



The impact of challenging behaviour on you: When your disabled brother or sister's behaviour is harmful or aggressive

A brief guide to **challenging behaviour** for adult siblings
of people with a lifelong learning disability and/or autism

Sibs is the UK charity for brothers and sisters of disabled children and adults
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What's in this guide about challenging behaviour?

This guide is for adult siblings of someone with a lifelong learning disability and/or autism. It briefly outlines common questions we receive from adult siblings about challenging behaviour that their brother or sister displays.

This guide does not suggest specific ways of responding to challenging behaviour. This is because the same behaviour may have different causes in different people so it is not possible to provide generalised strategies. Your brother or sister must have their individual needs assessed - a psychologist or a specially trained learning disability nurse should carry this out.

For siblings, challenging behaviour can feel more than challenging at times – it can feel devastating. Alongside the physical aspects, do not underestimate the emotional and psychological impact that this behaviour may have had on you. It is vitally important for your own wellbeing that you seek support if you experience distress.

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk to meet other siblings at a support group or become a volunteer support group facilitator yourself.

The information in this guide was accurate at the time of writing - March 2018.

My brother has learning disabilities and he can be violent towards people. Why is it called 'challenging behaviour'?

'Challenging behaviour' is a wider range of behaviours than physical force alone. It describes a range of culturally abnormal behaviours that may result in the harm of the person or those around them. These behaviours may also exclude the person from ordinary community activities. Examples 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 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 person as the problem. It focuses on the effects of the behaviour and how others can respond to it.

Everybody behaves in a certain way for a reason. Challenging behaviour is often displayed due to an inability to communicate something - for example, frustration, fear, hunger or pain. 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.

When you have grown up with someone who displays challenging behaviour - especially hurting others and destructive behaviours - it may feel like the term 'challenging behaviour' doesn't 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 in order for change to take place. 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
- Frustration or confusion around a change of environment or staff
- Distress or boredom in particular situations
- Abuse

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 an assessment of her needs; a psychologist or specially trained learning disability nurse should carry this out.

My brother is 45 years old, has severe learning disabilities and displays challenging behaviour. 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.

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; a psychologist or a specially trained learning disability nurse should carry this out.

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. A link to further advice on taking action on safeguarding concerns is available at the end of this document.

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 a very common 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 challenging behaviour.

As soon as your brother is admitted, a person-centred assessment and treatment plan should be started. This should involve your brother, you and your family and should have clear aims and actions. Part of this should include 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. Visit the links at the end of this document and read "*My family member has been sent to an inpatient unit - what do I need to know?*" jointly produced by Mencap, The Challenging Behaviour Foundation and Respond.

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 is 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. A link to further advice on taking action on safeguarding concerns is available at the end of this document.

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 anyway.

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.

You may want to write about some of your experiences, as this can often help. You may want to join a sibling support group – go to www.sibs.org.uk to find your nearest group. If you find you are significantly affected by childhood experiences, it is important that you seek professional help by going to your GP and asking to be referred for counselling. You can also find a local therapist privately – visit the links at the end of this document.

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 challenging behaviour.”

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 challenging behaviour 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 affect 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 challenging behaviour 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 challenging behaviour."

I am the main carer for my sister, Beth, who has Cri du chat syndrome. I only recently took over co-ordinating 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 challenging behaviour, 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 challenging behaviour are something a lot of us have in common.

When I was growing up, I always felt like such an outcast when Beth 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.

Further reading on challenging behaviour

The Challenging Behaviour Foundation

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

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 <http://www.challengingbehaviour.org.uk/learning-disability-files/4-My-family-member-has-been-sent-to-an-inpatient-unit---what-do-I-need-to-know.pdf>

Taking action on safeguarding concerns

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

Directory of private therapists and counsellors

<https://www.bacp.co.uk/search/Therapists>

Next steps in supporting yourself and your disabled brother or sister

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

1.
2.

Further support

Being a sibling can be a complex and challenging experience. You are not alone – visit www.sibs.org.uk for more information, to talk to someone about sibling issues, or to meet other adult siblings at a support group.

About Sibs

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

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Sibs relies on donations and grants to support siblings – please consider making a donation through our website.