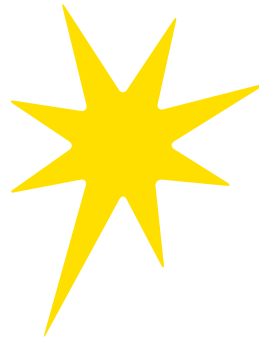




Looking after your
own wellbeing as a
parent/carer of a child
with a brain condition



Working wonders for children with brain conditions

Families where a child has a brain condition face challenges every day. Just to learn, play, make friends and experience the world can feel difficult, even impossible. But we don't believe there's any challenge that can't be overcome.

So we listen to families, we learn from them. We carry out research, we design and innovate, we make and share. From new equipment to new learning resources, to new ways to play and support each other, everything we find out together makes life better. It opens doors to discovering the world.

It's an incredibly rewarding journey for everyone involved. Why not be a part of it? You never know what we'll discover together.

www.cerebra.org.uk

Our guides for parents help you find the answers you need. You can view and download the full series of our guides and factsheets completely free from our website www.cerebra.org.uk.

If you would like to make a donation to help cover the cost of producing our guides give us a call on **01267 244216** or donate at <https://cerebra.org.uk/get-involved/donate/>.

Thank you.

Aims

Looking after your own wellbeing is one of the most important things you can do for the wellbeing of the whole family. You are the most important person in your child's life, championing their wellbeing needs every day. For this to be sustainable, it's really important that you find ways to look after your own wellbeing needs too.

We know this is not always easy, so we've written this guide to provide some information, resources and guidance to help you find ways to focus on your own wellbeing and happiness, while caring for your child. It will cover different aspects of your wellbeing that might need extra attention. There is a personal wellbeing plan provided that you can complete while reading this guide to help you document and action some changes that you think are likely to benefit you.

This guide will be useful for anyone with caring responsibilities for a disabled child.

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Focusing on your own wellbeing as a parent care giver

Parenting is a really rewarding experience. However, even at the best of times it can have an impact upon parental wellbeing. When you have a child with a brain condition, there are additional day-to-day challenges as well as extra thoughts, feelings and daily tasks that you will need to prioritise and manage. You might have less time to do things for you for longer periods of time compared with other parents and suitable support networks might be more difficult to find as well as access. It's really important that steps are taken at the earliest opportunity to develop the support networks and routines that you need to make space to focus on your own wellbeing, the benefits for you and your family will be far reaching. [This video gives a good introduction to self-care for parents/care givers and why it is important.](#)

'Parent carers need to realise that it's not selfish or self-indulgent to think about their own needs. You can't look after everyone else if you don't look after yourself' – Parent carer

'Join a support group and keep looking if you don't find the right one first time' – Parent carer

'Being in a room with other parents of children with autism and realising that we are not alone even if it feels like it was so helpful' – Parent carer

What government funded help is available to support my wellbeing?

If you have any worries about your own wellbeing and feel you could do with some external support, you could:

1. **Contact your GP and tell them you are a carer and discuss any concerns you have. They will be able to look at any factors affecting your wellbeing and offer tailored support.**

You can ask them to assist you with ideas to keep fit and well in your community and it's a supportive place to discuss how caring might be affecting your health (e.g. risks of depression, stress, high blood pressure or back pain). You

might be eligible for regular health checks.

You may be referred to a counsellor to provide emotional support for yourself or to Child and Adolescent Mental Health Services (CAMHS) if you are seeking emotional support for your child.

It must be noted that there can be long waiting times for emotional support services and they may be time limited. Ideas are provided later in this guide about accessing other emotional support services directly yourself.

2. Request a Carer's assessment.

As well as practical help, support is also available to help relieve stress, improve health and promote wellbeing. For more information about carer's assessments and how to get one, please see the CarersUK information sheet about [how to get a carer's assessment in England, Ireland, Scotland and Wales](#).

Cerebra have produced a guide for parents of children with a brain condition in [England](#), and a separate guide for [Wales](#), who want to know how to get help for their child's social care needs. It principally deals with the responsibilities of the local authorities to provide social care for disabled children, as well as support for the parents/carers of those children. The guides provide information about the duty to provide an assessment of your needs as a carer and also information about how to get a short break. Also provided are [template letters](#) that you can use to request an assessment from your local social services department. Alternatively you can request that your child's GP or a professional involved in your child's care make this referral for you.

Contact charity provide an easy access infographic about the [difference between a needs assessment \(for your child\) and a carer's assessment \(for yourself\)](#).

3. Getting in touch with your local carers service to see what general carer support is available in your area.

You can search for your local carer service [here](#). You can also find nationwide carer support organisations in the 'Support organisations' section in the back of this guide.

It is important to note that accessing Government funded services to support your child and family can be difficult to access and may take a long time. If you are having difficulties accessing the support services you are entitled to the [Cerebra Legal Rights Service](#) may be able to offer advice.

4. Consider applying to the Carers Wellbeing Fund.

This is a grant of up to £ 150-300 (depending on location), for something that benefits your own wellbeing. This could be, a short break, gym membership, therapy, a piece of equipment for a hobby (such as a bicycle), or college course fee's/ books, for example. It can be applied for every 12 months. Applications are made through your local carers support service (search for your local service using the link above) or through another nominated organisation in your area.

'I wish I had reached out for more support when my son was a baby and (I realise with hindsight) I had postnatal depression. I kept telling myself that I was managing and there were lots of other mums with really challenging things to deal with, but I needed and deserved help and support' – Parent carer

What can I do to support my own wellbeing?

CarersUK have developed a free to access '[You and your wellbeing](#)' e-learning course, designed to help carers build strategies to maintain their physical and emotional wellbeing. The course looks at physical and emotional wellbeing together, as each can have a significant impact on the other. Consider taking the course and including any useful strategies on your wellbeing action plan.

How can I look after my physical wellbeing?

Parents and caregivers of a child with a brain condition might experience poorer physical wellbeing, perhaps related to care responsibilities and the number of hours spent caring. Recognising this is important as there may be things that you can do to look after your physical wellbeing which is then key to supporting your overall health and wellbeing.

Research has suggested that carers may have poorer physical wellbeing when they lack support, both practical support and financial support. It will be important as a carer to develop networks that can support you emotionally, practically and financially where possible. The later sections of this guide will provide ideas about how to develop stronger emotional and social support networks in the community, and there are resources provided in the 'further help' section about financial support you may be able to access.

Other things that you can work on to improve your physical wellbeing:

- **Eat healthily**

As well as the e-learning course above, The Carers Trust provide a good overview of resources to get you thinking about [eating healthily](#) when you are a care giver, for example batch cooking (and freezing) so there is always something nutritious on those more difficult days, also explaining how simple changes to your diet can improve your mood and how you can eat well on a budget.

- **Get enough sleep**

It is common for children with a brain condition to have sleep problems. The resulting lack of sleep can affect the wellbeing of family carers as well as children themselves.

You should initially talk to your GP about any sleep difficulties you or your child are having to get some medical advice.

The [Sleep Charity](#) is a good place to seek information and advice in the community if you are having sleep issues yourself. The [Cerebra sleep advice service](#) offers tailored advice to families of children with brain conditions that are

having problems getting a good night's sleep. Cerebra also provide an information guide [Sleep: A guide for parents](#) with useful information to help you support your child's sleep.

- **Exercise regularly/stay active**

As a carer it's important to place focus on exercising and staying active, it's very easy to fall out of this habit when you caring for someone else. Remember how good you feel after exercising and try your best to make it happen. Finding an exercise buddy can be motivating. It's worthwhile as physical activity can help improve sleep, mood and help to manage stress and anxiety as well as being good for maintaining good health and physical wellbeing.

Don't be hard on yourself if you haven't managed to exercise/be active, or if you just don't feel up to it. You could make a mental note and make a plan about how you can work on being more active in the future – even simple things such as taking a brisk walk round the block more often can help you to get started, add a walking break to your day. You can use that time to mindfully

notice the birdsong or buildings around you, allowing you some time to pause and be in the moment. Watch this [video](#) to help you get in the mood, with suggestions about how to get moving and feeling better.

If you are finding it difficult to get out to do some exercise, the NHS lists some [free fitness studio exercise videos](#) and there is lots of fitness content on Youtube. Scope have compiled a list of places you can research [exercise inspiration of you are disabled](#) and have specific access needs.

- **Alcohol consumption and smoking**

The NHS provide information and support to help you cut down on your alcohol consumption and

quit smoking. Working on these two things will immediately improve your physical health and wellbeing if they are featuring heavily in your life and you feel ready to make a change.

Note that high caffeine intake can also increase anxiety and negatively affect sleep.

'A bit of mindfulness I quite like that ...I might take the dogs and pick some blackberries and just notice what's around me, keeping in the moment. Can't change your past and can't dictate your future'. – parent carer



How can I look after my emotional wellbeing?

Caring for someone else brings many positive feelings and it's really rewarding knowing you are doing your best for your child. It's also common to experience a range of more complex emotional responses, that can impact upon your overall wellbeing. Parenting a child with a brain condition involves so much more than providing support and care for them, you will likely be managing a number of external organisations to manage any professional input that they might need. The high mental load can be stressful and can easily lead to overwhelm and burnout. Burnout is a state of severe emotional, physical and mental exhaustion. Symptoms of emotional exhaustion can be lack of motivation, difficulty sleeping, feeling anxious and/or depressed, not enjoying activities that used to bring you joy and experiencing physical exhaustion.

In addition to accessing the government funded support described above, you could consider organising professional emotional wellbeing support privately. You can find out about private practitioners (psychologists, counsellors, therapists) with expertise in supporting parents of children with additional needs [here](#).

In addition, some other things you can do to support your emotional wellbeing and help reduce the impact of the increased mental load while caring are listed below.

● Discuss and communicate

Share your feelings with your partner, friends, family members or discuss with a professional, particularly the things that are weighing heavily on you. Write a list, and think about changes that could be made to more evenly distribute responsibilities. Delegate where you can. There is space on your wellbeing plan for you to write down anything in family life that is affecting your wellbeing and requires attention or a change. Think about the best place to get support with this.

● Set boundaries

Personal boundaries are important and not setting boundaries can lead to you taking on more mental load, such as agreeing to do things you don't really want to do or doing things which are someone else's responsibility. Set some boundaries to ensure you get time to rest, relax and do some things you enjoy. First steps will include identifying what your boundaries are, and then communicating them with others e.g. your partner, family, friends and professionals. Learning to say 'no' will be important to maintain your boundaries, helping you to not take on too

much. Many people find saying 'no' difficult, so it can help to have some other phrases in mind such as:

'That's a good idea but that won't work for us as a family at the moment'

'I appreciate the thought but I can't do that right now'

When caring your time and energy is limited and priorities need to be set.

● Take regular breaks from caring

Parenting is more than a full time job. When your parenting role involves taking care of a child with high care needs, the workload is significantly higher. Therefore, it becomes even more essential, but often more challenging, to factor in regular breaks from caring to recharge yourself and return to your family and caring role feeling refreshed.

Initially, you could talk to your GP, child's paediatrician or social worker about any [short break](#) options that are available, as part of your carer's assessment. There are different types of breaks you can consider, CarersUK provide a factsheet detailing [short break options](#) to

consider, whether you are getting help from social services or arranging a break yourself e.g. through a charity or other means. [Scope](#) provide an information sheet about [finding respite care](#) when you care for a disabled child and also provide information about [finding a carer](#) so you can plan time that your child is cared for by someone else to take a break from caring.

- **Spend time doing things for yourself that you enjoy every week**

Making sure that you protect some time to enjoy activities that refresh and replenish you every week is really important to ensure that you get enough personal enjoyment, away from family life to maintain your own wellbeing.

You can start with small things like taking a relaxing bath, having 10 minutes with a cup of tea and a biscuit undisturbed. Include these things into your daily schedule. You could try to establish a nourishing weekly activity outside of the home to participate in such as a yoga class or anything that you'd enjoy, that is away from your parenting role. Identify the things you'd like to do, when they might take place and arrange for someone else to look after your child so you can participate. Perhaps your partner, another family member, a friend or an identified childcare provider.

- **Learn something new and find ways to be creative**

Carers UK provide a range of free [online 'share and learn' sessions](#), relaxed online sessions where visiting speakers offer tips and skills on a range of topics, including photography, pilates, yoga, latin dance and many others. You can sign up to get involved in any sessions that might be of interest. Carers support organisations in your own area are likely to offer activities you can get involved in too. Tips on finding carers support organisations in your area are provided later in the guide.

If you are looking to upskill yourself the following websites offer paid and free short and longer courses, depending on what you are looking for. Visit the [Coursea](#), [Futurelearn](#) and [Openlearn](#)

websites to find out more.

- **Give to others**

Research has shown that the act of giving to others and kindness can help your emotional wellbeing, creating positive feelings and feelings of self-worth. Small acts like saying thank you to someone, or asking friends, family or colleagues how they are or writing a card for a neighbour can go a long way, when your time is limited. You child will benefit from and enjoy participating in any small acts of kindness you can think of too.

- **Managing guilt and negative emotions**

It is common for carers to feel guilty and feel complex emotions for a whole host of reasons, although this is not often talked about. This [video](#) talks about this important issue, validates parent carer's experiences and aims to provide strategies for parent carers to use to alleviate any difficult feelings where possible.

The exercise demonstrated in this [video](#) has been designed with breathing, mindfulness, and self-compassion in mind to help you to deal with negative emotions and support you to take a little time to focus on you.

- **Get out into nature**

Spending time in green space or bringing nature into your everyday life is a well-known way to boost physical and emotional wellbeing, the reasons for this are still being studied. There are likely to be quite a few reasons for this and everyone experiences the benefits of nature differently on any given day. Getting outside increases our exposure to natural light, fresh air, increases the likelihood of exercise and access to positive calming and sensory experiences.

The [Mental Health Foundation](#) and WWF-UK offer a free guide '[thriving with nature](#)' to assist everyone to make the most of the UK's natural environment for health and wellbeing.

The mental health charity [Mind](#) also have useful suggestions to help you [get out into nature more often](#).



- Reach out to a community emotional wellbeing service for carers

[Scope Navigate Service](#), offers online emotional support for parents and carers of disabled children who are finding out about their child's additional needs. This service is available for parents whose child is on a pathway to diagnosis or has received one in the last year.

[Contact Listening Ear Service](#), is a national service for parents of disabled children, offering 1 - 1 telephone appointments with a family support adviser for those looking for a listening ear, reassurance and practical and emotional support.

[Carers UK Listening Support Service](#) offers carers a series of calls from friendly trained listening support callers. Callers will phone you once a week/fortnight, up to four times, for a chance to chat and will be able to signpost to useful organisations.

- Learn a relaxation technique such as mindfulness or meditation

Mindfulness helps you to pay attention to the present moment, while tuning you in to your body and helping you acknowledge and accept feelings, thoughts and bodily sensations. Practicing mindfulness can help you to feel calmer, more grounded and more able to manage stress and anything affecting you emotionally.

Meditation is another useful method to reduce stress, training you in awareness and helping you to develop a healthy sense of perspective. Meditations are often short practices that help to settle the mind.

The [Mindful Life charity](#) offer a free 4 module introductory programme to mindfulness and meditation for family carers. These groups are delivered online. You may also be able to find a mindfulness and meditation group in your area,

to take part in as a weekly wellbeing activity.

There are also a number of good quality Apps you can access on your device to access relaxation techniques and stress reducing methods at any time for free or a small charge:

The Healthy Minds Program App is freely available and trains your mind through meditation and podcast-style lessons to develop skills - to gain focus, reduce stress, and maintain positive social connections.

Pause is freely available and provides guided meditations and relaxing sleep stories. The sleep stories could also be useful to support your child's sleep.

Be Mindful offers an online clinical-grade mindfulness course for improved mental health. You can have a look and get a taster for free, however, the full course costs £40.

Headspace provides a meditation and mindfulness app to help to reduce stress and support your mental health. There is a monthly cost for a subscription.

What's up? App offers free access to CBT (Cognitive Behavioural Therapy) and ACT (Acceptance Commitment Therapy) methods to help you cope with any depression, anxiety, anger, and stress.

- **Resources to support emotional wellbeing for parents/care givers**

The **NHS 'one you'** website provides information supporting you to keep well and healthy. This includes the **every mind matters** website, offering emotional support information, including Cognitive Behaviour Therapy (CBT) self-help strategies. CBT teaches you coping skills for dealing with different problems, including reframing unhelpful thoughts, problem solving, tackling your worries and bouncing back from life's challenges.

NHS inform mental wellbeing advice provide advice on dealing with low mood, anxiety, phobias, stress and where you can get help, including links to free courses designed by clinical

experts. Complete the questions in the guide to be referred to a free Silver Cloud course to **help with your mental wellbeing**, for example coping with challenging situations.

Affinityhub is a wellbeing website for parents of children with special educational needs. It is a supportive place for families to learn about supporting their own emotional wellbeing and provides high quality signposts to emotional support (including counselling).

Book: **Day by Day – Emotional wellbeing in parents of disabled children** focusses on supporting the emotional wellbeing of parents of a child with a disability. A supportive validating read for parents/care givers themselves, but also anyone that cares for or supports parents/care givers of a child with a disability.

Fathers of disabled children: supporting their wellbeing. Information and resources to support fathers of a disabled child in their parenting role.

Murmuration community therapy video for professionals. A training video for professionals in which parents of children with additional needs share their experiences to increase empathy and understanding of their circumstances. You could share this with the professionals you are working with if appropriate.

Unique charity have compiled a **mental health and wellbeing guide** for those affected by or living with rare chromosome and gene disorders. Much of the information will be useful for most families of a disabled child to understand and support mental health and wellbeing.

The **Challenging Behaviour Foundation** website includes links to their **wellbeing of family information pages**, family support service, family carers email network and other support resources, including a **family carer wellbeing and resilience information sheet**.

'I wish I had learned early on that one of the most important things I could do for my child was to stay calm myself – parent carer

How can I build a social network?

Developing a good quality social network of support and finding your community is important for everyone, but it is extra important when you are caring for a child with a brain condition. Although it might be more difficult to achieve and need to be carefully curated. It's really worth putting in extra effort to build a supportive community as most parents say connecting with other parents in a similar position to themselves is one of the best sources of all round support they have found. You might need to persevere, and develop different networks for different things at different points in your child's development.

● Online or face-to-face?

Meeting face-to-face, if possible, can provide a positive environment for peer support although for some parents getting out into their community can be difficult. Other parent carers connect online via social media such as Facebook groups or organisation online forums. Much of the support we gain comes from meeting people with a common interest or need, over a cup of coffee, in a supportive and non-judgemental location. This can provide a sense of belonging and reduce isolation.

● Local support groups

Local support groups provide an opportunity to listen, to ask questions and to spend time with a group of people who understand your situation and concerns. The words 'non-judgmental', 'personalised support' and 'respite from caring' are often used to describe these informal get togethers. Parent carers understand the stresses and pressures each other have and local groups often incorporate wellbeing activities into their meetings.

You could try the following ideas to find a local support group near you.

- ◆ Find your local [Carers Centre](#) that will run or provide information about local support groups.
- ◆ Find your local [SENDIAS service](#), a free government run information, advice and support service for families of children with SEND in every area of England and Wales. Your local SENDIAS service often run or provide information about local support groups.

- ◆ Contact [Enable Scotland](#) to find out about any local support groups.
- ◆ Contact [Enable Ireland](#). You could get in touch with their children's service for your area to find out what's going on.
- ◆ Online – search '(your child's diagnosis) parent support group – location specific'.
- ◆ Online – search 'parent carers support groups (all disabilities) – county / city / town'.
- ◆ Leaflets in your local hospital / GP.
- ◆ Recommendations from Social Workers / Health Visitors / Children's Centre / other parents.
- ◆ Conversations with school SENCO/ALNCO.
- ◆ Local Authority Carers Team.

● National support groups

National support groups are useful to connect with, as they often focus on a single condition and may be able to provide good quality medical information, put you in touch with another family of a child with the same condition, they may run family days out and produce newsletters to keep you in the loop with what's going on.

[Contact](#) provide information about many [health conditions](#). These information pages are a great place to find out about national condition specific support groups if you scroll to the bottom of the page. If you are unable to find a suitable support group you can get in touch with Contacts helpline (0808 808 3555, 9-5pm) as there might be other suitable national groups that they can put you in touch with.

- **Making contact with other families directly**

- ◆ Scope offer a **Parents Connect Service**, a 6-week support program for parents and carers of young disabled people (in England and Wales). Their website also offers suggestions about **how to search for support groups** to connect with other parents.
- ◆ Enable Scotland offer a **Family Connect Service**, an online community for family carers.
- ◆ Join your **Local Parent Carer Forum** to connect with a parent forum in your area. These forums often offer local meet ups for members.
- ◆ **Unique** charity, can match you with other families for information and support if your child has a rare chromosome disorder, copy number variant or single gene disorder..
- ◆ Condition specific charities (searchable through the Contact **health conditions** web pages) may also be able to connect you with other parents directly.

- **Get in touch with a befriending service**

- ◆ **Social prescribing** is becoming increasingly used in the NHS, as way for local agencies to refer people to a

link worker. Link workers give people time, focusing on 'what matters to them' and taking a holistic approach to people's health and wellbeing. They connect people to community groups and statutory services for practical and emotional support. You can contact your GP if you think you could benefit.

- ◆ Join a **befriending scheme** if you are feeling lonely or isolated. Befriending offers supportive, reliable relationships through volunteers, providing people with a new direction in life, opening up a range of activities and increased self-esteem and confidence.

- **Online communities**

- ◆ The **Scope online forum** offers a space for you to ask questions, make friends and find support.
- ◆ **Contact has online communities** you can join, dedicated to families of disabled children.
- ◆ The online social media pages of other reputable condition specific charities and organisations (searchable through the Contact **medical conditions** web pages) may also be useful to connect with others.



Parent story - Being the parent of a child with complex care needs, autism and a hearing impairment.

When our son was born in 2006, we envisaged a similar parental journey to that of our two older children, that of the never-ending birthday parties, play dates and school trips. To begin with everything seemed to be similar, I took Edward to a baby and toddler groups, we thought about primary school. I envisaged a time when he started school that I'd go back to work and begin my 'adult' life of being Louise again.

Life changed when Edward was two years old. Whilst we knew he had a hearing impairment, we both carry a gene for this so it wasn't a shock when we were told, we weren't prepared for the subsequent severe autism diagnosis that came. It was probably around this time that my life, as a mum, and that of friends I'd made through various groups, started to change. As their children all started to hit their developmental milestones and Edward didn't so the social aspect of having a child started to change.

At first people didn't know what to say to me, should they tell me how brilliantly their child was doing? For the record the answer to this is 'yes'. My life became a series of appointments at hospitals, with therapists, play specialists, speech and language teams, social services... the list goes on. Whilst friends started going back to work and enjoying their child's primary years, we spent our days in meetings and as a series of battles to make sure Edward had the best support in place.

I spent my time researching autism and trying to find support workers. Our lives became increasingly inward facing, our little bubble of a family became everything. I became increasingly aware of how lonely I was, how my life had changed so much, from a job I loved and a great social life to my main social interactions being with the professionals supporting Edward. When he started primary school, it was 20 miles away travelled by taxi, so I missed out on the school gate conversation at his school. School holidays were spent just trying to cope with a child who grew up physically but stayed the same cognitively. Our house became a fortress of locked doors and windows to stop our increasingly bigger escapee from making a break for it. We stopped having people over to the house as his care became more complicated.

I think that there is a huge underestimation of the effect of loneliness on parent carers, it isn't a short-term situation but one that envelops every part of life. The friends that stay the course are few and far between but the ones that stayed are the best I could ever hope for. And I have found a new group, one where we can talk about our children's achievements and challenges, one where we don't compare our children's educational triumphs and one where we celebrate the diversity of our brood.

What further help is available to support me when parenting a child with a brain condition?

Your local authority, is required to have a local offer, this details the support and facilities across, education, health and social care for all children with Special Educational Needs and Disabilities (SEND) that you can expect in your area. Mencap charity provide information about the types of things you can expect in your [local offer](#) and how to find the webpage for the local offer in your area.

Reaching out and getting some help with the things that you have identified as having an effect on your wellbeing is really important. The support organisations, services and resources below might provide the help you need or act as a useful starting point.

In addition, the Challenging Behaviour Foundation provide a comprehensive [Family Information Directory](#) detailing useful organisations and resources available to support families on a range of topics.

Contact provide a free [Helpful Guide](#) for families of disabled children, an all-in-one book with all the information and help you need to enjoy family life. You can order your printed copy free of charge.

Support organisations

Carers UK

[Carers UK](#) run a telephone advice and support service for carers who want to talk about caring. If you're looking for answers, the online information and support is a good place to start. You can contact their helpline on 0808 808 7777

Carers Trust

The [Carers Trust](#) is a national charity that provides support to carers.. They can support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands-on practical help and access to much needed breaks. Visit their website to find out more.

Cerebra

[Cerebra](#) is a national charity dedicated to helping families with children with brain conditions discover a better life together. We offer a range of parent support services including a [sleep service](#), information and advice about your [legal rights when accessing services](#), an equipment innovation centre and a [book and toy lending library service](#). We also offer a free monthly [newsletter](#). You can find out more on the website or contact our national freephone helpline: 0800 328 1159.

Challenging Behaviour Foundation

[The Challenging Behaviour Foundation](#) is a national charity for children with severe learning disabilities whose behaviour challenges, providing information and support to families and others involved in service delivery and provision. Visit their website or contact their family support line: 0300 666 0126.

Contact

[Contact](#) is a charity registered in England and Wales, that provides direct advice and support services to families with disabled children. They host a free national helpline which is open Monday to Friday between 9.30am and 5.00pm: 0808 808 3555

Enable Scotland

Enable is a registered charity in Scotland and provides information and support for people who have learning disabilities and their families. They have a helpline called ENABLE Direct that aims to answer any questions you have: 0300 0200 101

Enable Ireland

Enable is a registered charity in Ireland and provides information and support for children and adults with disabilities and their families. Visit their website or telephone 01 8727155.

Mencap

Mencap is a national charity that provides information and support for children and adults with learning disabilities and their families, and offers a range of services across England, Wales and Northern Ireland. Mencap have a free learning disability helpline to help you find information, support and services in your area. Advisors are available 10am-3pm Monday - Friday: 0808 808 1111.

Portage

Portage is a national charity providing a home-visiting educational service for pre-school children with additional support needs and their families. They help support the development of play, communication, relationships, and learning for young children within the family and the family's participation and inclusion in the community in its own right. They aim to help you to identify what is important to you and your child and plan goals for learning and participation. For more information visit their website or telephone: 0121 244 1807

Scope

Scope are the disability equality charity for England and Wales, providing practical advice and emotional support whenever people need them most. For more information visit their website or contact their helpline: 0808 800 3333

Sibs

Sibs, for brothers and sisters of disabled children or adults. If you are parenting a child with a learning disability and other children, Sibs is a great place to seek information and support for yourself in your parenting role and for your other children to help them understand disability and support them in their sibling role. You can get in touch with Sibs by completing their [contact form](#).

Unique

Unique is a charity that provides support, information and networking to families affected by rare chromosome disorders, copy number variants or single gene disorders associated with learning disabilities or developmental delay. For more information visit their website or contact their helpline: 01833 723 356

Resources and services

Accessing public services

The [Cerebra Legal Rights Service](#) provides families of children with brain conditions with help when facing difficulties accessing support services they are entitled to. Contact the team by completing this [referral form](#). The scheme can help with accessing health and social care related services such as adaptations and disabled facilities grants, assessments, child and adolescent mental health services (CAMHS), care & support (plans / services), carers' rights, continence services, direct payments, school transport and short breaks.

Advocacy services

Do you find it difficult to understand your child's care and support or find it hard to speak up, an advocate is someone who can act as a spokesperson for you. The NHS Choices webpages provide information about [advocacy services](#) and where you can access them.

Caregiver training

The World Health Organisation (WHO) have developed a freely available [caregiver skills training course](#). The course is for parent/care givers of children with developmental delays or disabilities, between the ages of 2-9 years old. The course aims to enhance caregivers' capacity to use every day play and home routines as opportunities to build their children's communication, engagement in activities, positive behavior and daily living skills, while improving caregivers' overall wellbeing. There is a module specifically on problem solving and self-care.

Child behaviour support resources

[Cerebra](#) in association with leading academics have published a number of behaviour and wellbeing support resources to help parents/care givers of children with a learning disability understand and support their children's behaviour.

- [Factsheet: Managing challenging behaviour](#)
- [Improving the well-being of young children with learning disabilities: A parent's guide](#)
- [Anxiety in children with intellectual disability: A guide for parents](#)
- [Emotional outbursts: A guide for parents](#)
- [Cognitive inflexibility and impulsivity: A guide for parents](#)
- [Sensory processing: A guide for parents](#)
- [Pain in children with severe brain conditions: A guide for parents](#)

The [Yvonne Newbold](#) website offers lots of resources and subsidised webinars to help parents understand and reduce extreme behaviour in children with Special Educational Needs and Disabilities (SEND). The blog, [mental strength and emotional resilience](#) for parents coping with violent challenging behaviour is a useful read.

The [Challenging Behaviour Foundation](#) provide information and guidance on understanding and supporting children, young people and adults with severe learning disabilities whose behaviour challenges.

Financial support

Cerebra have published a [money matters guide](#) for parents of a child with a brain condition to help understand the financial help that may be available for them. Useful organisations and resources are listed at the back of this guide. A [Guide to claiming Disability Living Allowance](#) is also available providing support and guidance to families when completing the lengthy and complicated DLA application form.

Relationship support

Sometimes being a parent/care giver can put a strain on your relationships. Carers UK provide an information sheet, listing useful organisations where you can go to get support and advice to [manage your relationships](#). [Relate](#) offers relationship support to people and provide an online, telephone and face-to-face relationship counselling service.



About the authors

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To discuss the contents of this guide or for a copy of a wellbeing plan, please contact:

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Working wonders for children with brain conditions

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