Factsheet

After diagnosis: what now?

CEREBRA

Working wonders for children
with brain conditions

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.

After diagnosis: what now?

Aims

Getting a brain condition diagnosis (any neurodevelopmental disorder that affects the developing brain, including those caused by illness, genetics or traumatic injury) for their child is challenging for the majority of parents. However, it is only the first hurdle and families often feel overwhelmed and unsure of what to do next.

This factsheet has been prepared as a starting point for parents of children that have just been diagnosed with a brain condition. It aims to provide an overview of the resources and information they need to get advice, help and support for their child and family.

Key points

- Understanding a diagnosis
- Social care
- Financial aid
- Education
- Support
- How Cerebra can help
- Useful contacts
- Available resources

1. Understanding a diagnosis

You may already know the basics of your child's diagnosis, or you may be facing the topic for the first time. Learning all you can and understanding the condition will help you make informed decisions about all aspects of your child's life and treatment.

The health care professionals you have already met (your GP, paediatrician or other specialists) can answer your initial questions and provide information. Take notes and ask them to explain anything you don't understand or feel unsure about. You can ask your doctor to recommend books and websites with additional information. Some people find that learning about their child's condition gives them a sense of control over what is happening.

For more information on the NHS structure, as well as an overview of the primary, secondary and tertiary care, Contact provide detailed information here:

https://contact.org.uk/advice-and-support/health-medical-information/health/an-introduction-to-the-nhs/

Where can I find out more?

The internet provides a huge amount of information, much of which is freely available and easy to access. Although there are many reputable websites that provide good quality, reliable information, there are also websites which are less reliable and should be treated with considerable caution. When searching for information about childhood brain conditions on the internet, it is important to make a judgment about the quality of what you find before you use it. We provide below some reliable sites that will help you learn more about your child's condition in the first instance.

Contact

Contact provides up-to-date information on hundreds of medical conditions, including details on symptoms, diagnosis and support.

NHS Health A to Z

A complete guide to conditions, that provides information on symptoms, causes, diagnosis and treatments, including what to do and when to get help.

Great Ormond Street Hospital for Children

Great Ormond Street Hospital for Children provides information sheets covering a wide range of conditions, treatments and medications.

Health Talk

Healthtalk provides reliable information about health conditions from the patient perspective.

Patient

Patient provides health information for patients and professionals around the world. The site contains over 4000 health information leaflets and thousands of discussion forums.

Ensuring the quality of the information you find

The Cerebra guide, Finding and Appraising Information and Evidence on the Internet, provides information and suggestions about how to search the internet efficiently and how to appraise the huge amount of information freely available. These strategies will help you to ensure you are using quality and reliable information for your individual circumstances.

Charities and National Societies

There are numerous non-profit organisations associated with specific conditions. They can not only be useful sources of information, but also support individuals and families of children with brain conditions.

- You can find a short list of organisations to help you start your search on page 10
- You can also find charities using the Charity Commission Advanced Search, where you can combine keywords with other criteria to find the charity you want then view its profile.

Genetic and Rare Conditions

There are more than 6,000 known rare conditions. Your GP or paediatrician may be able to provide you with adequate information if they are familiar with the condition. As is often the case, you might require more in-depth information as you continue to learn about your child's diagnosis. The websites below provide more detailed, reliable information about genetic and rare genetic conditions.

Unique

Unique provides specialist information relating to many hundreds of different rare chromosome disorders and autosomal single gene disorders, for parents, carers and the professionals working with them.

National Organization for Rare Disorders (NORD)

NORD is an organisation based in America, dedicated to individuals with rare diseases. Their Rare Disease Database provides brief introductions for patients and caregivers to specific rare diseases as well as further links.

Orphanet

Orphanet provides information on individual conditions based on published scientific articles. Orphanet can also serve as a valuable resource for discovering alternative names associated with the condition. These alternative names could prove beneficial when seeking support, or information.

Further Inform Neurogenetic Disorders (FIND)

FIND provides clear, accurate and balanced information about genetic syndromes. To find out more you can choose the syndrome you are interested in or ask a question about a syndrome using the interactive database.

Syndromes without a name (SWAN)

SWAN is the only dedicated support network available for families of children and young adults with undiagnosed genetic conditions in the UK. It is run by the charity Genetic Alliance UK.

2. Social care

Local authorities have a duty to provide any non-medical care services to disabled children. This could include equipment for daily living, home care assistance, access to play schemes, educational provisions, transport assistance, home adaptations, respite care and other services.

To access any of these services, you will need to contact your local authority and ask for an assessment of your child's needs by social services, through a process called a needs assessment.

You can ask for a care needs assessment (also known as a social care assessment) over the phone, in writing, or in some cases online. You can find out your local council's website, where you can get contact information as well as more information on services, on GOV.UK by entering your postcode. This is for England and Wales only. Carers UK offer separate information sheets for those living in England, Ireland, Scotland and Wales here.

Contact provides further details on what to expect at an assessment on their website, found here.

Our factsheet on Carers' Assessments provides an overview of carers' assessments for parents and carers of disabled children living in England. We have also published a factsheet for parents and carers in Wales.

Carers UK, as well as Carers Trust, provide more information on the rights of carers, the assessment process and what sort of support may be available.

If you would like more detailed information on the support you are entitled to in getting help for your child's social care needs, please see our Social Care: A Guide for Parents. It outlines exactly what social care the local authorities in England are responsible for and the support that is available to you as a parent or carer. We have also created a guide for parents and carers in Wales.

3. Financial aid

Benefits and tax credits

Your family may qualify for a range of benefits or other types of financial support. The information below is for parents of children aged under 16.

Disability Living Allowance

Disability Living Allowance (DLA) can be claimed for children who have a disability or health condition and as a result need extra help. It is not means-tested so your financial circumstances will not be considered. DLA is also not taxable and does not reduce other benefits.

The DLA care component is paid at a low, middle or higher rate; you get one of these rates depending on how much help you need.

You can claim DLA by filling an application form. The form is available via the Department for Work and Pensions. You can order one by phone, or download the application form online.

For more details, see our free guide to understanding and applying for DLA.

Carers Allowance

You are entitled to Carers Allowance if your child receives the middle or higher rate DLA care component and you look after your child for 35 hours a week or more. You must earn less than a set amount (currently £139 per week) after deductions including tax, national insurance and certain expenses.

Carers UK provide more information and details on how to claim.

Universal Credit

Universal Credit (UC) has replaced the majority of 'legacy benefits' (e.g. Income Support, Tax Credits). Generally you need to be aged 18 or over to make a claim, but many disabled students and 16/17 year olds are able to claim UC if they are in receipt of DLA or PIP.

It is a means-tested benefit and so the amount you receive depends on your income and capital (money in the bank and assets); as well as other factors such as who is in your household, what their capacity to work is, whether you have childcare responsibilities, housing costs and other factors.

You can make a claim by setting up an online Universal Credit account at https://www.gov.uk/apply-universal-credit. This is followed by an interview at your local job centre when you will need to bring in evidence to support your claim.

Housing Benefit, Income Support and Tax Credits

These benefits have been replaced by Universal Credit unless you have reached the state pension age, or are in very rare exceptional circumstances.

Help with Council Tax, fuel and water bills

You may be able to get a reduction in council tax under the disability reduction scheme if anyone resident in the property (adult or child) is 'substantially and permanently disabled'.

In addition, one of the following conditions has to be met:

- there is an additional bathroom or kitchen in the property which is needed by the disabled person
- there is a room (other than a bathroom, kitchen or toilet) needed by and mainly used by the disabled person
- there is enough space in the property for the disabled person to use a wheelchair indoors

To apply for the reduction contact your local authority, if you are in Northern Ireland you should contact Land & Property Services.

You might be able to get a Cold Weather payment (which runs from November to March) to help with home heating costs if your child has a long-term health condition or disability and you are getting one of these benefits:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance

- Universal Credit

and you have any of the following:

- A child under five in your family
- A child for whom you get child tax credits or income support with an extra amount for their disability

You do not need to apply. If you are eligible to get a Cold Weather Payment, you will be paid it automatically after the temperature in your area has dropped below 0°C for seven consecutive days or more.

Under the Warm Home Discount Scheme you could get £150 off your electricity bill for winter 2023 to 2024. The money is not paid to you - it's a one-off discount applied to your electricity bill.

You'll usually get the discount automatically if you're eligible. If you do not get a letter and you think you're eligible, you must contact the Warm Home Discount Scheme before 29 February 2024.

Water Sure (England and Wales) helps with water bills. It caps your water bill so you won't pay more than the average metered bill for the area your water company covers. To qualify you must:

- Be on certain benefits
- Have a water meter (or be waiting for one to be installed)
- Have a high essential use of water (this means you have three or more children under 19 in full-time education, or a child with a medical condition or disability that requires your household to use a lot of water)

Children who have certain conditions may automatically qualify under these schemes. Contact your water company directly to find out more and to apply.

In Scotland if you receive council tax reductions or your property has been adapted for a disabled person, you might be entitled to a discount on your water charges. Speak to your local council for further information or visit the Scottish Water website.

Households in Northern Ireland are provided with water by Northern Ireland Water. Vulnerable customers, including those with a disability, can join the Customer Care Register to receive priority support and other free services. Find out more on the Northern Ireland Water website.

Benefits calculators

You can use an independent benefits calculator to find out what benefits you could get and how to claim.

The calculators below have replaced the Benefits Adviser service, are free to use and anonymous.

- entitledto- for information on income-related benefits, tax credits, contribution-based benefits, Council Tax Reduction, Carer's Allowance, Universal Credit and how your benefits will be affected if you start work
- Turn2us- for information on income-related benefits, tax credits, Council Tax Reduction, Carer's Allowance, Universal Credit and how your benefits will be affected if you start work or change your working hours
- Policy in Practice- for information on income-related benefits, tax credits, contribution-based benefits, Council Tax Reduction, Carer's Allowance, Universal Credit, how these are calculated and how your benefits will be affected if you start work or change your working hours

Challenging Benefit Decisions

If you disagree with a decision about your benefits, you have the right to ask for the decision to be looked at again. For more information, visit GOV.UK

Other useful resources:

- www.gov.uk
  Online government information about benefits for England and Wales
- www.citizensadvice.org.uk
  The online site for Citizens Advice giving independent guidance including benefits advice
- www.advicenow.org.uk
  Help about your rights if you need to challenge a decision on a claim

You can find more information in our Money Matters guide. This guide has been written for parents of disabled children who want to know what financial help may be available for them and what arrangements they may need to put in place to manage their children's finances from birth and as they get older.

4. Education

Every child has a right to education. But children with a brain condition often face extra difficulties and need support in getting the education they are entitled to. Schools have a legal duty to support children and young people with additional needs and disabilities and to treat them fairly.

Our Education guide provides the parents of children with special educational needs and parents of disabled children in England all the information they need on how to get help for their child at school. We have also published a guide to education in Wales.

You can find more information on the additional help available for parents and children with special educational needs and disabilities on GOV.UK, as well as Contact and Mencap websites.

Independent Provider of Special Education Advice (known as IPSEA) is a registered charity which offers free and independent legally based information, advice and support to help get the right education for children and young people with all kinds of special educational needs and disabilities.

SOS!SEN also offers a free, friendly, independent and confidential advice and support for parents and others looking for information and advice on special educational needs and disability.

5. Support

Most parents need some time to adjust to their child's diagnosis. You might feel a range of emotions, including a sense of relief (to finally know what is going on). But the news can also be traumatic and leave you feeling worried about the future for your child and family. You might feel overwhelmed, not knowing how to deal with the challenges that might come next. It can take time to learn how to manage day-to-day life and to find new ways to live well for yourself and your child. During this time, it's important that you look after your own health and wellbeing. Below we've outlined some ideas and resources that might be helpful when looking after yourself too.

GP Carers Register

If your GP's surgery has a carers register, you could ask to be added. If your GP knows you're a carer, they can keep an eye on your health and you'll have someone to speak to in confidence about how you're feeling.

Take steps to look after your own emotional well-being

The Cerebra Emotional Well-Being factsheet 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.

The Cerebra Wellbeing Guide provides information, resources and guidance to help you find ways to focus on your own wellbeing and happiness, while caring for your child. There is also a Wellbeing Plan that you can complete while reading the guide to help you document and action some changes that you think are likely to benefit you.

Get in touch with Scope Navigate Service

Navigate, a national mentoring service offered by Scope, provides online emotional support for parents and carers of disabled children who are finding out about their child's additional needs.

Advice about coming to terms with a diagnosis

Scope offer useful tips about coming to terms with your child's disability diagnosis. Click here to visit the website.

Respite care

Time away from your child can often be beneficial for you both. Being overwhelmed and exhausted by your caring responsibilities can affect your health. If family and friends can't always step in, respite care may be a possibility. Find out more about carers' breaks and respite care.

Support Groups

Talking to other parents who have children with the same disability or health condition as yours can be reassuring. Parent support groups are a great way to meet other parents for practical and emotional support.

National support groups

National support groups are usually for parents of children with specific conditions and can offer a range of support.

You can search for your child's condition on Contact's website to see if there's a national support group.

Local support groups

Local groups cater for parents who live in the same area whose children might have a variety of different disabilities or the same condition.

Your local Carers Centre, should be able to put you in touch with a local support group. You can search for a local Carers Centre on the Carers UK website.

The National Autistic Society hosts a comprehensive directory of services and support for people on the autism spectrum, their families, and people who work with them. Find more information here.

The National Network of Parent Carer Forums (NNPCF) is the independent national voice of parent carer forums. To find your local parent carer forum check their website.

Online discussion forums

There are many people who care for others sharing their stories and offering support online. You don't have to join in conversations, but it might help to see what's being said.

Carers UK forum

HealthUnlocked carers community

Contact a free disability helpline

Get in touch with a disability specific helpline to ask any questions or discuss any concerns you might have.

Contact – helpline for families with disabled children
Tel: 0808 808 3555 (Monday-Friday 9am-5pm)
Web: https://contact.org.uk/advice-and-support/our-helpline/

Mencap – learning disability specific helpline
Tel: 0808 808 1111 (Monday-Friday 10am-3pm)
Web: https://www.mencap.org.uk/advice-and-support/our-services/learning-disability-helpline

Scope – for disabled people and their families.
Tel: 0808 800 3333 (Monday-Friday 9am-6pm, Saturday and Sunday 10am-6pm)
Web: https://www.scope.org.uk/helpline/

6. How Cerebra can help

We at Cerebra help children with brain conditions and their families in many different ways. Through our services we can help you overcome obstacles you may be facing and enable you to discover a better life together with your amazing child.

All the support we offer is research-driven and evidence-based. From advice on legal, financial and social affairs to support with physical and mental health issues, our work is driven by listening to what you need.

Our research work across neurodevelopmental conditions gives us a unique perspective within the charity research sector allowing us to provide research-driven solutions and advice to those who need it most.

Being the parent of a child with a brain condition or learning disability means you may need to access legal, social and financial help at various times for different reasons. We have created a wide range of resources and guides that offer comprehensive and current information on a wide variety of issues and support you with some of the difficult decisions and tasks involved:

Cerebra Innovation Centre

The Cerebra Innovation Centre (CIC) designs and builds innovative, bespoke products to help disabled children discover and engage with the world around them. From fish tanks to oxygen tanks via specialist buggies and surfboards – our award-winning team are brimming with ideas and solutions.

Sleep Advice Service

At Cerebra we understand that if you have one child that doesn't sleep, the whole family suffers. Our Sleep Advice Service offers various resources including our Sleep guide, workshops and a one-to-one telephone support service to help your child – and everyone in your family – get a better night's sleep.

Book and Toy Library

We have a range of books, eBooks and audio books about brain conditions in our library for both adults and children. Our Toy library is also available for children with special needs. Both services are free and easy to use.

Parent Guides and Factsheets

We publish a series of guides and factsheets to help families of children with brain conditions with common problems they may be facing. They offer comprehensive, up-to-date advice and strategies to help you deal with a wide range of issues.

Legal Rights Service

Our Legal Rights Service provides free information to families who need help getting the right support for their children. It runs alongside our innovative problem-solving LEaP project at the School of Law at Leeds University. To find out more and see whether you are eligible for help, please look at our project guidelines before filling out an online request form.

7. Useful contacts

ADHD Foundation, www.adhdfoundation.org.uk

Ambitious about Autism, www.ambitiousaboutautism.org.uk

Autism Education Trust, www.autismeducationtrust.org.uk

Autistica, https://www.autistica.org.uk/

Childline, www.childline.org.uk

Contact, www.contact.org.uk

Council for Disabled Children, www.councilfordisabledchildren.org.uk

Disability Rights UK, https://www.disabilityrightsuk.org/

Epilepsy Action, www.epilepsy.org.uk

Foundation for People with Learning Disabilities, www.foundation-for-people-with-learning-disabilities

Include Me TOO, www.includemetoo.org.uk

Mencap, www.mencap.org.uk

National Autistic Society, www.autism.org.uk

Scope, www.scope.org.uk

SIBS, https://www.sibs.org.uk/

The Challenging Behaviour Foundation, www.challengingbehaviour.org.uk

Young Epilepsy, www.youngepilepsy.org.uk

YoungMinds, www.youngminds.org.uk

8. Available resources

Right from the start toolkit

Ambitious about Autism provide a Right from the Start toolkit that contains information to guide parents and carers of a child with autism through their child's journey in the early years.

Autism: A guide for parents and caregivers following diagnosis

ASDinfoWales have a guide for parents and carers following an Autism Spectrum Disorder diagnosis.

Managing challenging behaviour

This Cerebra Factsheet, describes what challenging behaviour is, why it happens, how we understand it and what we can do about it.

A Parent's Guide: Improving the well-being of young children with learning disabilities

The University of Warwick in collaboration with Mencap, the Challenging Behaviour Foundation and Cererba have produced 'A Parent's Guide: Improving the well-being of young children with learning disabilities'.

Mencap: Information about getting a diagnosis

Mencap, the charity for people with learning disabilities, have a section on their website that focuses on providing information for parents when they receive a diagnosis of a learning disability for their child and/or other disability or condition.

Yvonne Newbold: The special parents handbook

A very well put together, and highly acclaimed book by Yvonne Newbold, a mother of three children with special needs. The book covers issues such as, getting the bad news, dealing with emotions, understanding the army of professionals, your child, dealing with siblings, building a support network, being in hospital and finally covering the wider issues of social services, education and Child and Adolescent Mental Health Services (CAMHS).

Contact: 'The helpful guide for families with disabled children'.

Packed with useful information, from advice from other mums and dads, common concerns about your child's health and development, your right to practical help as well as a multitude of resources that are available on a wide range of issues and the support that Contact can offer families.

About the author

Georgia Mappa is currently working as part of the Cerebra Research Team. She holds a degree in Genetics and is carrying out a PhD at the University of Leeds focusing on understanding pregnancy complications and identifying their detection as early as possible, with the aim of establishing preventative strategies that will reduce the incidence and burden of childhood brain injury.

About the reviewer

Jane Margetson is the Lead Research Officer at Cerebra. She is currently undertaking research at the University of Warwick related to Cerebra's 1,000 families study. Jane has a background in psychology.

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

First edition: 2020

This edition: 2023

Review date: 2026

Working wonders for children with brain conditions

Postal Address
Cerebra
The MacGregor Office Suite
Jolly Tar Lane
Carmarthen
SA31 3LW
Tel: 01267 244200
Freephone: 0800 328 1159

www.cerebra.org.uk

Registered Charity no 1089812 Company no. 4336208

amrc
ASSOCIATION OF MEDICAL RESEARCH CHARITIES

Registered with FUNDRAISING REGULATOR

INVESTORS IN PEOPLE