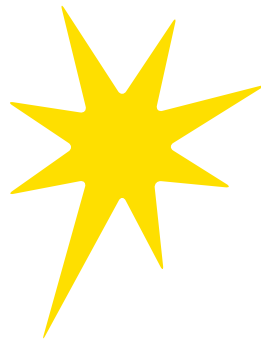




# Factsheet

Emotional well-being for parents/  
carers of children with a learning  
disability



# 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](http://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](http://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 [www.cerebra.org.uk/fundraise/donate](http://www.cerebra.org.uk/fundraise/donate).

Thank you.

# Emotional well-being for parents/carers of children with a learning disability

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## Aims

This guide aims to highlight the importance of your own emotional well-being as a parent carer, provide information about factors that may have an effect and help you navigate and access the information, support and resources that are available.

## Key points

- Why is my emotional well-being at risk?
- Who can I contact if I am worried about my well-being?
- How can I look after my own well-being?
- What further help is available to support me when parenting a child with a learning disability?

## Why is my emotional well-being at risk?

Parenting is a rewarding experience. However, at the best of times it can also be tough. When you have a child with a disability, there are additional challenges for you and the whole family. Research has shown that parents of children with a learning disability are up to twice as likely to experience high levels of stress, than other parents.<sup>1</sup> This additional stress can lead to a reduction in your emotional well-being and you might experience feelings such as depression, anxiety and lack of confidence in yourself. This can have a negative impact on your happiness and your family's well-being.

An important part of working to improve your well-being is to identify what might be having a negative effect. This might include things such as:

- worries about your child and aspects of their care, for example, difficulty dealing with a diagnosis, managing any behavioural and emotional problems, managing their care and supervision needs, any health problems, sleep problems, educational issues, problems managing services, and perhaps worries about what the future holds.
- personal problems, for example, physical health problems, lack of sleep, social isolation, inactivity, a bereavement, relationship problems, financial difficulties or housing worries.

There could be a number of things going on in combination that are having an effect. You give considerable energy to support your child and family's needs and this might lead to you needing some support yourself. It might be useful to write down your feelings and difficulties. You could talk to a health professional about them or talk them through with a trusted person and think about some solutions together. The information and resources below aim to help you find ways to work through any problems.

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<sup>1</sup> Totsika, V., Hastings, R.P., Emerson, E., Lancaster, G.A., Berridge, D.M (2011) A population-based investigation of behavioural and emotional problems and maternal mental health: associations with autism spectrum disorder and intellectual disability. *Journal of child psychology & psychiatry*. 52 (1), pp. 91-99 Oxford: Blackwell Publishing.

# Who can I contact if I am worried about my well-being?

If you have any worries about your well-being and feel you could do with some support, some useful first steps might include:

1. Contacting your GP. They will be able to look at any factors affecting your well-being and offer tailored support.
2. Requesting a carer's assessment from your local social services department, or via a referral through your doctor or your child's health professional. As well as practical help, support is also available to help relieve stress, improve health and promote well-being. For more information about carers' assessments and how to get one, please see the CarersUK website below. It provides information about how to get a carers' assessment in England, Ireland, Scotland and Wales and in-depth information about the types of support that you can expect:

<http://www.carersuk.org/help-and-advice/practical-support/getting-care-and-support/carers-assessment>

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.

England—<https://cerebra.org.uk/download/social-care-in-england/>

Wales—<https://cerebra.org.uk/download/social-care-in-wales/>

3. Finding out about any emotional support services for carers in your area. You can search for such services in your area through the NHS website below:

<http://www.nhs.uk/Service-Search/Carers%20emotional%20support%20services/LocationSearch/374>

4. Getting in touch with your local carer's service to see what general carer support is available in your area. You can also find nationwide carer support organisations in the 'Support organisations' section in the back of this guide. You can search for your local carer service using the search function provided by Carers Trust:

<https://carers.org/search/network-partners>

## A parent's perspective

'As a parent carer of a teenager with severe learning difficulties and autism, I feel that emotional well-being is very important and you must take time out to look after yourself. Ultimately my well-being improves and I am content when my 13 year old disabled son is able to accomplish new things, or we are able to spend time together in a positive way.

Having a child with a learning disability has brought housing and income problems to our family. I have found maintaining my independence and being proactive has helped protect my well-being, as well as my faith in God.'

Manjeet

# How can I look after my own well-being?

## 1. Look after your health

- ◆ Eat healthily
- ◆ Get enough rest
- ◆ Exercise regularly

CarersUK provide a useful information sheet to help you look after your health:

<http://www.carersuk.org/help-and-advice/health>

NHS Together suggest 5 steps you can take to improve your mental well-being:

<https://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/improve-mental-wellbeing.aspx>

MIND, the mental health charity, provides a factsheet for carers titled 'How can I look after myself?' It provides useful resources and things to think about:

<https://www.mind.org.uk/information-support/helping-someone-else/carers-friends-family-coping-support/looking-after-yourself/>

## 2. Get in touch with a befriending service or support group, to talk to other parents going through a similar experience to you.

Scope, a charity for disabled people, runs face-to-face, a service connecting parents of disabled children for emotional and practical support. For more information, please visit:

<http://www.scope.org.uk/support/services/befriending/about-face-2-face>

Contact (formerly Contact a Family) provides information about many health conditions that might lead to a learning disability. The information pages also provide links to condition specific support groups:

<https://contact.org.uk/advice-and-support/health-medical-information/conditions/>

## 3. Learn a relaxation technique such as mindfulness or meditation.

Be Mindful offers an online mindfulness course. You can have a look and get a taster for free, however, the full course costs £30. To find out more about mindfulness and the online course please visit:

<http://bemindful.co.uk/>

You can get a free taster of Headspace, an online meditation course from Carers Club:

<http://www.carersclub.org/mind/>

## 4. Take regular breaks from caring.

CarersUK provide an information sheet on how you can organise a break:

<http://www.carersuk.org/help-and-advice/health/looking-after-your-health/taking-a-break>

SENDirect provide information about overnight stays and breaks away for your child. You can search for accessible and inclusive holidays, accommodation, and respite options for your family.

<https://www.sendirect.org.uk/categories/overnights-breaks-away/>

## A parent's perspective

'Someone has said, 'Challenges are either stumbling blocks or stepping stones; they either make you or break you.' Our latest challenge was transition; our daughter Alissa who has Down's syndrome moving to independent living. It was as hard for her as it was for us. Yet we knew with our increasing age, we were sitting on a time bomb. Could she live on her own with support?

We had one professional say we would have to make her homeless to get enough points on the housing register. Another said she would not get enough housing benefit or council tax benefit to cover the costs. The social worker would try, but could not guarantee, that Alissa would get enough hours approved for Direct Payments with the austerity pressures.

We kept talking to our social worker who was brilliant. Their work load is such as they don't have time to be a Housing officer too. Then we heard Social Services had a word with a local Housing Association. The Housing Association was building a brand new block of flats in the town nearby 4 miles away. The flats would be finished in a few months and we received a letter that Alissa was invited to view it.

A few months later we saw the most beautiful one bedroom flat on the top floor. All spanking new with great heating efficiency. The Housing Association has a worker to help with housing benefit and council tax. Because Alissa was on DLA, we found that her rent and council tax were all covered. We met with the social worker who arranged for enough hours of Direct Payments to help her in the evenings. Her mum stayed with her the first week. A special social worker came every week for a month teaching Alissa personal safety.

Now she has been in the flat for a year and a half. She has made so many steps to being independent. She comes to stay at our house on the weekends so she is not alone. Having her own flat is cheaper for the local Authority than Supported Housing. The advantage is she has a sofa bed so sometimes her siblings can sleep over and she and one of her PA's invite others for dinner and offer hospitality.

I found it so important to look on the bright side and stay positive. If I take things too seriously and don't find a way to relax, I won't be much help for anyone.'

Alex

# What further help is available to support me when parenting a child with a learning disability?

Reaching out and getting some help with the things that you have identified as having a negative effect on your well-being is vitally important. The support organisations, services and resources below might provide the help you need or act as a starting point on your research journey.

## Support organisations

### Carers UK

Carers UK run a telephone advice (0808 808 7777) 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.

[www.carersuk.org](http://www.carersuk.org)

### Carers Trust

The Carers Trust is a national charity that provides support to carers, including carers of someone with a disability. (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.)

<https://carers.org>

### Carers direct helpline

The NHS-run carers direct helpline (0300 123 1053) can give you information to help make decisions about your personal support needs and the needs of the person you're looking after, including information about [assessments](#), benefits, direct payments, individual budgets, [time off](#) and maintaining, leaving or [going back to work or education](#). They can put you in touch with specialist national or local sources of help, including social care, healthcare and self-help networks and resources.

[www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-direct-helpline.aspx](http://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/carers-direct-helpline.aspx)

### Cerebra

Cerebra is a 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 about your legal rights when accessing services, an equipment innovation centre and a library service. We also offer a free monthly newsletter. You can find out more on our website or contact our national freephone helpline: 0800 328 1159.

[www.cerebra.org.uk](http://www.cerebra.org.uk)

### Challenging Behaviour Foundation

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.

[www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

## Contact (Formerly Contact a Family)

Contact, a charity registered in England and Wales, provide 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

[www.contact.org.uk](http://www.contact.org.uk)

## Enable

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

[www.enable.org.uk/Pages/Enable\\_Home.aspx](http://www.enable.org.uk/Pages/Enable_Home.aspx)

## Family Information Service

Find your local Family Information Service (FIS) using the search function provided. FIS provides a range of information on all services available to parents in the UK, including parents of disabled children. Contact your FIS for up-to-date details of local childcare and early years provision in your area.

<http://findyourfis.familyandchildcaretrust.org/kb5/findyourfis/home.page>

## Mencap

Mencap 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 has launched a new Familyhub, an online portal where you can connect with other parents and family carers of someone with learning disability. You can connect with others, share triumphs and challenges and give and receive support and tips.

[www.mencap.org.uk](http://www.mencap.org.uk)

## Portage

Portage is 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, helping you to identify what is important to you and your child and plan goals for learning and participation.

[www.portage.org.uk](http://www.portage.org.uk)

## SENDirect

SENDirect is a website run by the charity Contact (see above), where families of children with disabilities or special educational needs can search for and compare accessible support, activities and services that are right for their family.

[www.sendirect.org.uk](http://www.sendirect.org.uk)



## Useful services

### Advocacy services

#### NHS Choices

The NHS webpages 'Your guide to care and support' provides information about what advocacy services are available and where you can access them.

<https://www.nhs.uk/Conditions/social-care-and-support-guide/Pages/advocacy-services.aspx>

### Relationship advice

#### Relate

Relate offers relationship support to people and provide an online, telephone and face-to-face relationship counselling service.

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

### Sleep services

#### Cerebra sleep service

We have a team of sleep practitioners who can offer help and advice (over the phone, email or face-to-face) on children's sleep issues, including settling problems, difficulty sleeping alone and early rising.

<https://www.cerebra.org.uk/help-and-information/sleep-service/>

# Resources

## Cerebra

We have produced a number of guides for parents of disabled children, including information that might help reduce your stress and anxiety.

- **Accessing Public Services: A problem solving toolkit**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/problem-solving-toolkit/>
- **Factsheet: Managing challenging behaviour**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/managing-challenging-behaviour-factsheet-2/>
- **Anxiety: A guide for parents**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/cerebra-anxiety-guide-guide-parents/>
- **Pain: A guide for parents**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/pain-in-children-with-severe-intellectual-disability-a-guide-for-parents/>
- **Guide to claiming Disability Living Allowance**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/dla-guide/>
- **Social care in England: A guide for parents**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/social-care-in-england-a-guide-for-parents/>
- **Social care in Wales: A guide for parents**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/social-care-in-wales-a-guide-for-parents/>
- **Sleep: A guide for parents**  
<http://www.cerebra.org.uk/help-and-information/guides-for-parents/sleep-a-guide-for-parents/>

For a full list of Cerebra guides please visit: <http://www.cerebra.org.uk/help-and-information/guides-for-parents/>

## The Foundation for People with Learning Disabilities

The Foundation for People with Learning Disabilities has produced a planning guide for families to help them plan for the future. This is free to download and will help you think about things such as decision-making, planning in a person-centred way, building friendships and support networks, talking about difficult subjects, making financial plans, housing and support plans and making a plan for emergencies.

<https://www.mentalhealth.org.uk/learning-disabilities/our-work/family-friends-community/thinking-ahead/>

## About the author

Jane Margetson is the Lead Research Officer at Cerebra, based in our Bristol office, working between the University of Warwick and Cerebra head office. She has a background in Psychology and her research is specifically focused on learning disabilities and autism.

This guide is one of a series now available on our website.

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The findings of this report are those of the author, not necessarily those of Cerebra.

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# Working wonders for children with brain conditions

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