

INFORMATION SHEET



making a difference
to the lives of people with
severe learning disabilities

The impact of caring on families

Life is never straightforward for mums, dads, grandparents, brothers and sisters of someone with a learning disability whose behaviour challenges. Caring for your relative can have a huge effect on your life and it often feels like they are the focus of everything, leaving little time to step back and think about how you are doing or what you might need to continue to support them. This information sheet recognises the impact of the caring role and provides ideas to help you lessen that impact on your life.

'As parents we have to spend a lot of time fighting for our children, and we need all our energy and resources to do this. We need to care for ourselves so that we can be the best for our children.'

- Mother of Chrissy

First experiences

When a child is diagnosed with severe learning disabilities it can be an extremely difficult, isolating and frightening experience for a family. You may not be sure of the full extent of the disability or associated health problems, or what to expect your child to be able to do or not do.

'When my son was diagnosed with a disability, it felt as if I was entering a whole new world.'

- Mother of a son with severe learning disabilities and Cri Du Chat Syndrome

'When Dougie was younger I didn't appreciate why he behaved like he did; it's been a very big learning curve for us as parents to understand why he does what he does. I don't think we were told exactly how it would be and how difficult he would find things. The problem is they won't tell parents who have a child of six to twelve months that their child is going to be like this because they don't want to frighten anybody. But you need to realise how difficult your life is going to be and how much it's going to change. It might seem too early to some people but I think we'd have been so much better off if we'd known when he was really young what to do and what not to do.'

– Mother of Dougie

It is often the first time families have heard of the condition their child has been diagnosed with, so there might be a lot to learn and understand. Things you've never had to think about before suddenly become a priority, as this parent describes:

'I don't remember where it started all I remember was that it was difficult'

to get him to be interested in anything, to be stimulated by toys. He would rock his cot to the windows when he woke in the morning and pulled his curtains down and I think that was the beginning probably. And then a bit later when he wanted people's attention he'd start pulling hair. We're parents, we're not professionals. When our child was born, they didn't come with the skills to teach us or we weren't given the skills to manage them. You might know how to give a baby a bottle and you might know how to change a nappy but you don't know how to respond to challenging behaviour. We can't put our heads inside somebody that has a learning disability to know how it feels and where their level of learning is. It's a new situation that we find ourselves in so we do need that help from the beginning'

- Mother of a son with severe learning disabilities

'If you have a disabled child there isn't a fairy godmother who suddenly bestows you with all this knowledge and information, and resilience and the capacity to go for months without a good night's sleep.'

- Mother of a son with severe learning disabilities

Seeing challenging behaviour appear in a young child can be distressing and confusing. You may be given conflicting advice from people or possibly not be taken seriously about their behaviour. Some parents may not recognise that these behaviours are different or more severe than 'naughty' behaviour in other children. Recognising the problem and getting past hopes that the behaviour will go away with love, care and standard parenting techniques is an important step towards seeking help early on. However, getting specialist advice can be a real challenge, as this parent found:

'If there was one thing I could change, it would be to have had access to really good early intervention for Dominic and everybody else involved in his life, as soon as he started to display challenging behaviour. We only started to receive intensive support as Dominic got older, bigger and stronger. By this stage, many of his behaviours were so entrenched and challenging behaviour was his default communication style. We were able to make changes to his behaviour and teach him alternative methods to convey his message, but it took a long time. If we had received this support when he was 2 or 3 years old, when his challenging behaviour was emerging, his life and ours may have been very different.'

- Mother of Dominic

On the other hand, families can also find what's offered from professionals overwhelming, as this parent describes:

'Looking at it from the family perspective, from the very beginning when we had gone through diagnosis, we were inundated by professional assessments - whether that is social services, whether that's education, the Disability Living Allowance assessment... all these assessments seem to be separate to one another. For instance the speech and

language therapist gives you an example of a strategy, the Occupational Therapist might give you an occupational example of how to deal with another behaviour and then you've got behavioural strategies that come from the psychologist. From a families point of view what would be really useful is to be given the tools to actually deliver what it is the professionals want us to do, but do it in a way that is part of our daily lives. In most of the professional assessments that I've got, the terminology is right over my head and it's a document that's filed away because I don't understand it.'

- Mother of a son with autism and learning disabilities

How caring impacts on families

Emotional and social well-being

Reactions like stress, frustration, anger, guilt, shame and loneliness can all feature at times for family carers. These are natural reactions to the way severe learning disabilities affect your family member's life and your own; that doesn't make it easy to talk about though. Many carers say that no-one understands how they are feeling, so seeking support from other families with similar experiences can really help.

Family carers are often socially isolated and can be excluded from family events, friendship groups or community facilities because of their family member's behaviour.

'It's a lonely place to be when you're a parent of a child with challenging behaviour.'

- Mother of a son with severe learning disabilities

'We are very much isolated due to Christopher's disability, but in particular, with regards to his challenging behaviour. We visited family until it was no longer safe to do so and few family members now visit us in return. We have never attended family celebrations together as this has not been possible.'

- Parents of Christopher

'Having a child/young person with severe learning disabilities is isolating. Having a child/young person with challenging behaviour is doubly isolating, because you can't even access the activities and events designed for disabled children. Most advice and support (such as it is!) seems to be directed at parents of children; those of us who care for an adult offspring at home feel even more isolated!'

- Mother of a son with severe learning disabilities and autism

Even if family and friends are supportive, it can be difficult to find the energy to get out and get involved in things. It's important to fit in quality time with people who care about you and find ways to include your family member in things you all enjoy doing. Spending time with different people can bring new ideas and coping strategies for behaviour support and other challenges.

'Most support you get is from other families and friends that have lived that experience, and I think that's really important.'

– Mother of son with autism and severe learning disabilities

'I'd say try and involve your friends. All my friends have become involved they know all about Daniel now and a lot of my friends are doing fund raising. Don't be afraid to talk to your friends and because they all think it's fine and they like coming round to talk to Daniel when he's here.'

– Sister of Daniel

Feeling low or stressed can sometimes lead to mental health problems such as depression or anxiety disorders. It's important not to view this as par for the course, but a health need that can be supported and treated.

'I think times when Sally was quite difficult it was quite hard to remain positive and I guess we probably did go through periods of mild depression.'

– Mother of Sally

'I can recall walking into the carers centre wanting to commit suicide. Feeling really useless but knowing I could not let those I cared for see just how useless I had become. I walked in, a smile plastered on my face and all it took was "Hi Steph..... How's you?" and the floodgates opened and I was sobbing and shaking. I was quickly steered into the meeting room and sat with my head in my arms and left to cry for a short while. No one tried to console me or talk to me until the sobbing subsided and I was physically exhausted – then there was the quiet voice from the doorway asking me if I wanted to talk. To me the carers centre was the only place I could go where I would be safe and not judged.'

- Sister of a man with severe learning disabilities and autism

Relationship breakdown is unfortunately more common for couples whose son or daughter's behaviour challenges. The normal family stresses are heightened when a member of the family has complex needs, and extra strain is put on couples to be consistent in their approach to behaviour and to find time to communicate and have time alone.

'I think inevitably it puts a strain on a relationship with your partner. I had more opportunity to learn about things like ordinary life styles and positive behaviour support, which my husband didn't get, so sometimes we didn't agree in the right way to try and help Sally; so that causes tensions. That has got a lot better now.'

– Mother of Sally

'As a single parent whose immediate family lives abroad I often feel very alone in the fight to enable my daughter to be heard and supported. I resent having to be "a victim" and yet if I don't dwell on and emphasize

our neediness all the time we don't get the support that we need. I feel parents are viewed as inadequate if they need help. It can be a soul-destroying experience. I'm not sure there will ever be a time when I don't need encouragement.'

- Mother of Katie

Physical health

For all the time and effort you spend getting your family member to medical appointments and worrying about their health, how much time do you take thinking about your own health? Caring for someone can be physically demanding and exhausting, and stress related illnesses are more common in carers. Don't put off seeking help for any health worries you have, so that they don't worsen and affect your caring role.

'I have been referred to physiotherapy services for problems with my hips, back and neck as a direct result of caring for Christopher. My husband suffers with sciatica as Christopher's main interest is in throwing and catching ball-pit balls. This play activity can last up to 12 hours each day and sitting on the floor to play for this length of time has affected his back.'

– Parents of Christopher

Finding time to eat properly and exercise when your family member's needs are the priority can be tough. Going to the park or beach, regular walks, swimming, kicking a ball around in the garden, dancing and interactive computer games are all healthy activities your family may be able to do together.

Sleep problems

Sleep is a huge difficulty for many families, as children and adults with learning disabilities often don't have 'normal' sleep patterns so can disturb the rest of their family during the night. If your family member wakes during the night or early in the morning and needs your support then you have to fit in with their sleep pattern. Sleep problems can be increased by feeling anxious about whether your family member is asleep or their safety if they wake in the night. This is often a hidden problem and others may not realise the huge effect sleep deprivation has on your day to day life. Being constantly exhausted will also have an effect on your ability to care for your family member, so improving your sleep should be a priority for you and those supporting your family.

'We are constantly tired as our son only naps during the night and spends much of the time running or pacing in the hallway. We moved into a purpose-built bungalow, which has enabled us to nap knowing that he is as safe as he can be.'

- Parents of son with severe learning disabilities

Sleep clinics are available to help with solutions for severe night time disturbance: see our 'Further Information for Family Carers' information sheet.

Finances and work

Having a family member who displays behaviour that challenges can be very expensive. Things can get broken, you might need specialist equipment or adaptations around the home, and you might have to take out public liability insurance.

It's often not possible for parents to work and careers might be put on hold due to the demands of the caring role. If you do work you might feel you can't give your all to either your work or family.

'The cost of caring for someone with severe disabilities is extensive, but when challenging behaviours are also present – particularly when behaviours are so challenging – it creates a very real financial burden for families. It was necessary for my husband to give up work to become a second carer for Christopher as a direct result of his challenging behaviour and having to regularly replace items of furniture, clothing and decoration in our home leaves us facing financial hardship.'
– Parents of Christopher

'There's the balance between work and caring responsibilities. And it's really important that employers show flexibility on that issue.'
– Father of son with autism and learning disabilities

Positive impact on families

Having a family member with severe learning disabilities brings positives to family life, whether that's the pleasure of spending time with them and seeing their achievements, or new experiences and opportunities. People may develop resilience, assertiveness or compassion for others, or develop new skills. Two parents describe the positive impact for their family here:

'My other kids were all adults by the time Andrew was born, so I don't think they've been affected by it, apart from in a positive way, because he has been able to educate them about difference. And I have seven grandchildren now, who have all been able to understand difference. I think that's the only way that anything is ever going to change in life, that people have the opportunity to have that experience. So I don't think that it's been a negative influence on them, I think that it's been a positive experience.'
– Mother of Andrew

'She has changed my life completely – she has changed everything about me and the way I look at things. She's helped me make some very valuable friends who have also got children with challenging behaviours and learning difficulties that I would never have met if I hadn't got her. She can make you laugh, because as much as the challenging behaviours are there and the learning difficulties, there is also a very literal element to her and she's got a great sense of humour. To have a child who is so gifted in that way and brings so much to my life I can't describe it... there are negatives but there are a lot of positives too.'

– Mother of a daughter with severe learning disabilities

Support available for carers

Different families need different types of support with the challenges of their caring role. The most commonly accessed kinds of help for family carers are listed here:

Emotional support and healthcare

- The Challenging Behaviour Foundation's Family Support Service offers confidential emotional support by telephone or email, on 0845 602 7885 or support@theCBF.org.uk. We also have a Parent's Email Network to put you in touch with other families.
- Organisations such as carers' charities, parent networks and the Samaritans offer different types of support.
- Professional help: if you are feeling very low, hopeless, depressed or stressed then tell your GP and discuss your options. You might consider the way you're feeling to be normal or to be expected, but if you're struggling then seek help before you reach breaking point.
- Relate and disability charity Scope offer a live web chat counselling service for relationship difficulties. Go to: www.scope.org.uk/Relate-live-web-chat-counselling-service
- You are entitled to time off work for medical appointments (for physical and mental health concerns) and you have a right to ask for a telephone consultation or home visit from your GP if you are unable to get to the surgery due to your caring commitments.

Carer's assessment

A carer's assessment is not a test of how well you're doing, but a check to see whether you need extra support. The process starts by asking social services for an assessment and depending on the outcome, you may be able to get respite, financial support, or other things of benefit to you such as exercise classes.

If you have had a carer's assessment in the past, you are entitled to an annual review– so you can see if there's any extra support available to you.

Information on getting a carer's assessment is available from the Carers Trust here: www.carers.org/carers-assessment

Financial support

The following benefits and sources of financial support may be available, depending on your family's circumstances and financial situation:

- Carers allowance
- Housing benefit, income support or tax credits
- Your family member may be entitled to Disabled Living Allowance and other benefits
- Direct payments made to you or your family member can be spent on short breaks
- Grants are available for certain household items, trips out or specialist equipment that are needed because of your family member's disability. See our information sheet 'Specialist equipment and safety adaptations' for who to contact.
- Jobcentre Plus offer extra help for carers to get back into work
- See our 'Further Information for Family Carers' information sheet for more information on support with finances.

Short Breaks

Short breaks, also known as respite care, should be whatever you need them to be:

- A break for you where your family member is taken out for the day or stays at a respite centre overnight.
- A break for all the family to go away together, with support from care staff if needed.
- Care staff coming into your home to help with caring – for instance every morning to get your family member up and ready for the day.

Respite should be offered for a meaningful length of time so you can have quality time by yourself or with other family members.

For organisations that have information about short breaks and holidays for people with learning disabilities, see our 'Further Information for Family Carers' information sheet.

Messages for families

It can be hard to remain positive when your family member's behaviour is challenging and you are battling for support for them and yourself. We hope this information sheet helps you to be better prepared to face any challenges that your family member brings you and that the world brings your family.

These messages are from family carers who have 'been there':

'To other families I would say get as much information as you can as early on as you can. Don't beat yourself up if it doesn't happen as fast as you want it to, because you can only go as fast as you can go. It's never too early and it's never too late, there is always time to do it and it's never the case of "if I start now it will be a waste of time" - it won't be.'

- Mother of Chris

'My message to other families would be first of all that you are not the only one, because we felt that we were the only people in the whole world that had a child as difficult as Daniel, and that's not true. You know there are lots of people out there we are just not connected up and because there's not that many of us it's unlikely that you are going to have someone living down the road who is going to have the same sort of issues as you. Another message is that there is a lot known about understanding challenging behaviour and what the function of it is. And so it's about getting that help and getting some direction and support, and it's about doing that before you get to absolute crisis point. And that's hard to do as well because each day is just a little bit more difficult and you think "well we got through yesterday so well get through today" and I think it's about doing that before you get to the point where you can't carry on any more. Don't feel guilty because you are just doing the best that you can.'

- Mother of Daniel

'The message I'd give to other families is have confidence in yourself - you do know your child. Don't be intimidated about saying the little things that make a huge difference for your child. And also when professionals are involved try and work with them and certainly learn from them, but try not to feel that they have all the answers. The best scenario for us as a family has been when professionals and us have sat down together as equals and tried to work out what's going on for Rhys, and nobody knows more than anybody else, but we work together to get the best outcome for Rhys.'

- Mother of Rhys

'I know it's tough because just caring for the child is exhausting enough, but just keep going mums and dads because we do know what is best for our children and they do have those rights just like any other child has those rights. And one day it will happen.'

- Mother of Andrew

Support organisations

Contact a Family

Supports the families of disabled children whatever their condition or disability.

Free Helpline: 0808 808 3555 Email: helpline@cafamily.org.uk

Website: www.cafamily.org.uk

National Family Carers Network

A network linking support groups for family carers of someone with a learning disability. Provides information and resources. Hosts the National Valuing Families Forum.

Tel: 07718 134877 Email: info@familycarers.org.uk

Website: www.familycarers.org.uk

National Parent Partnership Network

Supports and promotes local Parent Partnership Services (PPS) that offer free, confidential advice, information and support to parents and carers about special educational needs. For details of your nearest PPS, contact:

Tel: 0207 843 6058 Email: nppn@ncb.org.uk

Website: www.parentpartnership.org.uk

Samaritans

24 hour emotional support.

Tel: 08457 90 90 90 Email: jo@samaritans.org Website: www.samaritans.org

SIBS

Supporting brothers and sisters of disabled children and adults.

Tel: 01535 645453 Email: info@sibs.org.uk Website: www.sibs.org.uk

We would like to thank all the families who contributed to this information sheet.