your parents may have changed. For siblings of terminally ill children, this may have happened some time before the child's death

Complicated grief:

- Some siblings find the original bereavement of their brother or sister is intensified or relived following the death of another relative, friend or pet, and that their reaction to a subsequent death is, in their view, out of proportion to the loss. This is a frequent experience for siblings who have not had the opportunity to grieve openly for their brother or sister
- Childhood sibling loss can affect how adult siblings raise their own children, for example experiencing fear when their own child reaches the age their brother or sister was when he or she died

## Sibling bereavement in adulthood

### **Disenfranchised grief**

Grief is a response to loss. It is different for everyone and each bereavement you experience will feel very different. You may find yourself coping differently this time around to how you did with a previous loss.

"I feel lost without him. I don't know what my life will look like now." - Sibling

Adult siblings often experience disenfranchised grief i.e. the way you grieve is not considered socially acceptable or the grief isn't considered worth it. Loss of a disabled brother or sister sometimes means that their death and its impact are not fully acknowledged – some deaths seem to be less valued than others in society. People may say things like: *'Well you knew they were ill..'* *'Her health has always been bad...'* *'He wasn't expected to have a full life expectancy...'* *'It's for the best, you won't have to be his carer now'.*

### **A continuation of earlier grief**

Siblings who have grown up with a disabled brother or sister may experience grief at different stages of their life. For example, grief for the brother or sister they did not have, or grief for a brother or sister they might lose one day. You may have experienced the death of another family member recently too.

## **Other family members grieving**

At a time when you need the support of parents or other family members, you may find that they aren't able to be there for you because they are grieving too. You may feel the loss of this support very strongly. You may feel guilty because the grief of others seems more justified or that your grief is trumped by the grief of others.

"When my autistic brother Kevin died in 2015, I was deflated – shedding tears alone didn't seem to be enough to let loose the unbearable sadness I felt." - Sibling

You may be supporting your parent(s) with their grief and not had the space to grieve. You may feel you have to help your parent find a new purpose in life, if all of their energy and purpose was around looking after your brother or sister. You may be very concerned about how they will cope and if he or she will be motivated to look after themselves properly.

Adult siblings are often used to putting their needs second place to another person and you may find it difficult to acknowledge your own grief and your need for support with this.

## **Loss of role and identity**

You may have been one of the main caregivers for your brother or sister and may feel a loss for the caring role you undertook.

Many adult siblings' identity is closely connected to that of their disabled brothers or sisters and you may be asking '*Who am I without them or without this part of my life?*' You may have often been referred to as someone's sister or brother since childhood. The work you do or the social networks you have may have been influenced by your identity as a sibling.

You may also have unfulfilled expectations. For example, your parent may now want to get on with their own life at a time when you had hoped that they would be able to spend more time with you.

## **Feelings**

Intense feelings: At different times you may experience acutely intense feelings of grief – these may be happening a lot or may be triggered off by something you see, hear, smell, etc. or may happen when you have a family gathering or around a specific date or

occasion. Some people struggle to cope with upsetting intrusive thoughts that they cannot get out of their head, especially at night.

**Anger:** You may feel very angry that services or treatments were not available for your brother or sister, or that he or she was treated with less dignity than others in hospital or a care home. There may

have been neglect or negligence in your brother or sister's care leading to their untimely death and you want to seek justice on their behalf.

**Guilt:** You may feel guilty about things like – how much time you have spent with your brother or sister; resentment about care tasks; relief that you will not have to care in the future; having survived...

**Loneliness:** You may be the only sibling left in the family and begin to question your own mortality. As well as missing the time you spent with our brother or sister, there may be no one else in your family now with a shared history of your childhood and all the unique things that your family did.

Your position in the family may have changed – perhaps you have become the eldest or the youngest sibling. It is often difficult to find the right words to the question '*How many brothers or sisters do you have?*'

## Coping strategies

Remind yourself that you are resilient. No matter how difficult this is or has been, you are here today and you have been leading your life since the loss, and that you will find the strength and resources to be able to continue to do that.

### **Feel your pain and express your grief**

It's important to allow yourself to experience the pain of losing your brother or sister. As a sibling you might feel that you should just 'get over it'. But unmet feelings don't disappear – they will only come up again at other times. We need to experience the powerful and painful feelings, in order to find a way of living with the loss.

Some siblings express their grief by talking about it. Finding a listening ear from a friend or family member to talk about your feelings of sadness is a good way of processing your grief. It is important to share how you feel. You may feel the need to talk about

"Now my brother has gone, my parents focus is all on me for the first time in my life. I am not sure how I feel about it. I have never come first." -

Sibling

some aspects of your grief over and over. This is normal. It is also important if you can to have a good cry either by yourself or with others. It is an important part of the grieving process.

Some siblings find talking about their loss too difficult or that it doesn't help them and it may be useful to find other outlets for your grief. You might need to shout, scream or cry. Keeping a diary for example, might help you process your feelings but is also a good way of seeing how things are going for you over time. You might express your grief through music, art, or perhaps putting together a memory box to remember your brother or sister. Remember your grief is unique to you. You may behave in ways that you don't recognise, but difficult experiences call for different methods of dealing with them. Focus on what you need as much as you can.

**Keep healthy.** Looking after your physical health is a good way of keeping you mentally healthy. Take regular exercise and make sure you eat and sleep as well as you can. Exercise is a good way of releasing endorphins, which can help improve your mood. Walking, running, yoga, swimming and gardening are things to try and you may have other activities that work for you. Remember that relying on drugs and alcohol will only give you temporary relief and can lead to future dependence.

**Be kind to yourself.** It's OK to take a break to do something nice for yourself – grieving can be hard work. Remember it is perfectly OK to laugh and enjoy yourself even though you are bereaved. Life does go on and grief is best described as a rollercoaster – there will be ups and downs.

And it's important to keep being kind to yourself too. Try not get bogged down in regrets about what you might have done differently in your relationship with your brother or sister, or what you did or didn't say. If you can let go of these regrets it will help you to focus on some of the good memories and the positive things. Some grief is complicated because of negative relationships or the manner in which your brother or sister has died – you may need extra support to process these feelings.

Give yourself plenty of time. There is no set time or pattern for grief and it varies for all people. Be patient and take the time you need, without feeling pressure. Also, it is best not to make big decisions soon after brother or sister has died. Give yourself the time and space you need before returning to these.

**Maintain a bond with your brother or sister.** Although your brother or sister has died, this doesn't end your relationship with them. If you were used to regular contact with your brother or sister (for example, telling them your news) then perhaps continue to do this by emailing or writing this down. Many people continue to have conversations with the person who has died. Some have a sense of their presence or experience them in dreams.

### **Find meaning in the loss**

- Some siblings may need to find out more details about how their brother or sister died. This will be a particular challenge if your brother or sister's death was unexpected or preventable.
- Some siblings find it helpful to look for meaning in the loss. This could be by recognising how your relationship has shaped you and the strengths you have developed as a sibling.
- It can help to re-imagine the future. Allow yourself to think about ways in which parts of your future may be positive for you. It will be a very different future but with aspects that are now possible for you that were not previously possible.
- Spend just a few minutes each day to notice three things that you are grateful for in your life at present. These may be small everyday experiences like 'enjoying a nice cup of coffee' to 'feeling glad that I have a close friend who cares for me'. For the small amount of time invested, this activity is surprisingly effective at improving wellbeing.

**Seek extra help.** If you feel you might be developing [anxiety](#) or [depression](#) in addition to the [grieving process](#), it's important to talk to your GP about this. Some people can get very 'stuck' in certain feelings – such as the feeling that grief will always be this painful and that there will never, be anything, good about life again. Talking therapy can help you explore these feelings and move through them.

Some people find peer support helpful. Being with people who understand what it's like is can be both supportive and empowering. Hearing about the coping strategies used by others can give you the permission or motivation to try similar things.

## Bereavement support

- Speak to your GP about local bereavement support
- [Cruse Bereavement Care](#) – support during loss and grief
- [The Compassionate Friends](#) – for parents and their families; including specific support for siblings

## Books on sibling bereavement

White, P,G.(2006)

Sibling Grief: Healing after the Death of a Sister or Brother

iUniverse

Farrant, A (1998)

Sibling Bereavement: Helping children cope with loss

Cassell

(Adult siblings share their experiences of sibling loss in childhood)

You never stop being a sibling. Some siblings feel that they don't share the same experiences as other adult siblings because they don't have the same concerns about the future or about care, if their brother or sister has died. But once you're a sibling, you are always a sibling. You will have been shaped by the experiences you've had.

# Further support

## How to find a counsellor

If you've been affected by this eBook, you might be thinking about having counselling to talk through some of your experiences. Talking doesn't change what has happened – but it can change how you feel about it. As an adult, this can help you going forward and stop you from being held back by habits or feelings that might be limiting how you live your life.

You can:

1. Go to your GP, explain how you are feeling and ask what counselling services are available in your area. Your GP may need to refer you, or you may be able to self-refer – it depends what is available.
2. Find and pay for a counsellor privately.

## Finding a private counsellor

The terms 'counsellor', 'therapist' and 'psychotherapist' are often used interchangeably. It can feel a bit daunting searching for someone to begin with, so take your time and read up on what you need to.

1. **Search online using accredited directories** – such as the [UK Council for Psychotherapy \(UKCP\)](#) and the [British Association for Counselling and Psychotherapy \(BACP\)](#).
2. **Narrow down the search** with words like 'family', 'relationships', 'disability', and 'autism' if these are relevant for you. A counsellor with a background in these areas may be beneficial.
3. **Search by postcode** and consider the distance you are able to travel. You may feel a bit worn out after a session, so it is worth thinking about the time and distance you're prepared to go.
4. **Read more about the type of therapy** someone offers on the [UKCP website](#). You can also call the UKCP for further advice.

What to ask a private counsellor:

1. **Most counsellors offer a short, free, phone consultation.** Make use of this, and ask as many questions as you would like. Everyone is different and it's important to find someone you feel comfortable with and who is a good fit for your needs.
2. **Always ask a counsellor about the training and qualifications they have.** There is no legislation that regulates counsellors – anyone can set up a website and decide to offer this service. Training courses can vary, from a few months to a few years.
3. **Ask them about their experience of working with siblings** or more generally with families where a person has a disability. If they don't have any experience in this area – it's not necessarily a barrier to you seeing them. What's important is that they are willing to listen and to understand. It may help a counsellor to read pages of the Sibs website or this eBook to understand sibling issues more widely and to have that context.

It is OK to try out a few counsellors before finding one to have ongoing sessions with. Every counsellor is different, and it's important that you have someone you feel comfortable with.

“Having counselling has had a beneficial impact on how I think and feel about my family relationships, and allowed me to move forward in terms of dealing with my feelings of guilt, sadness and loss associated with my brother's disability.” - Sibling



## Questions to ask a counsellor

*What is important to you? What would you like a counsellor to have experience in or to understand? What training and qualifications do they have?*

## Next steps in supporting yourself

What two actions will you take this month as a result of reading this eBook?

1.
2.

## Feedback

We would love to hear what you thought of this eBook. Drop us a line at [info@sibs.org.uk](mailto:info@sibs.org.uk) or fill in this [feedback form](#).

## Further support from SibS

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](#) LinkedIn [company/sibs\\_2](#)

SibS relies on donations and grants to support siblings. If this eBook has helped you, please consider [making a donation](#) or become a [Friend of SibS](#).