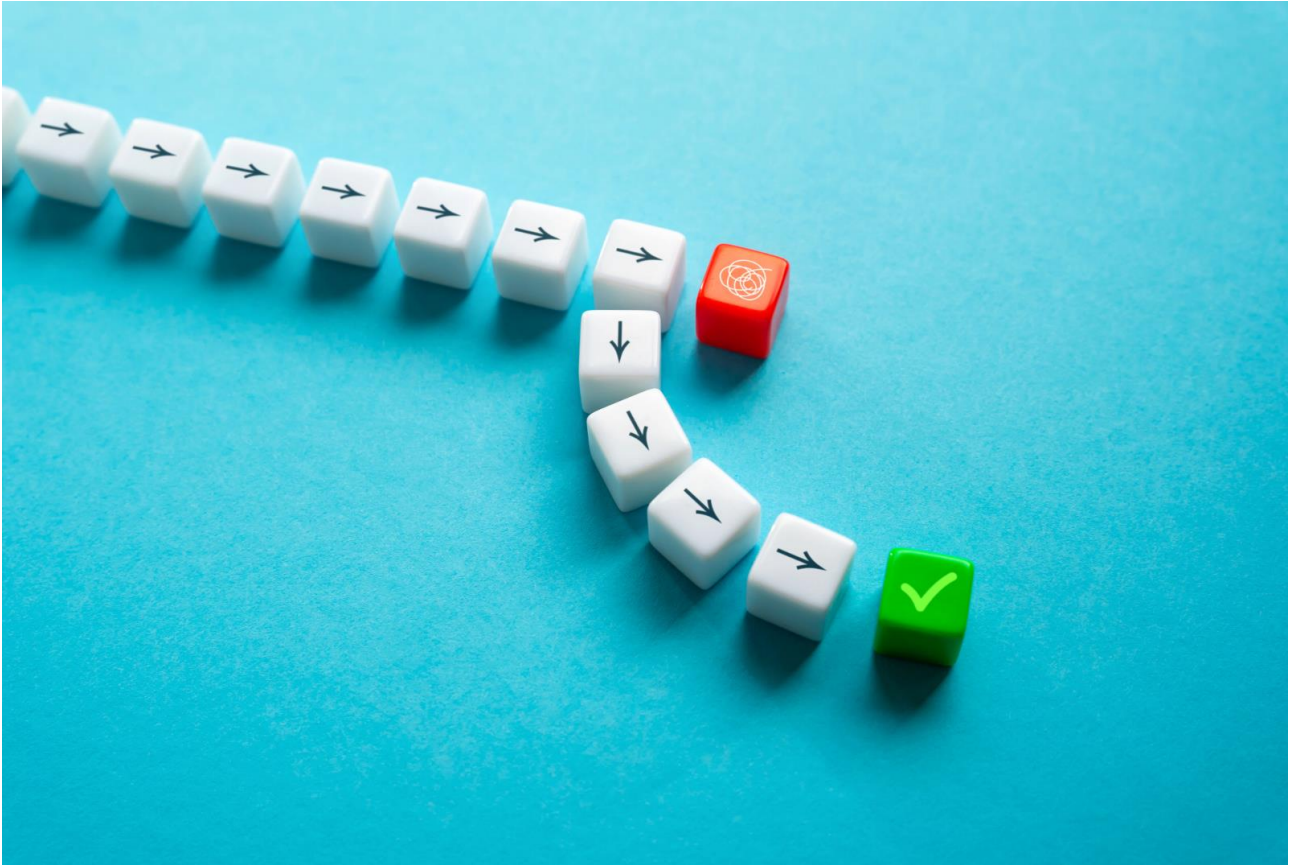


Sibs

For brothers and sisters
of disabled children and adults



Behaviour that challenges

A guide for adult siblings of people with a lifelong learning disability and/or who are autistic.

- What are behaviours that challenge?
- Why does my brother/sister do certain things?
- What can I do to support them and support myself?

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

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Welcome

Welcome to Sibs, the UK charity for brothers and sisters of disabled children and adults. Growing up with a brother or sister who has a lifelong disability and/or who is autistic can be a complex and challenging experience. Siblings often juggle multiple responsibilities and rarely receive recognition for their role. We've written this guide specifically with you in mind and we hope that it helps guide you through your questions. The guide assumes that your brother or sister is aged 18 or over, and lives in England, Wales, Scotland or Northern Ireland. If you're reading this, it's likely that you give emotional or practical support to your brother or sister. Siblings are used to coming second (or third, or fourth...) to the needs of another, so make sure that you seek support for yourself too. Go to www.sibs.org.uk/adultsiblings to find out more.

More guides from Sibs

Other guides available in this series include:

- Coping with managing care
- Decision-making
- Future planning
- Getting a care needs assessment
- Making a complain
- Managing money
- Savings, wills and trusts
- Talking to parents

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

More support from Sibs

You're not alone! Did you know there are over 1.7 million adult siblings in the UK?

- Meet other siblings at a support group www.sibs.org.uk/groups
- Chat with other siblings on our private Facebook community www.sibs.org.uk/sibliffe
- Download our eBook 'Self-care for siblings' www.sibs.org.uk/ebook

Disclaimer

We have made every effort to ensure that the information in this guide is accurate and up-to-date. Sibs cannot be held responsible for the outcome of any actions you may take as a result of reading this guide. This guide does not replace legal advice. Written March 2024.

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Thanks

We would like to acknowledge Dr Nick Gore for his help and expertise in supporting us with the preparation of this guide.

My brother has learning disabilities and he can be violent towards people.

Why is it called ‘behaviours that challenge’?

‘Behaviours that challenge’ is a wider range of behaviours than physical force alone. It describes a range of behaviours that result in harm to either the person displaying the behaviour or those around them. Harm may include physical and emotional impacts and the person (or their family) being unable to access the community. Examples of behaviours that challenge might include:

- Eating everyday objects such as clothing, pillows, cigarette butts
- Destructive behaviours including throwing, breaking or tearing objects
- Self-injury like hand biting, eye poking or head banging
- Hurting others through biting, pinching, hitting, head butting, hair pulling
- Repeatedly screaming, shouting and swearing
- Other behaviours such as smearing faeces, spitting, removing all clothing in public, running away

It’s described in this way because it is behaviour that challenges both the person and/or others around the person - such as family, staff and members of the public. This language is important because it takes the emphasis away from the whole person as the problem. It focuses on the impacts of the behaviour and how others can respond to it. Behaviours that challenge are harmful but people who display these behaviours are not purposefully trying to create harm.

Everybody behaves in a certain way for a reason. Behaviours that challenge are no different. People who display behaviours that challenge are often faced with a range of difficulties that influence their behaviour. In particular, people who display behaviours that challenge often experience communication difficulties. Behaviours that challenge can then become a person’s best, and often only, way to communicate important things they need - for example, that they are hungry and in need of something to eat, in pain and in need of support, or in a situation they need to stop. Behaviours that challenge also create a challenge for siblings.

People who are challenged by someone else’s behaviour have the difficult task of trying to understand what the need is and how to meet it. A Functional Assessment led by a trained professional in partnership with families is a vital step to help understand these needs and when and why a person displays behaviours that challenge. Findings from Functional Assessments can be used to help determine the best ways of supporting people to make their lives better and reduce the likelihood of behaviours that challenge. This approach is called Positive Behavioural Support

(PBS) which is an ethical and evidence-based way of supporting people at risk of behaviours that challenge.

When you have grown up with someone who displays behaviours that challenge – especially those behaviours that have a big and direct impact on you like behaviours that hurt others and destructive behaviours – it may feel like the term ‘challenging behaviour’ doesn’t fully reflect your experience. It perhaps doesn’t acknowledge just how much you have been physically, emotionally and psychologically affected. And when you use the term ‘challenging behaviour’ to others outside of your brother or sister’s care, they may not fully understand what it means.

Your needs and your brother or sister’s needs are important - equally important. It’s vital that we continue to recognise behaviour that is challenging so that people who display this can have support in place to have their needs met. It is also important that the effects of this behaviour on you as a sibling are recognised.

My autistic sister has started smearing her faeces on the walls and making groaning noises. It’s really upsetting my family – how do we stop it?

Many siblings tell us how upsetting it is to see their brother or sister smearing faeces – you are not alone. It’s difficult to talk about and many people don’t want to seek advice for fear of being judged.

It’s important to understand the reasons behind the behaviour for change to take place. Gaining a Functional Assessment for your brother/sister, led by a trained professional working in partnership with family members, is a vital step. A change in behaviour (such as the onset of smearing faeces) may be reflecting a change in a person’s world, for example:

- Physical pain or discomfort
- Mental health or emotional difficulties
- Frustration or confusion around a change of environment or staff
- Distress or boredom in particular situations
- Exposure to difficult life events including abuse

In the short term you might start by keeping a record of when and where your sister does this, and when it started as this may help identify patterns and recent changes in her life. Ensure that physical causes, e.g. constipation, are ruled out by arranging a GP visit for your sister. Your sister’s GP, or local adult social care department can then refer her for a Functional Assessment of her

needs. Findings from the Functional Assessment can be used to help determine the best way to support your sister, to make her life better and reduce the likelihood of behaviours that challenge. This approach is called Positive Behavioural Support (PBS).

My brother is 45 years old, has severe learning disabilities and displays behaviours that challenge. He lives with our elderly mum. The last time I visited, I noticed she had bruises on her arms. I'm worried his behaviour has become more aggressive and violent. I think my mum is afraid to tell social services.

This sounds like a painful situation for all involved – your elderly mum, who is being injured, and your brother who is trying to communicate something. This is a safeguarding issue and it's painful for you too, to see them both going through this.

It can be difficult to talk about aggressive and violent behaviour. Many parents don't want to seek advice because they are afraid that others just won't understand. Parents may feel a sense of failure if they are unable to manage their son or daughter's behaviour and may be worried that their son or daughter will be taken into care. Parents need to be reassured that they have not 'failed' – they have done the best they could with the situation they were placed in. Few people have had the training to deal with such complex situations that are beyond the boundaries of typical parenting. Your mum is not alone.

It is really important to seek advice because the behaviour is happening for a reason. A change in behaviour (such as increased aggression) may be reflecting a change in a person's world. Both your mum and your brother need more support with this situation. Gaining a Functional Assessment for your sibling, led by a trained professional working in partnership with family members, is a vital step.

In the short term, talk to your mum first and highlight the vulnerable position that she and your brother are in. If it helps, show her this guide or the Challenging Behaviour Foundation website which has a range of resources and case studies from other parents who have experienced similar situations. Encourage her to contact the local adult social care department and request an assessment for your brother so that his communication needs can be looked at long-term. This might be by a speech and language therapist or psychologist.

If you feel your mum will not contact adult social care, you need to report this yourself urgently so that she can receive further support with the situation.

Find out more

- Taking action on safeguarding concerns
<https://www.sibs.org.uk/safeguardingadults>

My sister behaves better with me so my parents ask me to look after her a lot. I can't cope with the strain, but I feel guilty if I say no. What can I do?

It's great to hear that you and your sister have such a positive relationship. The fact that her behaviour is less challenging when she is with you suggests that you are able to communicate well and that you are meeting her needs. This is a valuable skill to have developed and honed. Do not underestimate the significance of this achievement for both you and your sister.

When such good communication skills are developed between a sibling and their disabled brother or sister it can be a relief for others involved. It can be easy for families to slip into a pattern of the sibling spending more time with their disabled brother or sister, for the immediate benefit of the whole family.

However, the long-term consequences of this also need to be considered. If you are feeling under strain, it suggests that the amount of time you are spending with your sister is not sustainable. This isn't a good plan for you or your sister. If the strain were to develop into mental health conditions, such as depression or anxiety, you may no longer be able to provide that support at all. It's important that you don't accept depression and/or anxiety as a normal part of caring, but as health conditions that can be treated and supported.

Just because you are the person who communicates most effectively with your sister does not mean you are the person who is entirely responsible for her care. It is important to remind yourself of this when feelings of guilt arise.

Here are some actions you can try:

1. Share the communication techniques you are using that are improving your sister's behaviour with others involved in her care. Arrange a time to discuss this with all involved

and teach them what you know. Allow them to practice these without you present. It may take time for all to adjust.

2. Think about what time you *do* want to spend with your sister. What would be sustainable for you? For example, meeting every other Saturday rather than every week.
3. Meet with your parents and sister to discuss this. Stress the importance of the need for a sustainable plan and how you will all benefit from this. Discuss options for how your sister can spend her new free time without you. Write the plan down and put it somewhere the whole family can see and refer to. If possible, use a format that your sister will understand too.
4. Remind your family of the written plan that they can see and refer to. Changing a family set up like this takes time and it takes courage. It can be difficult for all involved to adjust. It is fairly inevitable that at some point, your parents or other family members may ask you to revert to the previous pattern. When this happens, remind yourself that the previous pattern was unsustainable and that you need to give the new one a try.
5. Review the plan. If you, your parents or your sister find that the new plan is not working, arrange a time and a date to meet and discuss it. Doing this – rather than responding on the spot – gives you time to think about what *you* need and come to the meeting holding that in mind.

My autistic brother is in a secure unit because his behaviour has got out of control. I don't like how they're treating him and I don't know what to do. He's been sent 270 miles away.

This is an incredibly difficult situation for you, your brother and your family. It's especially painful being so far away from him and not being able to see him frequently. Unfortunately, this is not an uncommon situation due to the lack of appropriate services.

The secure unit should be a temporary situation and should not be used as a long-term placement. If your concerns about how your brother is being treated are to do with the use of restraint or isolation, then you can question this. Ask to see the policy on restraint and seclusion and ask how your brother, you and your family will be included in the decisions around what methods are used to respond to behaviours that challenge.

As soon as your brother is admitted, a person-centred assessment and treatment plan should be started along with a Functional Assessment by trained professionals working in partnership with your family. This should involve your brother, you and your family and should have clear aims and

actions. These assessments should be used to create a Positive Behaviour Support Plan - this is a proactive and preventative approach to addressing the behaviours that are challenging.

Staying informed is important - it reduces your anxiety and empowers you to ask further questions.

Find out more

- *“My family member has been sent to an inpatient unit - what do I need to know?”* A guide jointly produced by Mencap, The Challenging Behaviour Foundation and Respond <https://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/assessment-and-treatment-units-atus/>

My mum leaves my 14-year-old sister to babysit our 22-year-old disabled stepbrother. He often kicks and bites her, as well as biting and hitting himself. I don't think either of them are safe, but I can't be there every time to help.

You are right – they are not safe. Your stepbrother may be struggling to have certain needs met and is attempting to communicate those needs through his behaviour. Your sister is a child and should not be left to deal with this alone. This is a safeguarding issue for both of them.

Talk to your mum first and highlight the vulnerable position that your sister and stepbrother are in. Encourage her to contact the local adult social care department and request a trained support worker to stay with him when she needs to go out. Request an assessment for your stepbrother, so that his communication needs can be looked at long-term; a psychologist or a specially trained learning disability nurse should carry this out.

A social worker in children's services needs to be aware of the danger your sister is in and her involvement as a young carer. A social worker in adult services also needs to be made aware of your stepbrother's needs. If you feel your mum will not contact social care, you need to report this yourself urgently so that they can receive further support with the situation.

Find out more

- Taking action on safeguarding concerns <https://www.sibs.org.uk/safeguardingadults>

When I was a child, I found my sister's behaviour very challenging and traumatic. It still affects me as an adult and I need advice on how to deal with this.

Many siblings have experienced the same – you are not alone. Children are not equipped to deal with these significant challenges at such an early stage in life. It can have a profound and lasting effect on the person into adulthood.

It's important to:

1. Acknowledge that it may have affected you.

Many siblings do not acknowledge this because they feel, or they were told, that their brother or sister “can't help it”. Regardless of the cause, their behaviour still has an impact on you. Acknowledging that impact does not mean that you are blaming your sister in any way.

2. Acknowledge how it affected you.

It may have been physical, psychological, emotional, social, and financial or a combination of these. You may have had limited opportunities as a child or been excluded from events as a family. Everyone's situation will vary and it's important to recognise the ways in which you were affected.

3. Seek support.

Find a way to process your experiences in a way that works for you. This might be writing about them privately, or it might be sharing them with others at a sibling support group (go to www.sibs.org.uk/groups to join). Many siblings find counselling helpful. Read our advice on how to find a counsellor at www.sibs.org.uk/findacounsellor

You are not alone. It is vitally important for your own wellbeing that you seek support. Although you can't regain your childhood, you can give yourself the compassion and support you need today. This can go a long way in shaping your future wellbeing.

SIBLING EXPERIENCE: “I resented my autistic brother because of his behaviours that were challenging.”

My brother Asif is four years younger than me, and he is autistic. When Asif was young, his behaviour was really challenging. He would scream when we were out shopping. He would bang his head against the wall repeatedly. I shared a room with him, so I hardly got any sleep when he did this at night. The thing I hated the most was that he would destroy my favourite toys. I couldn't keep anything in our bedroom, because it wouldn't be safe from him.

When I was growing up, I didn't understand my brother's behaviour at all. I thought he was just being difficult, doing it all deliberately and maliciously and I really hated him for it. It took all mum's attention, and I resented him for years.

As Asif grew older, mum learnt more about behaviours that challenge and what it actually meant. Asif's behaviour had always looked senseless to me – completely meaningless and spontaneous. But it wasn't – every behaviour had a reason. He was trying to communicate something like 'I'm bored', 'I'm thirsty' or 'there are too many people here and I'm overwhelmed'.

I'm not denying the effect it had on me – it was awful. But I can also empathise with him now. It must be like being in a foreign country and not being able to speak the language, not being able to say what you need. The behaviours that were challenging got him what he needed. Until we found other ways of managing it as a family, he had no choice but to keep doing it.

SIBLING EXPERIENCE: “My sister has learning disabilities and pulls my hair. I thought it was all my fault until I learned the real reason.”

My sister, Katie, is two years older than me and has severe learning disabilities, epilepsy and a hearing impairment. Katie is non-verbal and has always hit and bit herself and others. Pulling hair seemed to be her favourite thing, and it was really distressing when she pulled mine. She would do this to me more than others, and my dad used to say I was antagonising her. “Don’t wind your sister up!” he’d tell me. I thought I must have been doing something wrong.

It wasn’t until we had some more input from a psychologist that we worked out the reason behind the hair pulling – it was a sign of affection. Katie only did it to people she was closest to. Over time, we were able to teach her to put her hand on my shoulder when she wanted attention, or a cuddle and I learnt to respond differently when she tried to pull my hair.

Knowing that I wasn’t the cause of this behaviour was an immense relief. Being able to understand her better was wonderful – just to know a little bit more of what it’s like in her world.

SIBLING EXPERIENCE: “My sibling support group really helps me to cope with my sister’s behaviours that are challenging.”

I am the main carer for my sister, Aisha, who has Cri du chat syndrome. I only recently took over coordinating her care and I joined an adult sibling support group to get more information on the practical side of things like managing her finances.

I wasn’t expecting to talk about behaviours that challenge, but it was an enormous relief when I did. Members of the group all have brothers and sisters with different conditions, but the experiences of coping with behaviours that challenge are something a lot of us have in common.

When I was growing up, I always felt like such an outcast when Aisha behaved in a way that wasn’t culturally or socially acceptable. Whilst many people were patient and understanding...they just didn’t get it. The people in my sibling group have been there, and they get it.

Find out more

The Challenging Behaviour Foundation

This is the charity for people with severe learning disabilities whose behaviours challenge. They provide information about behaviours that challenge, peer support for family carers and professionals, support for families by phone or email and workshops to reduce behaviours that challenge. They speak up for families nationally and campaign.

<https://www.challengingbehaviour.org.uk>

“My family member has been sent to an inpatient unit - what do I need to know?”

A guide jointly produced by Mencap, The Challenging Behaviour Foundation and Respond

<https://www.challengingbehaviour.org.uk/information-and-guidance/when-things-go-wrong/assessment-and-treatment-units-atus/>

Taking action on safeguarding concerns

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

How to find a counsellor

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

Next steps

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

| |
|----|
| 1. |
| 2. |

Feedback

We would love to hear what you thought of this guide. Drop us a line at info@sibs.org.uk

About Sibs

Sibs is the only UK charity representing the needs of siblings of disabled people. There are over half a million young siblings and at least 1.7 million adult siblings in the UK, who have grown up with a disabled brother or sister. Sibs aims to enhance the lives of siblings by providing them with information and support, and by influencing service provision throughout the UK.

Being a sibling can be a complex and challenging experience. You are not alone. Visit our website, follow us on social media, and sign up to our mailing.

Website www.sibs.org.uk

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