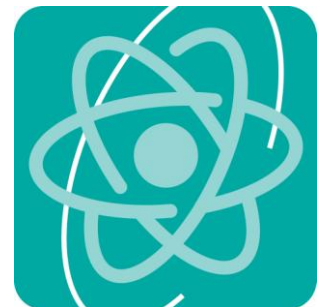


Early Support

for children, young people and families

Information about neurological disorders

Part 1



About this resource

This information resource has been devised to provide the following information to parent carers of children with neurological disorders:

- Types and causes of **neurological disorders**.
- Diagnosis and management.
- What you can do to help your child.
- Information about the issues you may face in daily life.
- Where you can gain further information and support.
- Perspective of families who have a child with a **neurological disorder** (where words are printed in italics, *like this*, it means that a parent of a child with a neurological disorder said it).

There are three parts to this information resource:

- Part 1 – Neurological disorders.
- Part 2 – Guide to neurological disorders – a table explaining the causes, symptoms and potential management techniques for a range of disorders, along with details of organisations able to offer support and advice.
- Part 3 – Useful organisations and websites.

There is a lot of information provided in these three resources, and you may consider just looking at particular sections that deal with your current concerns and return to other sections later.

The term neurological disorder applies to any condition that is caused by a dysfunction in part of the brain or nervous system, resulting in physical and/or psychological symptoms in a developing child. There are over 600 known neurological disorders; this resource covers some of those that are commonly known to occur in childhood and adolescence.

For further information on any neurological disorder, please visit **NHS Choices A-Z of conditions and treatments**.

Where a word or phrase appears in colour, **like this**, it means you can: look them up in the **Glossary** at the back of the resource. Where a word or phrase appears in colour, **like this**, you can find contact details for the organisation or agency highlighted in **Part 3 – Useful organisations and websites**.

This information resource was developed by Early Support and **Cerebra**.

Early Support

Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working.

Early Support is a core partner supporting the implementation of the strategy detailed in Support and aspiration: A new approach to special educational needs and disability, the Government's 2011 Green Paper. This identified Early Support as a key approach to meeting the needs of disabled children, young people and their families.

Early Support helps local areas implement the Government's strategy to bring together the services families need into a single assessment and planning process covering education, health and care. Early Support provides a wide range of resources and training to support children, young people, families and service deliverers.

To find out more about [Early Support](http://www.ncb.org.uk/earllysupport), please visit www.ncb.org.uk/earllysupport.

Explanation of the term parent carer

Throughout this resource the term 'parent carer' is used. It means any person with parental responsibility for a child or young person with special educational needs or disability. It is intended as an inclusive term that can cover foster carers, adoptive parents and other family members.

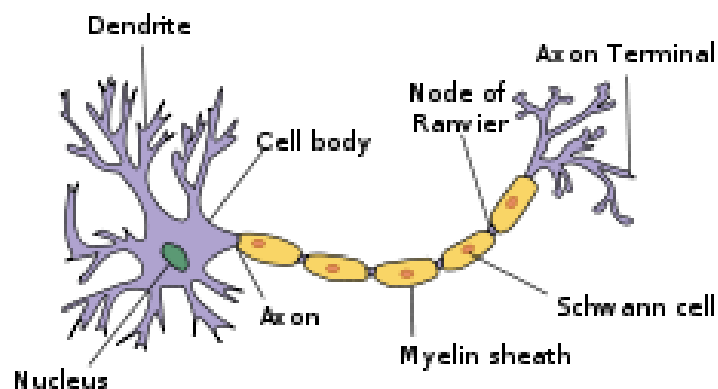
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What is a neurological disorder?

The development of the human **brain** begins during pregnancy and continues through infancy, childhood and adolescence. Most brain cells are formed before birth but the trillions of connections between these nerve cells (**neurons**) are not developed until infancy.

Diagram of a motor neuron



The brain is composed of grey matter (neurons and interconnections) and white matter (axons surrounded by a myelin sheath). A motor neuron (above) carries impulses away from the brain.

The brain is self-organising. It selects information to forward its growth and development. It also adapts to the environment. Experience of the environment through the senses of touch, smell, sight, taste and hearing produces connections in the brain.

The Science Museum provides an explanation of brain function on a question and answer website:

www.sciencemuseum.org.uk/WhoAmI/FindOutMore/Yourbrain/Howdoesyourbrainwork/Howdoesyournervoussystemwork/Whichnervecellsdowhat.aspx

An interactive guide to child development is provided by **NHS Choices**:

www.nhs.uk/Tools/Pages/Birhofive.aspx#close

What are neurological disorders?

All **neurological disorders** involve the brain, spinal column or nerves. Symptoms depend on where damage occurs (see [Part 2 – Guide to neurological disorders](#), www.ncb.org.uk/early-support/resources). Areas that control movement, communication, vision, hearing or thinking can be affected.

Neurological disorders are wide ranging. They have various causes, complications and outcomes. Many result in additional needs requiring life-long management.

Symptoms of neurological disorders vary. Physical, cognitive (to do with thinking), emotional and behavioural symptoms may be present, with specific disorders having combinations or clusters of these symptoms. For example, **cerebral palsy** tends to have more physical symptoms whereas **ADHD** tends to have more effect on behaviour.

Many **neurological disorders** emerge during the early years of development and may be diagnosed at birth. Some are diagnosed later because symptoms only appear when:

- A child misses developmental milestones or has developmental difficulties (e.g. **ADHD**).
- A damaging infection occurs (e.g. **meningitis**).
- An accident causes **brain injury**.

The guide to neurological disorders in Part 2 of this resource outlines potential symptoms of a number of neurological disorders and links to further information.

Causes of neurological disorders

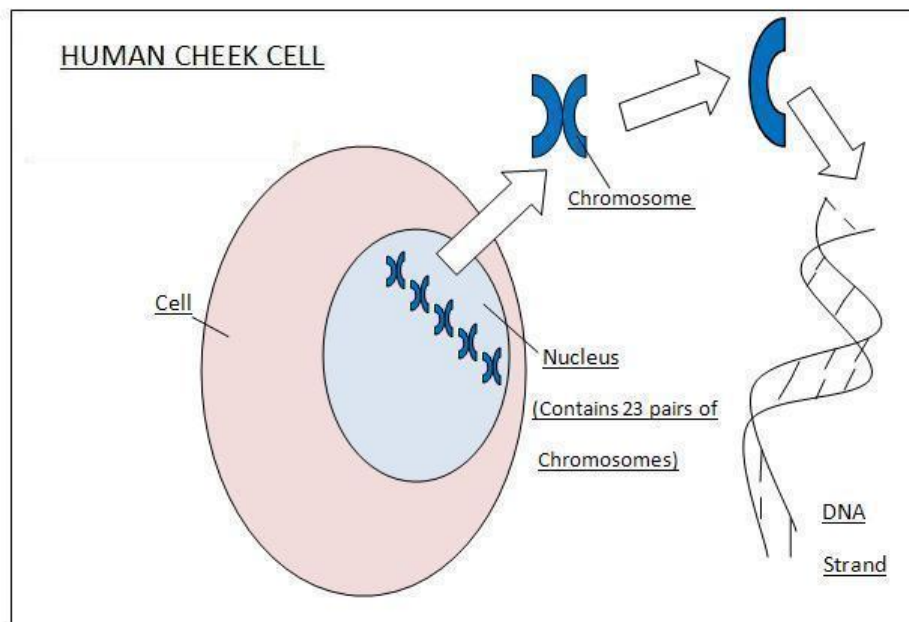
Congenital disorders are present at birth but some disorders are **acquired** (develop after birth). Those with an unknown cause are called **idiopathic**.

Congenital causes (present at birth)

Genetic factors can influence the development of a variety of neurological disorders that are typically inherited from parents through **genes** and **chromosomes**.

Chromosomes are long strands of **DNA** supported by protein that are found in the nuclei of human cells (see below).

Diagram showing human cell and chromosomes



Sections of DNA called genes carry the chemical code which makes us who we are. Chromosomes are composed of thousands of genes.

A human body cell normally contains 46 (23 pairs) of chromosomes, half inherited from the mother and half from the father.

Gene abnormalities

Genes are responsible for determining characteristics. Changes in genes (called mutations) therefore change characteristics. Some mutations cause abnormalities that are damaging to individuals e.g. cystic fibrosis. Mutations can be passed on to offspring affecting their characteristics.

Chromosome abnormalities

Changes in chromosomes have large effects on characteristics because they contain large numbers of genes. Chromosomes can change in number or in structure.

Change in chromosome number

The term **monosomy** refers to a loss of one chromosome out of a pair (e.g. **Turner syndrome**). In **trisomy** an extra chromosome has been gained by a pair (e.g. **Down syndrome**).

Change in chromosome structure

Micro deletions result in a loss of genes (fragments of DNA) from a chromosome. Micro duplications occur when genes (fragments of DNA) are gained. Examples of conditions include **cri-du-chat**, **Prader-Willis/Angelman's syndrome**.

Metabolic disorders

Metabolism refers to the chemical processes that occur in the body. Disorders of the Metabolism can cause lasting damage and must be identified as early as possible (e.g. blood or urine tests).

Examples of metabolic disorders include **phenylketonuria (PKU)** and **diabetes**. PKU is an inherited disorder where phenylalanine (present in food) can reach high concentration in blood serum. This causes damage to brain cells and to intellectual ability. Similarly in diabetes an inability to control blood glucose levels can result in damage to brain cells.

Congenital malformation

Congenital 'defects' are believed to be the result of complex interactions between genes, environment and behaviours. An example is **tuberous sclerosis**, a condition where children have growths in regions such as the brain, heart, eyes, skin, kidneys and lungs. They may also experience **epilepsy**, learning difficulties/impairments and **ASD**.

Immune disorders

Immune disorder such as **Paediatric Autoimmune Neuropsychiatric Disorder associated with Streptococcal infection (PANDAS)** can cause emotional challenges, abnormal body movements, **obsessive compulsive disorder (OCD)** and tic disorders including **Tourette's syndrome**. It is believed that the area of the brain responsible for movement and behaviour is affected by **PANDAS**.

Pre/perinatal causes of neurological disorders include:

Toxins and environmental factors

Neuro-**toxins** can enter and damage a child's developing system through the placenta during fetal development. Consequently a child may develop intellectual and behavioural problems. Neurotoxins include alcohol (linked to fetal alcohol syndrome), lead (linked to intelligence, learning and memory problems), mercury (linked to learning and development disorders), tobacco (linked to challenging behaviours and developmental impairments) and some food additives (linked to higher rates of **ADHD** in children).

Nutritional deficiencies

Nutrients are needed for growth. A deficiency of nutrients during the last three months of pregnancy can decrease the number of brain cells. A deficiency of folic acid (a B vitamin) could lead to a **neural tube defect (NTD)** e.g. **spina bifida** (open spine).

Infections

TORCH infections, including sexually transmitted infections, can be passed from mother to baby during pregnancy. **TORCH** infections (because of their initial letters) include **Toxoplasmosis**, **O**ther infections (hepatitis B, syphilis, varicella-Zoster virus, HIV and Parovirus B19), **R**ubella, **C**ytomegalovirus and **H**erpes simplex virus. These infections can cause developmental abnormalities in the unborn child. Chorioamnionitis can be a cause of **cerebral palsy**.

Hypoxia/asphyxia

Perinatal asphyxia is the condition resulting from deprivation of oxygen (hypoxia). **Hypoxic ischaemia** is insufficient blood flow causing reduced blood oxygen content. If a developing baby in the uterus does not have enough oxygen then it may have hypoxic ischemic encephalopathy (neurological damage caused by low oxygen). The effects of severe HIE can include cerebral palsy, intellectual impairments and epilepsy – these terms are explained more in Part 2 – Guide to neurological disorders.

Complications during childbirth

The protective skull is not fully formed at birth making the brain vulnerable to physical injury. The supply of blood and oxygen from the umbilical cord can also become affected at birth. As the brain is dependent upon this supply of oxygen, deprivation of oxygen can cause brain damage.

Prematurity/low birth weight

Low birth weight may indicate growth problems in the womb and has been associated with a greater likelihood of developing cognitive impairments, speech and language impairments, attention problems, social difficulties, hyperactivity and learning impairments. Some may arise because of associated complications during childbirth.

Interaction effects

A number of factors including heredity, gene expression, the environment, infectious disease, poor nutrition, stress, drugs and other chemicals can interact in complex ways to cause some neurological disorders.

Acquired causes

These are less common than congenital causes of neurological disorders, and include:

Postnatal infections

Encephalitis (inflammation of the brain) can be caused by many types of infection (usually viral). Some people may develop neurological long-term consequences following encephalitis, including memory problems, behavioural changes, speech impairments, and **epilepsy**.

Meningitis is caused by a bacterial or viral infection that inflames the meninges (membranes surrounding the brain and spinal cord). The inflammation and swelling can damage the brain and nerves. Complications are more likely following bacterial meningitis than with viral meningitis. Lasting symptoms include hearing impairments, memory difficulties, co-ordination and balance problems, learning impairments, **epilepsy**, **cerebral palsy**, speech impairments, and loss of vision.

Traumatic brain injury

This occurs when trauma to the head results in damage to the brain. There are three main types of **traumatic brain injury (TBI)**:

- Closed head injuries – where no damage is visible; common in car accidents.

- Open wounds – where the brain is exposed and damaged by an object.
- Crushing injuries – where the head is crushed and brain damage occurs.

Evidence suggests that children's brains are susceptible to lasting damage from TBI due to a disruption of the **nervous system** during development.

Spinal cord injuries

Car accidents, falls, or sports accidents can cause **spinal cord injuries**. The degree of damage depends on where the damage occurs and what part of the body the injured spinal area controls. Spinal injuries can lead to loss of muscle function.

Neoplasm

Neoplasm is an abnormal mass of tissue producing tumours. Tumours can develop in the brain or spinal cord. They can be benign (noncancerous) or malignant (cancerous). Malignant tumours are the most dangerous, so early diagnosis is very important. Benign tumours can have neurological consequences as they increase pressure on other parts of the brain, damaging healthy tissue. Symptoms include **seizures**, limb weakness, difficulty walking, speech impairments and swallowing difficulties, strange sensations, learning impairments or challenging behaviours, vision and hearing impairments.

Toxins

Exposure to environmental chemicals or **toxins** during childhood can lead to neurological impairment.

The guide to neurological disorders in Part 2 of this information resource provides an overview of some of the above disorders and provides links to organisations that offer more information and support.

In the beginning

Diagnosis

The process leading to a diagnosis for a child's condition is not always an easy one. Many questions are raised that can't always be answered easily. Some **neurological disorders** are usually identified and diagnosed at birth (e.g. **Down syndrome**), but others are not detectable or do not show themselves until later in childhood (e.g. **ASD, ADHD**). Some children have multiple diagnoses.

Even if a diagnosis is given at birth, it is not always possible for professionals to know exactly how the disorder may develop. It may be necessary to wait until developmental milestones such as speaking, walking, etc, are achieved or not achieved.

Doing as much as possible as early as possible is, however, vitally important in working towards the best outcome.

What to do if you are worried about the neurological health of your child?

If you are concerned about the health of your child, you should seek medical advice as soon as possible. Usually this means a visit to your **GP**. If, however, any change occurs very quickly (e.g. a head injury) you should go immediately to the accident and emergency department at the hospital.

For some neurological disorders you will be referred to a **specialist**. An initial diagnosis may be given and then a confirmed diagnosis will follow once all specific tests have been completed.

For information on waiting times to see a specialist, see:

www.nhs.uk/choiceintheNHS/Rightsandpledges/Waitingtimes/Pages/Guide%20to%20waiting%20times.aspx

Why is a diagnosis important?

It is important to get a diagnosis so that you and the professionals involved can begin to understand the cause of your child's symptoms or presenting features and identify his or her impairments or additional needs. Having identified the cause, professionals can design treatment strategies to help manage symptoms. Identifying needs makes access to support services much easier.

Difficulty getting a diagnosis

In some cases, identifying the cause of a condition can be very complex. Some children have a variety of symptoms or presenting features that make it difficult to associate with any one condition. A number of different conditions have similar symptoms and features and some children may have a range of symptoms. Children experience conditions

differently. Some features of a condition may not appear until a child gets older, resulting in a late diagnosis, or even a change in diagnosis.

A parent carer is with a child more than anyone else and gets to know them very well. Parent carers should therefore try to help professionals (e.g. **paediatricians**) by describing symptoms and presenting features and problems accurately. Early years staff, play workers, teachers or others may also notice symptoms or presenting features that could lead to a diagnosis.

What to do if you can't get a diagnosis

It may take a long time to get a diagnosis or a child may never get a diagnosis, despite having symptoms or presenting features. A child may have a condition about which little is known and a diagnosis may not be possible at all. This does not mean, however, that there are no treatment options available. There are many ways of treating specific symptoms and many ways to support additional needs, with or without a diagnosis. Information, advice and a range of services are available.

Ask your **GP** and local social services department what services are available for your child and your situation.

There are two Early Support information resources that might help – 'If your child has a rare condition' and 'When your child has no diagnosis' are available at:

www.ncb.org.uk/early-support/resources

Diagnostic techniques

A child may be referred for a range of assessments to identify what is causing his or her symptoms.

Some children with a suspected **neurological disorder** may need a neurological assessment, a neuropsychological assessment or a brain scan.

Some common brain scanning methods include:

Computerised tomography (CT)

This uses X-rays to show a 3D image of the brain. It can reveal underdeveloped parts of the brain, sites of impact, tumours, lesions or infections.

Magnetic resonance imaging (MRI)

This uses a strong magnetic field and radio waves to create pictures on a computer of the tissues inside the brain. It provides clear, detailed pictures of the brain and can detect any abnormalities or tumours.

Positron emission tomography (PET)

This produces a 3D image of functional processes in the brain (not just structures). The patient receives a small injection of radio-active material into their bloodstream. It has

proved to be particularly useful in monitoring visual problems, tumours and metabolic processes.

Cerebra provide further information on 'Brain scanning techniques'. Search this title at: www.cerebra.org.uk

Other assessments of physical changes

Other techniques to investigate physical changes might include:

- Blood testing.
- Ultra-sound scans.
- **Chromosome studies.**
- Developmental tests.
- Electroencephalogram (EEG).
- Electromyography (EMG).
- Facial scanning.
- Hearing assessments.
- **Gene (DNA) tests.**
- Genetic counselling.
- **Occupational therapists' assessment.**
- Vision assessments.
- X-rays.

Further information on neurological tests can be found on the **National Institute of Neurological Disorders and Stroke** website:

www.ninds.nih.gov/disorders/misc/diagnostic_tests.htm

Once your child has been diagnosed, you may require the following:

- General information about the condition.
- A description of potential symptoms.
- Information on the management of symptoms.
- Safety information.
- Details of treatment options and any risks.
- Information on the expected course of the condition.
- Information to help understand and come to terms with the diagnosis.

Tips when meeting a health practitioner:

- Don't be afraid to ask questions to find out about the needs of your child. Note questions you may want to ask beforehand. You can use the Early Support [Our family](#) for this.
- Take another family member with you for support.
- Take time to digest the information given to you. If you have English as an additional language and need translation and interpretation support, or are a signer or require other communication support, you should make this known to the people you meet.
- Ask for any written information about the diagnosis (including medical details). Read this when you get home.
- Arrange another meeting with the health practitioner. This will give you an opportunity to ask further questions once you have had time to digest the information. You can use your Early Support [Our Family](#) resource to record any details.
- Ask the practitioner to explain information to other family members so that you can discuss it further at home.
- Ask for information on other services that can help you deal with how the diagnosis is going to affect your child and your day-to-day lives.

Health care

A child with a neurological disorder may have a range of health care needs. The best source of information about health care (including treatments) would be a child's doctor or paediatrician. Parents carers should be involved in developing their child's health care plan.

[NHS Choices](#) provides a range of information about many conditions, symptoms and their treatment: www.nhs.uk/conditions/Pages/hub.aspx

[NHS Direct](#) offer online and telephone health advice should you have any health queries: www.nhsdirect.nhs.uk

[The NHS patient advice and liaison service \(PALS\)](#) provide you with information about the NHS and any other health related enquiry, including introducing you to agencies and support groups outside the NHS: www.pals.nhs.uk

When considering health care or treatment options many parents carers find it useful to investigate what is likely to be available, for example, what treatments are known to be effective for that particular disorder. The [Cerebra](#) guide 'Finding and appraising information and evidence on the internet' provides useful guidance on how to search for this information and find reliable, unbiased information. Search for that title at: www.cerebra.org.uk

Feelings

In coming to terms with a diagnosis of a neurological disorder parents carers may experience:

- Shock, denial and disbelief.
- Anger and rage.
- Stress and depression.
- Grief and fear - for your child or the family as a whole.
- Acceptance and adjustment – the realisation that a lot that can be done to improve the situation.
- Fight and hope – you may gain hope from dealing with challenges, and seeing positive progress in your child. Your culture and your religion or beliefs background may be a source of support for you, too, at this time.

Not all families experience these emotions, but it is helpful to understand that possible reactions could occur and to realise they are totally normal. Every family is different and may progress through stages in different ways.

Telling others about a child's difference/disability identity

Explaining your child's condition to others can be testing. Every family will have their own way of dealing with it. **Mencap** provide a useful publication 'Telling other people about your child's learning disability':

www.mencap.org.uk/all-about-learning-disability/information-parents-carers-and-family/telling-other-people-about-your-

Early Support provides a resource, called **Our Family**, which consists of blank templates that can be filled in by the family, with their practitioners. It brings together relevant information from all agencies and is useful in producing a single care plan:

www.ncb.org.uk/early-support/resources.

Early relationships and bonding

Bonding between mothers/fathers/co-parents and other primary carers and the baby is vital for their health and wellbeing. This happens at varying rates for different parent carers. Most babies bond immediately after birth. However, babies who have had complications and have been in intensive care may take longer. There is no set time period or set way for bonding to happen, it's a product of providing care for a baby through:

- Skin-to-skin contact, e.g. feeling and cuddling.
- Breast feeding or bottle feeding.

- Eye contact.
- Voice contact.

NHS Choices provides comprehensive information on many issues that come about during this time:

www.nhs.uk/Conditions/pregnancy-and-baby/pages/pregnancy-and-baby-care.aspx

Looking after yourself

Following a child's diagnosis, it is important for parent carers to talk about feelings and emotions with trusted people. They can be supported by family, friends, professionals or other parent carers in the same situation.

Carers UK provide information and support to help carers look after themselves:

www.carersuk.org/help-and-advice/looking-after-you

Managing stress

Managing the daily care of your child is very demanding. It can impact on your relationships with your partner, other family members and friends.

There are many things you can do to cope with stress. For example, because stress can impact on your immune system, you should try and eat a healthy, well-balanced diet and get enough exercise. It may be difficult to arrange time to relax but this will help you care for your child.

You may find it helpful to join a local support group or to spend time with other parents carers who have children with additional needs. They may have found ways of dealing with issues that you find particularly stressful.

If you feel that you have reached a real crisis point, it may help to:

- Call a support line. Many voluntary organisations, such as **Contact a Family**, **Parentline plus** and **Cerebra** provide a free helpline to help you through times that you find difficult. Contact details of these and other support organisations are provided towards the end of this resource.
- Contact your **GP**, who may provide contact details for your local counselling service.
- Read self-help books – Professor Ann Edworthy, a chartered psychologist, has written 'Managing Stress for Carers'. Search for this title at www.cerebra.org.uk

Many voluntary organisations, such as **Contact a Family** provide a free helpline to guide you through times that you find difficult and a **making contact service** that can help you get in touch with other parents. Contact details are provided towards the end of this resource.

Early Years

This section has been designed for parent carers who need information during the early years with their child. You may want to read this section along with the school years and into adulthood sections, as they may contain relevant information. The section aims to give an insight into some issues you may be faced with in everyday life, including school issues and meeting others. The section also provides a gateway to more comprehensive sources of information.

If your child has just received a diagnosis of a neurological disorder or you suspect your child may have a neurological disorder, you may want to find out as much information as you can about what to expect. The guide to neurological disorders and useful organisations and websites in Parts 2 and 3 of this information resource may help.

For more information about the legal rights of children with additional needs and their families in England and Wales please see 'Disabled Children: A Legal Handbook' that explains what public bodies must do to support disabled children and what they may do.

The handbook, written by Steve Broach, Luke Clements and Janet Read, is available free from the [Council for Disabled Children](http://www.councilfordisabledchildren.org.uk) website:

www.councilfordisabledchildren.org.uk/resources/cdcs-resources/disabled-children-a-legal-handbook

The handbook has sections on children's services, education, health, housing, welfare benefits, what's available for carers and transition issues. This is an invaluable resource for parents carers. If you need assistance in understanding its implications you can contact the [Council for Disabled Children](http://www.councilfordisabledchildren.org.uk).

Getting started

Being together

The bond between parent carers and a child begins at birth. Parent carers know the most about their child, they see them grow everyday and have the most influence on their development. Despite the range of difficulties a child with a neurological disorder may have they will benefit greatly from the close contact they have with their parent carers and families.

Building relationships with your child

The parent-child relationship is forever changing. Strong bonds of attachment form after birth, with the parent carer trying to meet their baby's every need. When the child reaches two years old the relationship starts to change as parent carers start to educate their child, guide them, teach them to begin doing things for themselves as well as encouraging desired behaviours. This is just as important for a child with a neurological disorder.

'Having a child with a neurodevelopmental disorder means that you have to completely re-adjust your expectations of what being a parent will mean, and accept that you will not have some of the experiences that most parents take for granted. You have to learn a new way of parenting and a new way of communicating with your child.'

'However, would I prefer he did not have a condition? No, the Asperger's characteristics are part of what makes him him... It's hard work, but very interesting, he teaches us to look at things differently.'

The Royal College of Psychiatrists provides a leaflet on 'Good Parenting: information for parents, carers and anyone who works with young people':

www.rcpsych.ac.uk/mentalhealthinfo/.../parenting/goodparenting.aspx

If you are experiencing particularly difficult behaviour in your child the Understanding your child's behaviour section may help you find some answers. There is also an Early Support information resource on Behaviour that you can read or download from

www.ncb.org.uk/early-support/resources.

Couple relationships

Managing the changes that take place in your life when having a child with any form of additional need has many positive aspects and can help to make a relationship stronger, help you develop coping skills as a couple, increase communication and promote a greater sharing of parent carer responsibilities. However, there are a range of extra stresses that your situation may put you under, such as social, emotional, physical and financial pressures. This can put strain on your relationship.

'He causes tension between us as he is quite capable of setting one parent against the other as a demand avoidance technique.'

'Because he has to make constant noise (to reassure himself that he still exists), we literally cannot even have our own thoughts until he is asleep, let alone have a conversation or get anything done around the house.'

Contact a Family have put together a booklet on 'Relationships and caring for your disabled child' that may help parent carers to understand relationships when caring for a child with additional needs, see:

www.cafamily.org.uk/media/450037/relationshipscurrent_updated_march2012final.pdf

Sibling relationships

Having a brother or sister with additional needs can have many positive aspects. However, many siblings are raised in a family where a lot of the family's time and resources, parent carer's attention, and the attention of professional services are given to their sibling with additional needs. It is important that siblings get information about their brother's or sister's impairments and other additional needs at different stages.

'Looking back now, I didn't realise the full impact my son's condition was having on my daughter. She became withdrawn and anxious because of his unpredictability and the attention he demanded. It would have been helpful if we had received more support for her needs too.'

Sibs provide information, advice and support for brothers and sisters of a child with additional needs.

There is a range of support available to help you through difficult times in your relationships. See the family relationships section of the useful organisations and websites in Part 3 of this resource for more information.

Relationships with practitioners

A child and family may need input from a range of professionals to meet their health, education, developmental, play, recreational and social care needs. There may be a range of practitioners involved in this care and support from an early age. It is important that parent carers try to have good relationships with these practitioners and keep in regular contact.

Early Support provides background information on **People you may meet** that will help you understand the roles of different professionals who may be able to help support the needs of your child and help you to manage everyday life. This can be read or downloaded at www.ncb.org.uk/early-support/resources.

Understanding your child's behaviour

The term 'challenging behaviour' is usually used to describe behaviours such as self injury, aggression, shouting and screaming and destroying the environment but it can also include many other behaviours. Some children with additional needs will exhibit challenging behaviour which is often linked to their impairments. For example, if your child is not able to communicate easily they may become frustrated. This could also be true if a child is unable to do things because of the physical aspects of their impairment or even pain they are experiencing. Challenging behaviour does not have one cause and can be difficult to manage.

The best thing to do is to start to develop a plan of the things that need to be done and how you are going to do them. Also:

- Do not do things on your own, unless you are confident about your plan.
- Try to build a team of people around you who you can trust and rely on and who have the right skills, whatever they may be, to help you take the right steps. The team may not necessarily be made up of skilled professionals but it will include people whose opinions you value and who you know will see things through.

If you have decided that there is a behaviour that is giving concern there are some things to think about below that may help to understand the behaviour and find a way forward.

Ask yourself:

- Is this behaviour really a challenge and if so for whom?
- What might be causing the behaviour?
- How can possible causes be assessed?
- What is the best way to change the behaviour?
- What sort of change am I aiming for?
- Is this the right time to try to change the behaviour?
- What help do I need to change the behaviour?
- How will I know whether things are getting better or not?
- What if I can't get the help I think I need?

[Early Support](http://www.ncb.org.uk/early-support/resources) provides an information resource on 'Behaviour' that may help parents carers answer some of these questions and to formulate a plan:

www.ncb.org.uk/early-support/resources.

[Contact a Family](http://www.cafamily.org.uk/media/380154/understandingchildbehaviour.pdf) also provide a comprehensive booklet on 'Understanding your child's behaviour' that might help:

www.cafamily.org.uk/media/380154/understandingchildbehaviour.pdf

As well as speaking to professionals, you can also get support with your child's behaviour from organisations such as the [Challenging Behaviour Foundation](#) and [Young Minds](#), or condition specific groups such as the [Cri du chat syndrome](#) support group or the [Fragile X Society](#) (please see [Part 2 – Guide to neurological disorders](#), www.ncb.org.uk/early-support/resources).

Interacting and communication

Some children with **neurological disorders** have communication impairments. Your child may have delayed development which means they may take them longer to learn how to communicate with other people. If you are concerned about your child's speech, speak to your **health visitor** or **GP**.

It is important that you talk to your child even if they cannot speak back and if they need extra help when learning to speak you should not be tempted to finish words and sentences for them all the time. You can also use fun activities such as reading stories and singing songs to encourage your child. Culturally reflective songs from your own ethnic background will support your child's positive sense of identity and their vocabulary. Songs and rhymes that are spoken in English will support this as well.

Your child may not be able to communicate verbally but there are lots of different forms of communication and equipment that you can use to help them. We don't just communicate by talking, we share lots of information non-verbally through body language and facial expressions, through cultural nuances. Some conditions will impact on the way your child is able to interpret non-verbal communication.

You could contact your local social services department or speak with your **GP** if you think your child may benefit from **occupational therapy** services. Other organisations that can offer information are listed in the back of this resource.

Early Support provides information on **Speech, language and communication needs** that you may find useful – www.ncb.org.uk/early-support/resources.

The communication section of the useful organisations and websites in Part 3 provide details of organisations that may be able help further.

General information

Everyday life

Every child will have individual strengths and areas for development and progress. This is even more important to identify in children with neurological disorders, to make the most of their strengths and to compensate for any areas requiring development and progress. Parent carers can facilitate this with help from family members and friends as well as a range of practitioners. Parent carers of a child with a neurological disorder are likely to need a range of solution seeking skills to help their child live with the fact they have additional needs, and to lead a happy fulfilled life.

Early Support provides background information on 'People you may meet' that will help you understand the roles of different practitioners who may be able to help to identify and support these individual strengths and weaknesses and identify problem solving methods to help manage everyday life. This is available to read or download from www.ncb.org.uk/early-support/resources.

Helping your child to make sense of the world

There are a range of things you can do to help your child make sense of the world. These include:

- Be consistent.
- Find ways to overcome problems and obstacles to teach them about their world.
- Help them to build resilience and to know their rights – including their right not to be subjected to discrimination
- Encourage your child to take part in play and a range of stimulating activities.
- Provide positive praise to reward your child.

- Support your child's multiple identities. Your child may have additional needs but he/she may also have their own ethnic background, they will have their own nationality, perhaps a distinct religion or belief, they may be a boy or a girl, have a home language etc. These all need recognition and positive support, too, if your child is to have an ordinary childhood.
- Take time to ensure they understand as much as possible.
- Monitor your child's progress and become responsive to their needs.

Do2learn provide a range of materials to help parent carers and practitioners help children to make sense of the world.

Early Years Equality's ENCO handbooks and related materials support practitioners and families to support children's holistic identities and requirements.

Developing the senses

Sensory experiences include things we take for granted such as touch, movement, body position, hearing, vision, taste, smell and even the pull of gravity. We describe the brain's processing of this information as sensory integration. Sensory integration is very important for the development of learning and behaviour.

The process of sensory integration begins before birth and continues through the lifetime. The majority of sensory integration happens before the early teenage years. If there is a problem with this integration of sensory information it can affect learning, behaviour and motor skills. Sensory integration problems usually become apparent in young children.

Difficulty tolerating or processing sensory information is common in children with a variety of neurological disorders, such as:

- Autism spectrum disorder.
- ADHD.
- Fragile X syndrome.
- Down syndrome.
- Intellectual disabilities.
- Specific learning disabilities.
- Post traumatic event, illness or injury.

'She cannot cope with any background noise, she finds it so distracting and cannot seem to filter it out. This makes it difficult to take her to places such as leisure centres or cafes, as she will just sit there with her fingers in her ears and will become more and more distressed until we have to leave.'

Some common sensory issues include:

- Being particularly sensitive to touch, sounds, movements, tastes and smells.
- Dislike of particular clothing fabrics, waistbands, etc.
- Avoiding a number of foods.
- Limited body awareness.
- Poor development of personal care skills.
- Poor attention and concentration.
- Dislike of social settings.
- Particularly high or low activity levels.
- High or low pain threshold.

'It was a nightmare getting him ready for school – every item of clothing would irritate him. He spent ages putting on socks then taking them off, adjusting them, putting them on again and getting more and angrier about it. He would even do this on the way to school on the pavement.'

Early intervention is important in the management of children with suspected sensory impairments, to help them interact with their environment in a more adaptive way as they develop.

If you think your child may be experiencing sensory concerns, you can mention this to your GP, who might put you in contact with a qualified occupational therapist, physiotherapist or speech and language therapist, who may be able to make an assessment should it be needed. Once an assessment has been made, the professional will be able to consider which course of action will be most suitable to address any needs.

The use of sensory based therapies are often used by occupational therapists as part of a broader treatment plan. However, the research on the effectiveness of sensory integration therapy is under-researched and inconclusive.

Hertfordshire Community NHS trust provide a useful information sheet on 'Understanding sensory difficulties':

www.hertschs.nhs.uk/Library/Children_Services/Childrens_OT/Childrens%20OT%20Understanding%20Sensory%20Difficulties%20December%202011.pdf

The Royal Free London NHS foundation trust provides a leaflet on sensory integration as a framework for occupational therapists to help children with sensory impairments:

www.royalfree.nhs.uk/paed_OT.aspx?top_nav_id=1&tab_id=1033

Early Support provides information resources on sensory impairments, including **Multi-Sensory impairment**, **Visual impairments** and **Deafness**. These resources can be read or downloaded from www.ncb.org.uk/early-support/resources.

Playing

Children with additional needs have the same requirement for individualised recreational activity provision as any other child, and want fun things to do in their spare time. The recreational activities they will be able to enjoy may depend on the extent of any impairments or additional needs, the child's age and the family's circumstances.

Children and young people with additional needs often miss out on leisure and play activities. Parents carers trying to access facilities for their child may find that many facilities available are unsuitable, transport to and from the activity is difficult, and issues regarding attitudes of staff and members of the public to be off-putting.

For help in accessing activities, it may be a good first step to contact your **local authority** for information about local play and leisure activities that may be suitable.

Contact a Family provides further information on play in their booklet 'Holidays, play and leisure': www.cafamily.org.uk/media/379738/holidaysplayleisure.pdf

The Disability Living Foundation offers a factsheet on 'Choosing children's play equipment': www.dlf.org.uk/factsheets/Choosing_childrens_play_equipment_sponsored.pdf

KIDS offer a range of activities for children with additional needs in the community: www.kids.org.uk

Many organisations offer advice on maximising recreation opportunities. The Recreation section of the useful organisations and websites in Part 3 of this resource provide details of organisations that may be able to help.

Sleep

Children with neurological conditions often have problems with sleep and this can impact on their wellbeing during the daytime. A child may not be able to settle at night, wakes frequently or very early, or is anxious about being left alone at bedtime.

If a child is not sleeping it can have an impact on the entire household. If parent carers don't get enough sleep it will be more difficult for them to care for a child and meet other responsibilities they may have. Parent carers often resort to sleeping in shifts to ensure that someone is with the child throughout the night, and this can result in years of little sleep and can cause problems for the whole family.

It is important to get the support needed to help your child sleep well, particularly as they grow older. Lack of sleep can have a real impact on children, particularly those who are

prone to seizures, and children who wake in the night and roam around the house can have accidents.

If you want to know more about sleeping problems and what might help there is an [Early Support Information resource on Sleep](#) – www.ncb.org.uk/early-support/resources.

There are a range of information and support out there for sleep problems. See the sleep section of the useful organisations and websites in Part 3 of this resource.

Eating and drinking

Babies

If a child has problems eating then it can make parent carers feel very anxious and upset.

Lots of children with neurological conditions begin life with impairments that affect the eating process. If a child has had problems with eating since they were born then advice should have been given from staff in the hospital. This may include using a specifically designed bottle to help your baby swallow, or learning techniques that will help to stimulate their oral reflexes.

Some babies and children may have to be fed by a tube in either the short or long term. If this is the case, it is possible that they will be able to eat some food by mouth, as well. Parent carers should talk to professionals about this, or contact the support group [PINNT](#) who can offer advice.

The [NHS](#) offer comprehensive information on feeding your baby:

www.nhs.uk/conditions/pregnancy-and-baby/pages/pregnancy-and-baby-care.aspx

Weaning

As a child develops and it is time to move them on to solid food, it is possible that they will find it easier to chew than they did to suck and so they will thrive better. However, if they have problems chewing, seem to choke on their food frequently or bite too hard on the spoon you feed them with, you should speak to your [health visitor](#). It is possible that a [speech and language therapist \(SALT\)](#) may be able to help with this. The [SALT](#) will also be able to discuss which foods will be easier for a child to eat.

Once on solid food, some children are prone to vomiting, or suffer from acid reflux. Reflux is when swallowed food comes back up the tube that leads to the stomach. You should always talk to your doctor about this because it is not only very uncomfortable for the child, it can cause damage if left untreated for a long time. Parent carers can try to alter a sitting position while eating and discourage lying down immediately after food to stop the vomiting. If it does continue then medical advice should be sought.

'Our son is five and still cannot eat solid food. He eats four month baby purees, custards, yogurts, etc. His diet is supplemented with milk called paediasure which is high in calories and has vitamins in it. I only discovered the milk (which you can get on prescription) by

chance from a friend whose child also has feeding difficulties. The milk helped Joseph get much stronger and he was sick much less because he was getting the nutrients he needed.'

Independent eating

Just because a child has impairments or other additional needs it does not mean they will not be able to feed themselves, but it may take a bit more time than for other children. There are many different kinds of special equipment available to aid your child with feeding themselves, such as non-stick mats and adapted cutlery.

You can also get more information and advice from [Contact a Family](#) which provides an information sheet on 'Feeding and eating':

www.cafamily.org.uk/media/379524/feedingeating.pdf

Personal care

When a child with a neurological disorder is very young, their care needs may be no different from those of neuro-typical children. If the child is the first born, parent carers may not be sure if they are developing as they should, or whether certain things might be related to their condition. Never be afraid to ask. You can speak to your **health visitor** or **GP** or ring one of the helplines offering support to families of children or with additional needs, such as [Contact a Family](#).

Routine

Having a routine is good for parent carers and children. Many children with a neurological impairment will gain a sense of security from a daily routine. This does not mean that things have to be done at the same time every day, just that there are regular activities.

Getting dressed

If a child has severe physical impairments then as they grow older, getting dressed can sometimes be difficult. However, wherever possible it should be encouraged that they do things for themselves.

Some practical tips are included in the [Early Support](#) information resource on [Cerebral palsy](#) – see www.ncb.org.uk/early-support/resources.

Challenges with motor skills

It is possible that a child may have challenges with motor skills. This could be their **fine motor skills**, such as being able to grasp a spoon or fasten buttons, or it could be their **gross motor skills**, which can mean they have difficulty with larger movements such as crawling.

To help with motor skills a child may see a **physiotherapist** who specialises in treating children. They will assess your child and show you exercises and positioning which you can encourage your child to do throughout the day. They may also advise you about special equipment which will help your child, for example a standing frame to help them to stand up. Your child may need to have an ongoing programme tailored to their needs.

There are things you can do at home to help with fine motor skills, such as colouring in and encouraging your child to try and do up their own buttons.

Toileting

Many children with neurological conditions can develop the skills needed for toilet training but may find them more of a challenge to learn. Children with severe conditions may never be able to use the toilet themselves but you will still want to develop a routine. You should talk to your **GP**, **paediatrician** or **health visitor** if you need support with this.

If you feel that your child may be ready to begin toilet training, it is best to try and choose a time when you don't have too much on. You will also need to make sure that all the other people your child has contact with (such as childcare providers) are able to support you.

If your child has an impairment that means they may not be able to sit on a potty or toilet easily, speak to your **occupational therapist** who may be able to offer advice or even supportive equipment.

You can get more detailed advice from healthcare providers as well as organisations such as **Contact a Family**. **Resources for improving childhood Continence (ERIC)** can be useful if you have particular continuing problems.

Cerebra provide a toilet training resource based on work by a clinical psychologist on 'Toilet training for children with autism and intellectual disabilities' that offers advice on overcoming specific toileting problems. Search for this title at: www.cerebra.org.uk

Home environment, equipment and aids

As your child grows up, you may find that you need to make changes to your home or to acquire specifically designed or adapted pieces of equipment. There is lots of help available to you in terms of deciding what is needed and covering the costs. For example, your local authority social services department is responsible for providing equipment for daily living needs and the NHS should provide equipment for medical needs.

You may also be entitled to a disabled facilities grant to adapt your home with things such as a ramp to the front door and a wet room to provide adequate washing facilities. If you think your home may need to be adapted to help your child, then you should contact your **social worker** or **occupational therapist** who can explain to you how to get an assessment. Safety issues will be taken into consideration.

It is very important that any assessment takes into account the impact that your child's impairments, and any adaptations, has on the child's and their family's ability to enjoy the home environment.

There may be equipment you want that is not provided by health or social services. There are a number of charities that provide grants for aids and toys such as **Cerebra** and **The Family Fund**.

Many organisations offer a range of equipment to make life easier. The equipment section of the **Useful organisations and websites** in **Part 3** provides further information – see www.ncb.org.uk/early-support/resources.

A US site called Safekids provides tips on how to keep safe in the home for children with additional needs: www.safekids.org/safety-basics/special-needs

Middlesbrough Council provide a booklet on 'Keeping children with disabilities safe': www.middlesbrough.gov.uk/CHttpHandler.ashx?id=2967&p=0

Meeting others

Parent carers of a child with additional needs may find tasks such as feeding, dressing, toileting and meeting the needs of their child demanding and time-consuming. The behaviour of the child may make interactions with others challenging. Going out with the child may place demands on relationships within the family as well as with others. Avoiding contact with others can, however, lead to the child missing essential experiences involved in developing social, communication and thinking skills and it stops the child from having an ordinary life.

Inclusive settings

It is against the law to discriminate against people with disabilities and this includes education and early years settings. The Equality Act 2010 sets out specific duties towards children with additional needs. In particular, the duty to make 'reasonable adjustments' so that children with additional needs have the opportunity to attend the school, college or early years setting that parent carers would like them to attend.

The intention is to enable everyone to take part in all educational and early year's settings such as Children's Centre Play and Share sessions, nursery schools, community nursery daycare services, childminder provisions, preschools, children's centres, primary and secondary, free schools, academies and colleges. These are all required to take account

of diversity and also to give due regard to each unique child's identities and needs. Some local authorities have settings and schools specifically for children with additional needs but in many cases children with additional needs can attend mainstream settings. If you need advice on this, particularly if there is a school, college or early years setting that you would like your child to attend but are finding it difficult, then contact your local Parent Partnership service – see www.parentpartnership.org.uk.

Choosing a school

Parent carers of children with additional needs, including special educational needs, have a right to choose which type of state school they would like their child to attend. They could attend state-run mainstream schools, special schools or specialist schools. Alternatively, they could attend a fee paying (private/independent) school. This choice depends on the ability of the school to meet the child's skills and ability needs. It also depends upon the placement conforming to the authority's efficient use of resources and not having a negative impact on the education of other children, or even on the families ability to pay for the fee paying school themselves.

Find schools through the following link:

www.gov.uk/browse/education/school-admissions-transport

For further information about the different types of schools that are available can be found at www.gov.uk/find-school-in-england.

Working with practitioners

The actions required to help a child with additional needs including with SEN may be written down by the child's teacher in an individual education plan. This includes what 'special' or additional help is being given, who provides the help and how often. The plan includes the child's targets and how and when progress is to be checked. It could also include any help that the parent carer could give at home. A school may use other record keeping systems but must always be able to inform the parent carer of how they are helping the child and what progress the child is making. If the child does not progress sufficiently under the school action plan then the school should inform the parent carer.

The child may require further help from other practitioners and the parent carer may ask for advice from people working outside the school. Such practitioners might include a specialist teacher, a **physiotherapist** or a **speech and language therapist**. Working with such professionals to get additional help for a child is called School Action Plus.

In circumstances where this additional help does not meet the needs of the child, one of the professionals working with the child can ask for a statutory assessment. This is an investigation of the child's educational needs to determine the nature of the further specialised help required. A statement of **special educational needs (SEN)** which clarifies the child's areas for development is issued. The learning needs and individual learning

style of a child is met by teachers modifying their approaches. Such help may come from professionals such as speech and language therapists.

As stated in the introduction above, proposals have been made to replace the existing system of statements and assessments with a single assessment and plan for children and young people aged from birth to 25, see the following links:

www.education.gov.uk/childrenandyoungpeople/send/sen/b0075344/government-proposes-biggest-reforms-to-special-educational-needs-in-30-years

www.education.gov.uk/publications/eOrderingDownload/DfES%200581%20200mig2228.pdf

View the following for guidance on special educational needs:

www.education.gov.uk/publications/standard/publicationDetail/Page1/DCSF-00639-2008

Or view the [Cerebra](http://www.cerebra.org.uk) guide 'Disabled children Parent's guide: Education' by searching for this title at: www.cerebra.org.uk

School Years

Many neurological disorders/impairments are not diagnosed until a child is starting school or during their school years. This can be for a variety of reasons.

This section has been designed for parent carers of children that need information during the school years. You may want to read this section along with the early years and into adulthood sections, as they may contain relevant information. This section aims to provide an introduction to some issues you may be facing in everyday life; including school issues and meeting others. It also provides a gateway to more comprehensive sources of information.

If your child has just received a diagnosis of a neurological disorder/impairment or you suspect your child may have a neurological disorder/impairment you may want to find out as much information as you can about what to expect. The guide to neurological disorders and useful organisations and websites in Parts 2 and 3 of this resource may help – see www.ncb.org.uk/early-support/resources.

For more information about the legal rights of disabled children and their families in England and Wales, please see ‘Disabled Children: A Legal Handbook’ that explains what public bodies must do to support disabled children and what they may do. The handbook has sections on children’s services, education, health, housing, welfare benefits, what’s available for carers and transition issues. This is an invaluable resource for parents. If you need assistance in understanding its implications you can contact the [Council for Disabled Children](#).

The handbook written by Steve Broach, Luke Clements and Janet Read is available free from the [Council for Disabled Children](#) website:

www.councilfordisabledchildren.org.uk/resources/cdcs-resources/disabled-children-a-legal-handbook

General information

Everyday life

Caring for a child with a neurological disorder may have an impact on your financial situation in a number of ways. For example, by reducing your income, or your living expenses and travel costs might increase. There is a range of financial support out there to help with these additional costs.

Cerebra provide an information booklet on ‘Money matters’ for parent carers who may 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. Search title at: www.cerebra.org.uk

Getting back to work for parents carers

Parent carers of disabled children find it difficult to manage the caring role and also working to bring money into the household, often due to ineffective support systems for them. As well as earning money, working has many other benefits for parents carers, including social benefits, providing an identity outside of the parenting caring role and an escape from pressures at home.

Working Families provide a publication on 'Getting into work: a guide for disabled children returning to work'. It provides lots of information to empower parents back to work if it is suitable, see: www.workingfamilies.org.uk/admin/uploads/Getting%20Into%20Work.pdf

GOV.UK provides information on your right to unpaid 'Parental leave' to look after their child's welfare, see: www.gov.uk/parental-leave/overview

Early Support provides an information resource on **Childcare**, available at: www.ncb.org.uk/early-support/resources.

Making sense of the world

Helping your child to make sense of the world is a huge part of being a parent carer and can be all the more of a challenge for a parent carer of a child with a neurological disorder/impairment.

As your child enters and progresses their school years they are more like to use the internet to learn, communicate with friends and to find out about the wider world.

Cerebra have collaborated with **Mencap** and **Ambitious About Autism** to produce a guide on 'Internet Safety'. The guide outlines some suggestions to help parents carers limit the risk of their child having negative experiences online and understand what action can be taken if they do.

This guide also suggests some resources that will help children get the most out of the Internet at home and in the community. Search title at: www.cerebra.org.uk

Developing the senses

What is experienced through the five senses of sight, hearing, taste, smell and touch creates neural pathways in the brain. It is through stimulating the senses by varied experiences that learning and memory formation takes place. It is essential therefore for children and young people to have such experiences throughout the period when their brains are developing. It is equally important however to be aware that some children with neurological disorders may process sensory inputs in different ways or may not as in the case of blindness and deafness have sensory inputs. **Occupational therapists** may be able to help your child to maximise their sensory experiences to aid their learning.

It is important to keep monitoring your child's sensory well-being during their school lives and trying to ensure their school aware of any sensory likes and dislikes (perhaps through a home school book) to minimise and problematic behaviour where possible. Information from your occupational therapist should be communicated to the school to ensure consistency across settings (see home/school communication in the choosing a school section).

The Indiana Resource Centre for Autism based in America offer information on 'Sensory integration: Tips to consider': www.iidc.indiana.edu/?pageId=471

You could use your individually created Cerebra personal portfolio to inform others of any sensory problems. Search title at: www.cerebra.org.uk

Playing

Play is a very important part of development, and this is no different for a child with a neurological disorder.

Play can aid your child's development by:

- Providing opportunities to develop their identity and self-esteem so they can have 'ordinary lives'.
- Helping your child understand they have the right not to be subjected to discrimination, to assert so and to build their resilience.
- Helping your child to manage and deal with difficulties and setbacks.
- Providing an opportunity to be in control of the situation.
- Allowing the practice of coordination and movement skills.
- Enabling your child to meet other children and interact.
- Aiding the development of an active imagination and improving concentration.
- Providing bonding time for you and your child.
- Teaching your child crucial cultural and family values.

What can be done to maximise play opportunities and enjoyment for your child?:

- Ensure your child engages in ordinary play.
- Your child will want you to be involved in their play, so ensure you make time to enjoy each other and have some silly play time.
- Ensure you go at your child's pace so they have the time to get as much from the play time as possible.
- Spend some time observing and thinking about what your child enjoys most and arrange fun, stimulating play times that incorporate these things.

- Ensure a wide range of play activities to aid development (for example turn-taking games, learning about food, play-dough and paint, music and movement games, and relaxation time e.g. reading a story).
- Provide opportunities for your child to play near a child who is doing something similar, so they can learn through one another.
- Keep verbal instructions simple, using descriptive words such as long, short, big, small, etc.
- Use gestures and facial expressions to make it clear what you are doing.
- Encourage your child to talk about what they are doing.
- Choose suitable equipment and avoid over stimulation, limit the amount of materials and toys that are out at once.

Many organisations offer advice on maximising recreation opportunities. The recreation section of the useful organisations and websites in Part 3 provides details of organisations that may be able to help – see www.ncb.org.uk/early-support/resources.

Sleep

School age children and adolescents often don't get enough sleep for a variety of reasons, this can be all the more so for a child with a neurological disorder/impairment. Children with many neurological disorders/impairments are more prone to sleep disorders/disturbances and also condition related factors that can interfere with getting a good night's sleep. Despite this, it is important to:

- Try and ensure a regular bedtimes and wake times.
- Have a consistent bedtime routine in place.
- Avoid sleeping in at weekends.
- Ensure the bedroom environment is conducive to sleep (e.g. dark, quiet and comfortable).
- Turn off equipment likely to affect sleep such as TV's, computers etc.
- Avoid caffeine and any stimulants.
- Contact your GP or a health practitioner if sleep problems persist.

There are a range of information and support out there for sleep problems. See the sleep section of the useful organisations and websites in Part 3 of this resource – see www.ncb.org.uk/early-support/resources.

Eating and drinking

Some children, as they develop, may be reluctant to eat and this may be related to their condition. For example, they may not like the texture of some foods, or may be seated in a position that makes it uncomfortable for them to eat. If your child has a condition such as autism they may need their food to be presented on the plate in a particular way.

Try not to worry too much, if you are anxious at meal times your child will recognise this.

If a child is having problems eating and drinking there are a number of practitioners that may be able to help. A team of practitioners (a multidisciplinary team) including a **speech and language therapist** (usually taking the lead), physiotherapist, occupational therapist and perhaps a dietician may be involved. To make contact with a practitioner, ask your **GP** or another health practitioner with whom you have regular contact.

Speech and language therapists can contribute to the assessment of a child to help discover why they have eating or drinking problems, refer on to other professionals who may be able to help, recommend food or drinks to try, develop techniques to help feeding and drinking, devising routines at meal times.

The NHS provide information that may help if your child is underweight or overweight. See more information at:

www.nhs.uk/Livewell/Goodfood/Pages/Underweightyoungchild.aspx

www.nhs.uk/Livewell/childhealth1-5/Pages/Overweight2to5.aspx

Scope provides information for parent carers on 'Eating at meal times', and 'Food talks: practical tips to include children with eating difficulties'. This information is aimed at children with cerebral palsy, however, much of the content is relevant to children with neurological disorders/impairments and eating difficulties.

See the following links for the information from Scope:

www.scope.org.uk/help-and-information/cerebral-palsy/eating-and-meal-times

www.scope.org.uk/sites/default/files/Scope_Food_Talks.pdf,

The Disability Living Foundation offers a factsheet on 'Choosing children's eating and drinking equipment'. This is available at:

www.dlf.org.uk/factsheets/Choosing_eating_and_drinking_equipment_sponsored.pdf

Growing pains

Many children experience growing pains, they usually occur when a child is between the ages of four and 12. NHS choices provide information to help understand and manage growing pains, see: www.nhs.uk/conditions/growing-pains/Pages/Introduction.aspx

Personal care

Many children with neurological disorders/impairments may require help with personal care tasks while at school such as dressing and undressing, toileting or continued toilet training, personal hygiene, medication and physical health tasks.

The Department of Education provides an online resource for teachers 'Training materials for teachers of learners with severe, profound and complex learning difficulties'. This is an

excellent resource for teachers or learning support assistants working with your child and contains information about personal care in school.

You might want to direct practitioners involved in your child's education and out-of-school play care to this resource: www.education.gov.uk/complexneeds

Providing personal care for a disabled child often causes additional expenses for parents carers. Cerebra provide a guide 'Disabled Children Parents' Guide: Money Matters' published in 2012 that explains the main sources of financial help available for parents carers of disabled children to help them provide personal care for their child. Search title at: www.cerebra.org.uk

Cerebra also provide 'Disabled Children Parents' Guide: Social Care, Housing and Health'. This guide provides information on how to get help for a child's social care, housing and health needs. This guide outlines the responsibilities of NHS bodies and local authority children's social care and services:

www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/DG_10018531

Home environment

Children may need help with a variety of daily tasks in the home, such as getting out of bed in the morning, preparing meals and preparing to go to school among many other things. An occupational therapist can help to provide solutions to daily difficulties.

Children can access occupational therapists through your local council or through the NHS. **NHS Choices** provide information on 'Occupational therapy – accessing occupational therapy':

www.nhs.uk/Conditions/occupational-therapy/Pages/accessing-occupational-therapy.asp

Equipment and aids

As a parent carer you will meet many professionals. It may seem like you are always attending appointments and it can be difficult to keep track of who is responsible for providing the different services that you may need. You can use the Early Support **Our family** resources to help you keep track of this – see www.ncb.org.uk/early-support/resources.

Your child may need additional equipment and aids to help them at school. This may be provided by the school or the education department of the local authority. It is advised that you make contact with them to see what they can do to help.

Your physiotherapist/Occupational therapist will assess and advise about suitable equipment.

NHS Choices Carers Direct provides further information about accessing equipment and aids, see:

www.nhs.uk/CarersDirect/guide/parent-carers/Pages/Aids-and-adaptations.aspx

Contact a Family provides comprehensive information for families on 'Aids, equipment and adaptations' that you may also find useful:

www.cafamily.org.uk/media/360503/aidsequipmentadapations.pdf

Choices and challenges

Friendships

Research (Lee 2008) suggests that very young children learn about different emotions through play. Both language and emotions develop side by side and affect each other powerfully. Establishing friendships, forming relationships and communicating with other children are therefore fundamental for learning and development. All children, including those with additional needs and special needs, should have opportunities to play and interact with other children in school and to develop skills in managing emotions and behaviour.

View the following link for more information (Lee 2008):

www.ican.org.uk/~media/ican2/Whats%20the%20Issue/Evidence/6%20Speech%20%20Language%20and%20Communication%20Needs%20and%20Primary%20School%20aged%20Children.ashx

Research also suggests that friends, even in the toddler stage, can help children feel good about themselves. Friends help them adapt more easily to childcare settings and build self-confidence. Establishing friendships, however, can be a challenge for some children with additional needs. Some do not have communication or social skills that allow them to form friendships, while others may have behavioural characteristics that prevent others from developing friendships. Children with **autism** for example, may ignore the activities of others, choosing instead to carry out activities on their own. Children with **ADHD** may be intolerant and exhibit outbursts.

According to Bloch (2012) 'some children endure painful experiences of being excluded, teased, or shamed. Such experiences can lead to feelings that damage a child's self-esteem, create anxiety, interfere with learning and contribute to loneliness'. She suggests some children 'seem to be born with a distinct social talent that allows for friendship formation; others have to be taught how to relate'.

The importance of play

Bloch suggests that 'encouraging frequent and appropriate play experiences with compatible age mates can help children with limited or poor social behaviours'. Small group interventions can be particularly effective when teachers provide experiences in which the child can work out problems that interfere with relationships.

See the following for more information (Bloch 2012):

www.aboutourkids.org/articles/promoting_friendships_preschool_children_special_needs

Coping with discrimination, differences and bullying

Doing different work or having additional support at school could contribute to them being ascribed to be different in a negative way. Frequent changes of groups and difficulty making friends tended to isolate them, making them easy targets. Some had difficulty telling people about bullying or were reluctant to do so. Some could be easily hurt by things that others could shrug off. Some did not recognise that they were being bullied.

Suggestions to prevent bullying in schools have been put forward by [Contact a Family](#):

- Have a named person your child can tell about the bullying and discrimination.
- Have a safe place your child can go to during breaks or lunchtimes.
- Create a signal your child can use with staff if they need to leave the room.
- Be responsible for the behaviour of pupils beyond the school gate on school transport.
- Provide training for school and local authority staff.
- Be aware of unstructured times, like lunchtime and breaks.
- Remove the child who is exhibiting bullying, not the child who is being bullied.
- Encourage communication between teaching staff and lunchtime supervisors.
- Provide a safe area of the playground which has more supervision.
- Allow children the opportunity to stay indoors at lunch and break times in e.g. clubs.
- Provide support at times of transition.
- Use the 'Circle of Friends' programme, a structured programme with six to eight volunteers.
- Review the anti-bullying policy regularly and involve parents and pupils.
- Work on social skills.
- Give praise and encouragement.

See also: [Independent Panel for Special Education Advice \(IPSEA\)](#)

Developing independence

Bullying and discrimination, along with an unsuitable environment, inappropriate grouping of pupils, inflexible teaching styles and inaccessible curriculum materials, can all act as barriers to achievement. These block children's progress as much as physical, sensory or cognitive impairments. Developing independence for children with additional needs involves removing such barriers.

The government's strategy for special educational needs, published in 2003, sets out ways of removing barriers and giving children with additional needs, including special educational needs the opportunity to succeed.

See: www.inclusive-solutions.com/pdfs/removing%20barriers.pdf

What if things aren't working?

Further guidance on resolving problems that can arise in schools can be found in Cerebra's 'Disabled Children's Parents guide to Education'. Search for the title at: www.cerebra.org.uk

See information on appealing against a special educational needs decision at: www.justice.gov.uk/tribunals/send/appeals

Choosing a secondary school

If children have a statement of **special educational needs (SEN)**, they will usually be educated in mainstream schools, but it is also possible for them to go to a special school. The choice, as for primary education, is dependent upon the ability of the school to meet the child's skills and ability needs. It is also dependent upon the placement making efficient use of the authority's resources and not having a negative impact on the education of other children. More information about the issues that may arise during this process see the Early Support website – www.ncb.org.uk/earllysupport.

Meeting others

Parent Carer groups and professionals/practitioners

Parent carers of children with additional needs will encounter a range of professionals from health, education and social services. These will extend from early years practitioners, advisory teachers to welfare rights advisors. A simple explanation of what these professionals do can be found by visiting the following link to **Early Support**: www.ncb.org.uk/early-support/for-families

Going out with your child

The importance of creating opportunities for children to develop social skills such as communication and sharing by being included with other children has been discussed in the early years section. Going out with a child can also help parents carers perform their caring role. Parents carers of children with additional needs perform demanding tasks. Frequently the child may experience sleep problems and demands are made of the parents carers during night time. The demands can be physical, emotional and financial. Parents carers have little time for sleep or relaxation and are frequently stressed.

Seeing, meeting and talking with other people and their children in similar circumstances can help to relieve stress. Getting support from other parents carers and offering support when possible can make parents carers feel less isolated. Local support groups in various regions offer emotional and practical support to parents carers. These support groups operate through face to face meetings or online, making access to others more convenient. Some are specific to particular conditions whereas others are more general carer centres. The groups offer opportunities for parents carers along with their children to socialise, to engage in activities and to discuss with like minded people. Some arrange speakers or arrange to meet in a cafe or pub. Details of carer support groups can be found in the directory of local carers' services. Parents carers might also benefit from meeting with and sharing their cultural experiences with other parents carers from their own equalities protected characteristic groups.

Further information on support for UK families with disabled children can be also obtained from [Contact a Family](#).

Short breaks

Children and families can sometimes benefit from enjoying time with friends away from the routines of home. Taking a child away for a short break could provide opportunities for the child to spend time and play with other children. Having fun and performing everyday tasks alongside other children could be stimulating and could promote learning. Parents carers could also benefit from such a break as they can interact, share tasks and share experiences with other parent carers and adults. Local authorities and the voluntary and community sector provide short breaks for families. These include overnight stays, day trips for groups of children, fun activities in the community and one-to-one support.

Information about short breaks is also available from the Transition Information Network (TIN). These include day, evening, overnight or weekend activities, which can take place in the child's own home, the home of an approved carer, or in a residential or community setting. For more details see the information on short breaks at [Transition information network](#).

Further Information about taking short breaks is available from:

- [Short breaks network](#).
- [Scope](#).
- [Break-charity](#).
- [3h fund](#).
- [Activities unlimited](#).
- [Direct short breaks](#).
- [Council for Disabled Children](#).
- [Special-needs-kids](#).

Alternatively, you could see [Part 3 – Useful organisations and websites](#), see – www.ncb.org.uk/early-support/resources.

Into adulthood

Some neurological disorders are not diagnosed until adolescence or early adulthood. This can be for a variety of reasons. There is still a lot of support out there to help you.

This section has been designed for parent carers of children that need information during their child's adolescence or early adulthood. You may want to read this section along with the early years and school years sections as they may contain relevant information. This section aims to give an insight into some issues you may face in everyday life; including school issues and meeting others. It also provides a gateway to more comprehensive sources of information.

If a young person has just received a diagnosis of a neurological disorder or you suspect your child may have a neurological disorder/impairment you may want to find out as much information as you can about what to expect. The guide to neurological disorders and useful organisations and websites in Parts 2 and 3 may help.

For more information about the legal rights of disabled children and their families in England and Wales please see 'Disabled Children: A Legal Handbook' that explains what public bodies must do to support disabled children and what they may do. The handbook has sections on children's services, education, health, housing, welfare benefits, what's available for carers and transition issues. This is an invaluable resource for parents carers. If you need assistance in understanding its implications you can contact the [Council for Disabled Children](#).

The handbook, written by Steve Broach, Luke Clements and Janet Read, is available free from the [Council for Disabled Children](#) website, see: www.councilfordisabledchildren.org.uk/resources/cdcs-resources/disabled-children-a-legal-handbook

Involvement in transition

The transition into adulthood has significant implications for the quality of life that young people with **special educational needs** or **learning difficulty** and their families experience. Research published by the NFER in 2011 found that relatively few young people with **special educational needs (SEN)** or **learning difficulty assessment (LDA)** were being systematically prepared for adult life. The report suggested that there was an increasing need to involve such young people in the choices and decisions made about their future.

The research identified a number of factors which could have a positive impact on the transition to adult life of young people. It suggested that the creation and development of transition strategies was essential. These include the establishment of **multi-agency transition panels** or teams, along with the employment of transition champions and key workers. Efforts should be made to work more effectively with parents carers and schools.

Throughout the transition period, the views, wishes and feelings of the child or young person should be considered and person centred planning approaches should be adopted. When possible he or she should be encouraged to take an active part in meetings discussing his or her future. This means that the child or young person should be fully informed about opportunities and choices and should have full access to all other relevant information. See: www.nfer.ac.uk/nfer/publications/SENT01/SENT01.pdf

Transition information network

Information about the transition process is available on the [Transition Information Network \(TIN\)](#) website. This network is hosted by the [Council for Disabled Children](#), a partnership of organisations and individuals running the government's transition programme. The network aims to improve the experience that disabled young people have of transition to adulthood. It offers free membership.

On the TIN website, see: www.preparingforadulthood.org.uk

A section for young people is also available with information, news and events. See: www.transitioninfonetwork.org.uk/young_people.aspx

See also: [Council for Disabled Children](#)

Further information on transition and employment is available on the Cerebra Website. See Cerebra's 'Disabled Children Parent's Guide: Employment'. Search title at: www.cerebra.org.uk

See also Cerebra's 'Disabled Children Parent's Guide: Social care, Housing and Health'. Search title at: www.cerebra.org.uk

Cerebra's 'Disabled Children Parent's Guide: Money matters' for guidance on the financial support available. Search title at: www.cerebra.org.uk

Developing independence

Everyday life

The process of moving from adolescence to being an independent adult can be exciting but also hold many uncertainties and challenges along the way. This move to independence is usually a gradual change and much support is required from family, friends and support services. Often the transition process can be characterised by trying to negotiate the many health and social care services they may need to rely on. The transition to adulthood process involves changes in the law and service provision for young people.

Rights of disabled children, young people and families

Once a young person reaches 18, the law states that parents carers no longer have the right to make decisions on their behalf, as they are legally an adult. Young adults with neurological disorders often still live at home with their parent carers at the age of 18 and may need considerable continuing support. Service providers will usually keep you informed and involve you in the services they provide as it is in the best interests of the young person.

If a disabled young person is receiving social care services before the age of 18, the basis they receive on which they receive this service may change when they turn 18. However, this legal basis for the provision should make any difference to the service being provided as long as the service continues to meet the assessed need.

For more information about the legal rights of disabled children/young people and their families in England and Wales, please see 'Disabled Children: A Legal Handbook' that explains what public bodies must do to support disabled children and what they may do. The handbook has a section on transition to adulthood, covering education, social care, health and mental capacity issues.

The handbook written by Steve Broach, Luke Clements and Janet Read is available free from the [Council for Disabled Children](http://www.councilfordisabledchildren.org.uk) website. See:

www.councilfordisabledchildren.org.uk/resources/cdcs-resources/disabled-children-a-legal-handbook

Support in going through the transition process can be found from the [Transition Information Network \(TIN\)](http://www.transitioninfonet.org.uk).

To keep young people informed about health and wellbeing, the Transition Information Network provides links to a number of resources to keep them in the know. See:

www.transitioninfonet.org.uk/home/health.aspx

Sleep

Young adults with neurological disorders may experience sleep problems into adulthood. Sleep problems are more common in individuals with a neurological disorder for a variety of reasons and can have an effect on health. It is important to get support if a young adult is not getting the right amount of sleep. Ask your GP or health practitioner for more information.

The Royal College of Psychiatrists offer an information sheet on 'Sleeping well'. See:

www.rcpsych.ac.uk/mentalhealthinfoforall/problems/sleepproblems/sleepingwell.aspx

There are a range of information and support out there for sleep problems. See the sleep section of the useful organisations and websites at the back of this resource.

Eating and drinking

The British Nutrition Foundation has two information sheets on nutrition through life for teenagers and adults. See the following links:

www.nutrition.org.uk/nutritionscience/life/teenagers

www.nutrition.org.uk/nutritionscience/life/adults

The NHS provides information on 'Nutrition and feeding problems' See:

www.nhs.uk/CarersDirect/guide/practicalsupport/Pages/nutrition.aspx

Personal care

Personal care involves anything that relates to the intimate care of a person. For example, washing, dressing, using the toilet, etc. Some children and young people with a neurological disorder/impairment may still need help with personal care tasks such as going to the toilet or changing regularly if they are unable to use the toilet.

If your young person needs help with personal care, contact your local social services department to arrange a social care assessment. This assessment will provide information about the level of support required and how the need will be supported.

You can contact your local social services department through your local authority. You can find your local authority from the following website:

www.gov.uk/find-your-local-council

Toileting

Incontinence is a major problem faced by young people and their parent carers. Continence is a major skill to master as it can really promote greater independence. Keep promoting toileting skills (see the toileting section of early years personal care section) with your young adult where possible as it can really improve their quality of life.

If toileting is a problem, visit your GP, who may help to identify the type of continence problem, suggest lifestyle changes that may help or if the problem persists refer you on to a continence specialist.

NHS Choices provide information on incontinence and how to get help and support. See:

www.nhs.uk/LiveWell/Incontinence/Pages/Incontinencehome.aspx

Asserting independence

(Also see the [Letting Go](#) section, below)

There are a number of issues for young people with a neurological disorder/impairment or other additional needs when asserting their independence. Independent living includes:

- Having choice and control over the support and equipment they need.
- Being treated as an equal for housing, health and jobs.

The [Transition Information Network](#) provides links to useful website to help young people know their rights, access advice and support:

www.transitioninforonetwork.org.uk/resources/support.aspx#3.KnowingYourRights

Advocacy

A young person with a neurological condition may require support when starting to develop independence. This particularly applies when trying to access benefits, employment or services.

An advocate is someone who can act on behalf of the young person when required. The advocate can listen to, discuss with and inform the young person about choices they can make. He or she can help the young person to make decisions about their lives as well as providing emotional support. An advocate can support a young person who does not live with his or her parents carers and can represent the young person making sure that others know what the young person requires.

Advocacy services within the [NHS](#) can represent the young person's interests and local councils may also have their own advocacy services. See:

www.gov.uk/find-your-local-council

Organisations such as [Action for Advocacy](#) and the [Citizens Advice Bureau](#) also offer advocacy services.

Transport options

[GOV.UK](#) (replacing Directgov) provides information about the transport options they can help with if you're disabled. See: www.gov.uk/transport-disabled

The [Transition Information Network](#) provides information on transport and travel issues for disabled young people. See:

www.transitioninforonetwork.org.uk/resources/transport_travel.aspx

Young people having a voice

The [Council for Disabled Children](#) promotes the participation of children and young people in making their voices heard. See: www.councilfordisabledchildren.org.uk

Equipment and aids

(Also see the [Early Years](#) and [School Years](#) section on equipment and aids.)

When your child grows and develops into adolescence and adulthood, their need for equipment and aids may change. The young person may:

- Outgrow the equipment they were using when they were smaller.
- Need more specialist equipment to help them learn and develop.

- Need equipment to help parent carers manage care on a day-to-day basis e.g. a hoist for personal care tasks.

Contact your local authority to find out more information. GOV.UK provides an online service to help you find your local authority. See:

<http://local.direct.gov.uk/LDGRedirect/Start.do?mode=1>

The [Disabled Living Foundation](#) is a national charity that provides impartial advice, information and training on daily living aids. The DLF provide a huge range of factsheets about choosing equipment and aids. See: www.dlf.org.uk

The government provides an access to work grant. The money you get can pay for things like, specialist equipment, travel when you can't use public transport or a communicator at a job interview. The link below provides more information and how to apply:

www.gov.uk/access-to-work

Letting go

Parent carers often find it difficult to 'let go' of their child and their early adolescent when they mature and reach their late teens. Young people begin to develop more independence such as going out with friends, etc. This can be an even more difficult time for parent carers of a young person with a neurological disorder/impairment and those with other additional needs. The young person may not have much confidence or self determination to become independent. It is important to encourage young people to try out new things even if they need additional support to do so.

Supporting choice and autonomy

Young people with a neurological disorder/impairment and those with other additional needs have aspirations and dreams like any other young person. Supporting them in moving towards their goals can make a huge difference to their happiness and wellbeing. Many young people with neurological disorders/impairments lead active lives, and with the right support can maximise their potential.

As a parent carer it is important to support choice and autonomy in a young person with additional needs. Ways of doing this include:

- Understanding and appreciate the young person's past achievements.
- Ensuring the young person take as much control as possible in decisions that involve them.
- Providing as much jargon free information for the young person about their options, services or activities as they want or need.
- Taking the time to ensure they understand the decision they have made.

- Ensuring they are involved in decisions that affects their care (e.g. food choices, what time they go to bed, what activities they participate in, etc).
- Supporting choices consistent with the young person's character.
- Supporting choices consistent with the young person's culture and heritage.
- Encouraging the young person to participate in community activities.

Developing self awareness

Self awareness and self image can become an issue for most teenagers, but for teenagers with neurological conditions the concerns may appear greater as they become aware of having learning and other impairments. Many adolescents with additional needs may benefit from discussing and learning more about themselves and their diversity and the aspects of their lives that are common to others also in wider society.

Everyone learns in different ways and traditional ways of teaching may not meet everyone's learning needs. Some learn by listening, some by seeing, some by reading, others, by having hands on experience. Young people with neurological conditions are the same. All benefit from flexibility and time to learn. Working in small groups with a teacher who is aware of learning differences can produce such flexibility along with time to think about, practice and review new ideas. Friendship and acceptance develops from knowing about and caring about others not from identifying differences or ignorance.

Young people are developing self awareness when they are:

- Communicating with others.
- Making decisions about their own lives.
- Exploring their culture and identities and sense of place and belonging.
- Developing confidence.
- Understanding their rights and responsibilities.
- Feeling good about themselves.
- Achieving things for themselves.
- Overcoming challenges and problems when they occur.

Physical and emotional health

Adolescence and young adulthood is a time of great physical, emotional and psychological change. The changes to a young person's body and sexual feelings that may develop during adolescence can be welcomed by young people as a sign that they are developing into an adult, but some young people may find them difficult to cope with.

Brooke is a registered charity that provides free and confidential sexual health information, contraception, pregnancy testing, advice and counselling, testing and treatment for

sexually transmitted infections and outreach and education work. It provide lots of information on how the body changes during puberty and information on the rights and information needs of disabled young people. See:

www.brook.org.uk/my-rights/sex-relationships-and-your-rights/sex-and-disability

South Gloucestershire children and young people partnership (SGCYP) provide a useful information sheet on 'Talking about sex and relationships with children and young people with additional needs':

www.sgcyp.org/LinkClick.aspx?fileticket=rq9kBMfwOKM%3D&tabid=414

If you are worried about the emotional or mental health of a young person contact your GP or a support organisation such as [Mind](#), [Young minds](#) or [Rethink](#) for help and support.

Supporting positive risk taking

It is important that as a young adult or an adult with additional needs develops they have support in making their own decisions. This means the young person needs to think about the pro's and con's of making one decision over another.

It is important for children, young people and young adults to be able to take risks and overcome them in order to develop emotionally.

Parent carers can support positive risk taking by:

- Empowering the young person and young adult to maximise their own abilities in the decision making process.
- Being mindful of the difficulties that can occur when trying to promote positive risk taking with a young person and young adult.
- Helping the young person and young adult learn from their experiences.
- Helping them to understand the consequences of different choices or decisions.
- Being understanding when things don't work out.
- Respecting the privacy of the young person and young adult while promoting positive risk taking.
- Thinking about when ensuring the safety of the young person and young adult may over-ride choice and empowerment.

Meeting others

Parent/carers groups

Even when your child reaches adolescence it is likely that you will need help from others in continuing to support the young person/young adult and share experiences with other parents in a similar situation.

GOV.UK provides a service to help children, young people/young adult and families find local support groups. See:

www.gov.uk/support-group-for-children-young-people-families

Going out

Young people and young adults with neurological disorders/impairments who have good relationships with friends and get out and about in the community are more likely to have happy fulfilled lives than those who are socially isolated. When a young adult moves from school to more adult services this becomes all the more important. Maintaining and building a young person's or young adult's independence, self-esteem and self confidence is vital.

Families and the people around the young person or young adult can help this process through creativity, planning and encouragement, and ensuring that the young person or young adult has opportunities to create social relationships of their own choosing.

Families and those supporting young people and young adults with neurological disorders/impairments can:

- Help the young person or young adult identify activities that they will enjoy.
- Help make others and the young person or young adult aware of the talents and positives things that they bring to any situation.
- Have a plan of action about how inclusion and participation in social activities can be maximised.
- Provide the young person or young adult with a choice of things they may like to be involved in, getting hints from known likes.
- Find a person at any given activity to get to know the young person or young adult, providing a buddy to help promote enjoyment, help to build new relationships and to make the most of the experience.

Social activities

Like other young adults and young people, many children with neurological disorders/impairments may enjoy to spend time with friends and take part in community activities.

Mencap have a number of groups around the country that hold activities and clubs for young adults with learning impairments. See: www.mencap.org.uk/local-groups

The [Transition Information Network \(TIN\)](http://www.transitioninfonet.org.uk) provide information for young people on a range of issues such as fun activities, keeping safe, relationships and much more.

www.transitioninfonet.org.uk/young_people/information_for_young_people.aspx

Scope provides an 'information for young people' section on its website. This includes a service named 'trendsetters', a group that helps young people with disabilities in England and Wales make new friends and share information with other young people.

www.scope.org.uk/help-and-information/young-disabled-people

The recreation section of the useful organisations and websites in Part 3 of this booklet provide more information about organisations that can help a young person to get involved in social activities – see www.ncb.org.uk/early-support/resources.

Short breaks

There are a range of avenues you can look into when arranging a short break. Asking friends and family members may be a good way of getting a break, and an opportunity for them to spend some quality time with the young person. However, sometimes this is not possible and you may need a more formal agency to help you organise a break from caring.

It is advisable to make contact with your local social services department as the first port of call when considering using any childcare, holiday or short break services. You can contact your [local authority](#) for more information. Additional information about other kinds of breaks for children, young people and families is available from the [Shared Care Network, Break, Scope, The Children's Trust](#) and [KIDS](#).

[NHS Choices Carers Direct](#) offer information on how to go about 'getting a break from caring'. See: www.nhs.uk/CarersDirect/yourself/timeoff/Pages/Accessingrespitecare.aspx

There is an [Early Support](#) background information resources on [Social Services](#) that provides information on how to get an assessment, including assessment for short break services – see www.ncb.org.uk/early-support/resources.

Top tips

- Parents carers may have a variety of feelings and emotions following the diagnosis of their child/young person/young adult with a neurological condition. It is important to talk about and share these with trusted people such as family, friends, other parents carers, professionals and support groups to gain support.
- Interaction and play are important experiences for developing social skills in very young children
- Early identification of learning needs is important in children with additional needs as it can lead to early intervention.
- Early intervention can help children with additional needs to acquire skills that they would otherwise not develop.
- An early years setting experience gives all children an opportunity to be supported to engage in playful learning, to interact with others and explore the world in these foundation years, and establishes a bridge between home and school.
- In choosing a new school, a child with additional needs should be encouraged to visit prospective schools and to take an active part in the decision making.
- Preparing a young person for transition into adult life is a long-term process and should start early in a young person's school experience.
- All services (education, social and health and related support services) should be involved at an early stage in assessing the needs of a young person and producing plans to meet his or her future needs.
- Involving young people with neurological disorders/impairments in training and work experience can give them an opportunity to develop skills, experience and confidence. For some this could be a stepping stone to full employment.
- Accessing relevant information, useful contacts and support can empower parent carers of children with additional needs. The support gained can make the task of bringing up a child/young person and in supporting a young adult easier and more effective.

Glossary

Acquired (as in acquired brain injury) - An injury or trauma sustained any time after the period of childbirth.

Additional needs - The term 'additional needs' used in this and other Early Support resources is used to refer to any child or young person who has a condition, difficulty, challenge or special need, whether diagnosed or not, who is likely to need additional support beyond universal services. Child will refer to primary age children.

ADHD - Attention deficit hyperactivity disorder. A person may have symptoms of ADHD if they exhibit a set of behavioural characteristics which include inattentiveness, hyperactivity and impulsiveness.

Angelman's syndrome - A neuro-genetic disorder. A person may have intellectual and learning disabilities and sleep disturbance. They may have seizures and may move their hands with jerky movements. They frequently smile and laugh.

ASD - Autistic spectrum disorders including autism and Asperger syndrome. ASDs are a range of neurodevelopmental disorders which can cause a wide range of symptoms. These symptoms can include social impairments, communication difficulties and restricted, repetitive and stereotyped patterns of behavior. Autism is considered a relatively severe form of ASD whereas Asperger syndrome is considered a milder form.

Bacteria - A member of a large group of unicellular micro-organisms, which have cell walls but lack organelles and an organised nucleus, including some which can cause disease.

Basal ganglia - Specialised brain cells thought to be involved in a range of functions such as motor function, emotion and learning.

Brain - An organ of soft nervous tissue contained in the skull of vertebrates, functioning as a co-ordinating centre of sensation and intellectual and nervous activity.

Cell - The smallest structural and functional unit of an organism, which is typically microscopic and consists of cytoplasm and a nucleus enclosed in a membrane.

Cerebral palsy - A neurological condition in which there may be abnormal brain development or injury to the brain during its development before birth, during birth, after birth or during early childhood. Individuals with cerebral palsy experience difficulties in controlling muscles and in moving.

Cerebro-spinal fluid - This is a clear fluid found in the subarachnoid space (inside vesicles) of the brain and the spinal canal.

Chromosomes - Thread-like structures of nucleic acid and protein, found in the nucleus of most living cells, carrying genetic information in the form of genes.

Cognition - The mental action or process of acquiring knowledge and understanding through thought, experience and the senses.

Congenital - Describes a disease or physical abnormality present from birth.

Cri du chat syndrome – This is a neurological condition caused when a piece of chromosomal material is missing from a particular region on chromosome 5. It results in unusual facial features, poor muscle tone (hypotonia), small head size (microcephaly), and mental retardation. Another characteristic is a cat-like cry made by infants with this disorder.

Degeneration - The state or process of deterioration.

Development - A specified state of growth or advancement.

Diabetes - This is a syndrome characterised by a persistently raised blood sugar level caused usually by a deficiency of or resistance to insulin (See gestational diabetes).

Di-George syndrome - This is a neurological syndrome caused by deletion on chromosome 22. It affects the palate of the mouth and causes speech facial and heart anomalies along with learning and thinking difficulties.

DNA - Deoxyribonucleic acid; a self-replicating material which is present in nearly all living organisms as the main constituent of chromosomes. It is the carrier of genetic information.

Down syndrome - Down syndrome is a genetic disorder caused by the presence of an extra chromosome (Chromosome 21). It develops when a baby is still in the uterus. It affects a baby's normal physical development and causes moderate to severe learning difficulties. Individuals also have a higher than normal chance of developing heart conditions.

Dyspraxia - An impairment or immaturity of the organisation of movement.

Equality named co-ordinator/equality co-ordinator - A member of staff at an early years setting, out of school service or school who has responsibility for coordinating equality provision.

Early Support and key working - Early Support is a way of working, underpinned by 10 principles that aim to improve the delivery of services for children and young people with additional needs and their families. Early Support enables services to co-ordinate their activities better and to provide families with a single point of contact and continuity of care and support through key working. Early Support focuses on ensuring that service delivery is child, young person and family centred and that services and practitioners work in partnership with children, young people and their families.

Early Years Action and Early Years Action Plus - Help that is extra to or different from the help normally provided for children in early years settings.

Encephalitis - An acute inflammation of the brain

Endocrine – This refers to glands which secrete hormones or other products directly into the blood.

Epilepsy - A common and diverse set of chronic neurological disorders characterised by seizures

Fragile x syndrome - This is a genetic condition which results in a range of developmental problems including learning disabilities and cognitive impairment. Males are more severely affected by this disorder than females. Children, young people and young adults may exhibit anxiety and hyperactive behavior such as fidgeting or impulsive actions. They may have attention deficit disorder (ADD). Many males and some females may have characteristic features such as a long and narrow face, large ears, a prominent jaw and forehead, flexible fingers and flat feet.

Genetics - The study of heredity and the variation of inherited characteristics.

Gene-environment interaction - A term used to describe any effects that are due to interactions between the environment and genes.

Gestational diabetes - Diabetes in the unborn baby.

Global delay - This is where the child is delayed in achieving their developmental milestones within most, if not all, development areas.

Grey matter - The darker tissue of the brain and spinal cord, consisting mainly of nerve cell bodies and branching dendrites.

Health visitor - A health visitor is a qualified, experienced nurse or midwife who has undertaken further training and education in child health, health promotion, public health and education.

Hypogonadism - A condition in which decreased production of gonadal hormones leads to below-normal function of the gonads and to retardation of sexual growth and development. (The gonads are the ovaries and testes and the hormones they normally produce include estrogen, progesterone, and testosterone.)

Hypotonia - Decreased tone of skeletal muscles. In a word, floppiness. Hypotonia is a common finding in cerebral palsy and other neuromuscular disorders. **Hypertonia** is also a common finding in cerebral palsy and it refers to an abnormal increase in muscle tone.

Hypoxia - Deficiency in the amount of oxygen reaching the tissues.

Hypoxic Ischaemia - Insufficient blood flow causing a reduction in blood supply to the tissues

Immune system - The organs and processes of the body that provide resistance to infection and toxins.

Intrauterine - Within the uterus (womb).

LDA - Learning difficulty assessment. Local authorities are responsible for the LDA - assessing the learning needs of young people leaving school and entering further education.

LEA - Local education authority. This is a local authority in England and Wales that has responsibility for education within its jurisdiction.

Malformation - An abnormally formed part of the body.

Meningitis - An inflammation of the meninges, the protective membranes covering the brain and spinal cord.

Metabolism - The chemical processes that occur within a living organism in order to maintain life.

Microcephaly - An abnormally small head due to failure of brain growth. In precise terms, microcephaly is a head circumference that is more than two standard deviations below the normal mean for age, sex, race, and gestation.

Micro-deletion - The removal of a section of the DNA present in a chromosome

Micro-duplication - The duplication of a section of the DNA present in a chromosome

Multi-factorial - Involving or dependent on a number of factors, especially genetic or environmental factors.

Multi-agency transition panels – This is a group of people from different services including those of health, social and education involved in planning the transition route of a young person with special educational needs, as they move into adulthood. The transition route includes leaving school, perhaps going on into further education, employment or training, maybe leaving home. It leads to that stage in the lives of most young people when they develop their independence.

Monosomy - The presence of only one chromosome out of the two chromosomes usually present as a pair.

Motor skill - Describes an activity involving the use of muscles e.g. movement.

Neonatal - Describes the first 28 days of an infant's life.

Neoplasm - This is an abnormal mass of tissue or growth.

Nervous system - This is a network of nerve cells and fibres, which transmits nerve impulses between parts of the body.

Neural tube - This is a tube-like structure that develops in the embryo into the central nervous system, and becomes the brain and spinal cord.

Neural tube defects (NTD) - These are birth defects of the brain and spinal cord. The two most common neural tube defects are spina bifida and anencephaly.

Neurology - The branch of medicine or biology that deals with anatomy, functions and organic disorders of nerves and the nervous systems.

Neuro-motor - Relating to a nerve fibre or impulse passing towards motor effectors.

Neurotoxin - A substance that acts as a poison to nerves or nerve tissue

Neurotransmitters - A chemical that is released from a nerve cell which thereby transmits an impulse from a nerve cell to another nerve, muscle, organ, or other tissue. A neurotransmitter is a messenger of neurologic information from one cell to another.

Nutrition - The process of providing or obtaining the food necessary for growth and health.

Obsessive Compulsive Disorder (OCD) - An anxiety-related condition which takes many forms – generally people with OCD experience repetitive and intrusive thoughts, images and impulses that they find hard to ignore.

Obstetric - Relating to childbirth and the processes associated with it.

Occupational therapist - A practitioner who assesses and treats physical and psychiatric conditions using carefully designed activity to prevent disability and to promote good health.

Operant conditioning - A process of behaviour modification in which the likelihood of a specific behaviour is increased or decreased through positive or negative reinforcement each time the behaviour is exhibited, so that the subject comes to associate the pleasure or displeasure of the reinforcement with the behaviour.

Oppositional defiant disorder - This is an ongoing pattern of disobedient, hostile and defiant behaviour toward authority figures, including parents and teachers, which go beyond the bounds of usual childhood behaviour

Paediatrician - A medical practitioner who specialises in the branch of medicine that deals with the medical care of infants, children and adolescents.

PANDAS - This stands for Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcus. This is a disorder which the body's defence system tries to attack streptococcal bacteria (causing a sore throat,) but in the process also attacks some parts of the brain.

Parent Partnership Services (PPS) - These are statutory services present in every local authority. They offer advice and support to parents and carers of children and young people with additional needs including special educational needs. They provide information to empower these parents carers.

Peri-natal - Relating to the time, usually a number of weeks, before and after birth.

PCP - Person-centred planning. Involving the person whose future is being discussed in any planning or decisions regarding his or her future.

Phenylketonuria (PKU) - This is a genetic condition present from birth (congenital). It arises because the body is unable to break down a substance (an amino acid) called phenylalanine which then builds up in blood and in the brain. High levels of phenylalanine can damage the body's central nervous system and the brain, resulting in severe learning difficulties.

Physical symptoms - Symptoms relating to the body, as distinguished from the mind.

Prader Willis syndrome - This is a genetic condition resulting from the deletion (or failure of expression) of seven genes on paternal chromosome 15. It causes low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behaviors and a chronic feeling of hunger that may lead to excessive eating obesity.

Pre-natal - Before birth, during or relating to pregnancy.

Post-natal - Relating to the period after childbirth.

Prognosis - The likely course of a medical condition.

Psychological symptoms - Symptoms relating to, or arising from the mind or emotions.

Seizures - A sudden attack of illness, especially a stroke or an epileptic fit.

SEN - Special educational needs. A child who experiences learning challenges/impairments that make it harder to learn than most other children of the same age has special educational needs.

SENCO - Special Educational Needs Coordinator. An early years practitioner or school-based teacher who is responsible for coordinating special educational needs provision.

Social worker - A practitioner who works with people in the community and assists them to live more successfully by helping them to find solutions to problems.

Spasticity - A state of increased tone of a muscle (and an increase in the deep tendon reflexes). For example, with spasticity of the legs (spastic paraplegia) there is an increase in tone of the leg muscles so they feel tight and rigid and the knee jerk reflex is exaggerated.

Speech and language therapist – A practitioner who assesses and treats speech, language and communication problems to enable people to communicate to the best of their ability. They also work with people who have eating and swallowing problems.

Subarachnoid - Literally, beneath the arachnoid, the middle of three membranes that cover the central nervous system. In practice, subarachnoid usually refers to the space between the arachnoid and the pia mater, the innermost membrane surrounding the central nervous system.

Transition – A period of transition is a period of change. For children and young people it may represent a period when they move into a new school or eventually the period when they move out of school and into adulthood. Leaving school may involve going on into further education, employment or training or maybe leaving home. It leads towards independence and for young people with special or additional needs requires careful preparation to ensure success.

TORCH syndrome - This is an infection of the developing fetus inside the mother which has passed from the mother through the placenta. The infections include Toxoplasmosis, Other infections (hepatitis, syphilis varicella-zoster virus, HIV, and Parovirus B19) Rubella, Cytomegalovirus and Herpes virus.

Tourettes syndrome - This is a neurological condition where an individual exhibits repetitive, involuntary movements and vocalizations called tics. This can take the form of shouting out words or making sounds.

Toxin - A poison, especially one produced by or derived from micro-organisms.

Trauma - A psychological trauma is a deeply distressing or disturbing experience. A physiological trauma is a wound or an injury.

Traumatic brain injury - This occurs when a blow or a bump, or any other head injury, causes damage to the brain.

Trisomy - Trisomy 13 is a genetic disorder in which a person has three copies of genetic material from chromosome 13, instead of the usual two copies. Sometimes, the extra material can be attached to another chromosome. It can cause a range of physical symptoms including cleft lip or palate, close set eyes, small head, scalp defects, skeletal malformations, clenched hands, along with mental retardation and seizures.

Tuberous sclerosis - This is caused by two genetic disorders that result in the growth of tumours in the skin, brain/nervous system, kidneys, and heart. The condition is named after a tuber-shaped growth in the brain.

Turner's syndrome - This is a condition that affects girls and women. It is brought about by the absence of one X chromosome. In almost all cases, the individuals are shorter than average and have undeveloped ovaries causing infertility. A wide range of other symptoms may be present including heart, kidney and thyroid problems.

Virus - An infective agent that typically consists of a nucleic acid molecule in a protein coat and is able to multiply within the living cells of a host.

White matter - The paler tissue of the brain and spinal cord, consisting mainly of nerve fibres with their myelin sheaths.

Early Support

for children, young people and families

www.ncb.org.uk/earlysupport

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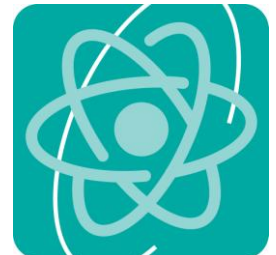
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2nd edition

Information about neurological disorders

Part 2 – Quick reference guide



A quick reference guide to some neurological disorders

There are a large number of conditions and a great deal of medical terminology included in this table. Not all of it is explained in this guide but if you would like to know more about anything in this table that is not explained elsewhere in the guide you might want to ask the practitioners working with you or get in touch with Contact a Family (details towards the end of the booklet) who will be able to help.

NHS Choices provide an A-Z of conditions and treatments - www.nhs.uk

The National Institute of Neurological Disorders and Stroke (NINDS) also provide an A-Z of neurological disorders - www.ninds.nih.gov

The Neurological Alliance provides information on a number of neurological disorders - www.neural.org.uk

The table shows the name of the condition, who you can contact to find out more information, the causes of the condition, potential symptoms, potentially co-existing conditions and treatment options.

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
ADHD/ADD Adders www.adders.org ADDISS www.addiss.co.uk	<ul style="list-style-type: none"> • Unknown definitively. • Potentially a lot of causes i.e. genetic predisposition and environment factors may contribute e.g. toxins or food additives. Brain injury 	3 types: <ul style="list-style-type: none"> • Hyperactive-impulsive. • Inattentive • Combined hyperactive-impulsive and inattentive 	<ul style="list-style-type: none"> • Learning difficulties/impairment • Oppositional defiant disorder (ODD) • Conduct disorder • Depression • Bipolar disorder • Tourette's syndrome • Sleep disorder 	<ul style="list-style-type: none"> • Focus on reducing symptoms and improving function • Medication • Psychotherapy • Education/training • Combination of treatments
Agensis of the corpus callosum Contact a Family information paper www.cafamily.org.uk/ Corpal www.corpal.org.uk	<ul style="list-style-type: none"> • Genetic: Recessive gene abnormalities on chromosomes 18,13,8 • Prenatal infections • Cysts or tumours 	<ul style="list-style-type: none"> • Learning difficulties/impairments • Poor muscle tone • Cognitive delays • Social and behavioural • Hydrocephalus ("water in the brain") • Cerebral palsy 	<ul style="list-style-type: none"> • Aicardi-Goutieres • Meckel-Gruber • Apert's syndrome • Walker-Walburg syndrome • Arnold-Chiari malformation 	Dependent upon disability services from: <ul style="list-style-type: none"> • Neuropsychologist • Physiotherapist • Educationalist • Occupational therapist • Speech and language therapist

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
Angelman's syndrome Epilepsy Action www.epilepsy.org.uk/info/angelman.html Assert www.angelmanuk.org	Neuro-genetic-deletion of genes on maternal chromosome 15	<ul style="list-style-type: none"> • Learning difficulties/ impairments • Seizures • Coordination problems (jerky movements) • Excessive laughter 	<ul style="list-style-type: none"> • Prominent jaw • Sleep disorders • Oral problems, swallowing, tongue projection • Irregular heart rhythms • Microcephaly 	<ul style="list-style-type: none"> • Anticonvulsant medication • Therapies for speech, sleep and behaviour • Physiotherapy
Aphasia Speak Ability www.speakability.org.uk Talking point www.ican.org.uk/talkingpoint Connect www.ukconnect.org	<ul style="list-style-type: none"> • Brain damage • Degeneration • Stroke • Cerebral tumours 	Difficulties in: <ul style="list-style-type: none"> • Speech • Comprehension • Reading and writing • Pronunciation • Forming sentences • Naming objects • Spontaneity in talking 	<ul style="list-style-type: none"> • Cerebrovascular disorders • Seizure disorders • Deafness 	<ul style="list-style-type: none"> • Speech therapy • Melodic intonation therapy
Arnold Chiari malformation Chiari Support www.chiari.co.uk	Downward displacement of the cerebellar vermis and medulla through the foramen magnum	<ul style="list-style-type: none"> • Hydrocephalus • Headaches • Nausea • Dizziness • Co-ordination problems • Weak facial muscles • Swallowing difficulties • Fatigue 	<ul style="list-style-type: none"> • Paralysis • Respiratory problems 	<ul style="list-style-type: none"> • Surgical removal of bone from the skull to relieve pressure • Shunt implant to divert excess cerebrospinal fluid
Asperger's syndrome National Autistic Society www.autism.org.uk	<ul style="list-style-type: none"> • Still under investigation • Potentially a lot of causes e.g. genetic and environmental factors may contribute to changes in brain development 	<ul style="list-style-type: none"> • Social communication/ interaction difficulties • Social imagination difficulties • Particular about routines • Sensory difficulties 	<ul style="list-style-type: none"> • Sensory processing disorder (SPD) • OCD • ADHD • Depression • Dyspraxia • Tourette's syndrome 	<ul style="list-style-type: none"> • Treatments to improve an individual's quality of life • Communication-based interventions • Behavioural therapy • Nutritional approaches

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
Autism National Autistic Society www.autism.org.uk Ambitious about Autism www.ambitiousaboutautism.org.uk	Still under investigation. Potentially a lot of causes e.g. genetic and environmental factors	<ul style="list-style-type: none"> • Social communication/ interaction difficulties • Social imagination difficulties • Language impairments • Particular about routines • Sensory difficulties • Learning difficulties 	<ul style="list-style-type: none"> • Seizures • Tourette's syndrome • ADHD • Anxiety • Mood disorders (e.g. depression) 	<ul style="list-style-type: none"> • Early intervention • Educational/behavioural interventions • Family counselling • Nutritional approaches • Medications to treat allied symptoms e.g. seizures/ anxiety, behaviour problems
Brain injury Bibic www.bibic.org.uk Brainwave www.brainwave.org.uk The Childrens Trust: Brain injury hub. www.braininjuryhub.co.uk Headway www.headway.org.uk Cerebra www.cerebra.org.uk	<ul style="list-style-type: none"> • Trauma e.g. Road accident or fall • Tumour • Stroke • Haemorrhage • Infection • Hypoxic/ anoxic brain injury • Medical accidents 	Dependent on brain region affected: <ul style="list-style-type: none"> • Cognitive deficits e.g. memory, understanding, concentration, problem-solving, language abilities • Emotional and behavioural changes • Physical problems 	<ul style="list-style-type: none"> • Epilepsy • Anxiety • OCD • Impulsiveness • Aphasia • Ataxia • Spasticity • Sensory impairment 	<ul style="list-style-type: none"> • Rehabilitation to help re-gain former skills • Physiotherapist • Occupational therapist • Speech and language therapy
Brain tumour National Cancer Institute www.cancer.gov Brain Tumour Action www.braintumouraction.org.uk Brain Tumour UK www.braintumouruk.org.uk The Brain Tumour Charity www.thebraintumourcharity.org.uk	<ul style="list-style-type: none"> • Rapid division of single brain cell giving rise to abnormal tissue: Types may be benign (non-cancerous) or malignant (cancerous) 	<ul style="list-style-type: none"> • Headaches • Nausea and vomiting • Seizures • Changes in hearing, vision and speech • Changes in mood, concentration, memory or personality • Jerkiness or twitching • Numbness or tingling in 	<ul style="list-style-type: none"> • Hydrocephalus • Circulatory problems • Learning difficulties 	<ul style="list-style-type: none"> • Surgery • Chemotherapy • Radiotherapy

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
y.org		arms and legs <ul style="list-style-type: none"> • Balance and walking problems 		
<p>Cerebral palsy</p> <p>Scope www.scope.org.uk HemiHelp www.hemihelp.org.uk Living With Cerebral Palsy www.livingwithcerebralpalsy.com</p>	<p>Oxygen deprivation during birth (5-10% cases)</p> <p>Injury to the brain before birth due to reduced blood supply to fetus from</p> <ul style="list-style-type: none"> • Maternal infection • Maternal low blood pressure • Premature birth (<6 months gestation) • Cocaine use during pregnancy • Mutations of genes • Trauma to fetus • Fetal intracranial haemorrhage <p>Damage to brain after birth</p> <ul style="list-style-type: none"> • Infection to brain e.g. meningitis or encephalitis • Traumatic brain injury (TBI) 	<p>Often becomes apparent during first three years of life but can be diagnosed at any time. Symptoms vary based on classification:</p> <p>Hemiplegia</p> <ul style="list-style-type: none"> • Altered muscle tone and decreased activity on one side of the body • May have curved spine • Speech problems <p>Spastic diplegia Muscle stiffness in legs</p> <p>Ataxic CP</p> <ul style="list-style-type: none"> • Clumsy/ uncoordinated • Tremors • Erratic speech <p>Dyskinetic CP</p> <ul style="list-style-type: none"> • Fluctuating or changing muscle tone • Speech problems • Eating problems • Drooling 	<ul style="list-style-type: none"> • Epilepsy • Intellectual impairments • Language delay • Pervasive developmental disorders • Behavioural problems • Sensory problems 	<ul style="list-style-type: none"> • Physiotherapy • Speech and language therapy • Occupational therapy • Physiotherapy • Medications e.g. muscle relaxant • Orthopaedic surgery to improve posture and mobility • Botulinum toxin injections, Intrathecal Baclofen, • Orthotics • Serial casting • 24 hour postural management <p>Treatment for feeding/drooling:</p> <ul style="list-style-type: none"> • Anticholinergic medications • Surgery • Devices for better tongue position • Biofeedback training • Removal of nerves in spinal column which are causing muscle

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
		Spastic quadriplegia <ul style="list-style-type: none"> • Most severe type • Stiffness in all limbs • Problems supporting head and body • Speech problems • Learning difficulties/impairments • Seizures common. 		stiffness (Selective Dorsal Rhizotomy (SDR)) <ul style="list-style-type: none"> • Extensive physiotherapy required following SDR
Cornelia de Lange Syndrome CdLS Foundation www.cdls.org.uk	A genetic mutation of genes on chromosomes 5 and 10	<ul style="list-style-type: none"> • Developmental delay • Visual and hearing problems • Excess body hair • Microcephaly • Abnormalities in body size, limbs, hands and feet 	<ul style="list-style-type: none"> • Cardiovascular malfunctions • Seizures • Cleft palate • Gastrointestinal problems 	<ul style="list-style-type: none"> • Medication to control seizures and gastric problems • Therapies to address individual impairments
Cri du chat syndrome Cri du Chat Support Group www.criduchat.org.uk	A genetic deletion on chromosome 5	<ul style="list-style-type: none"> • Low birth weight • ‘Cry of a cat’ • Unusual facial features • Developmental delay • Behaviours that challenge • Constipation 	<ul style="list-style-type: none"> • Microcephaly • Low set ears • Cardiovascular problems • Hypotonia • Renal problems 	<ul style="list-style-type: none"> • Interdisciplinary therapists for behavioural and feeding problems • Surgery for heart dysfunctions
Dandy Walker syndrome Ability www.ability.org.uk Shine www.shinecharity.org.uk Contact a Family www.cafamily.org.uk	Unknown congenital brain malformation	<ul style="list-style-type: none"> • Slow movements • Lack of muscle co-ordination • Increasing head size • Signs of pressure within the skull • Convulsions, abnormal eye 	<ul style="list-style-type: none"> • Abnormal internal organs • Intracranial cysts • Irritability • Vomiting 	No overall specific treatment individual problems addressed as child grows

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
<p>Down Syndrome (Trisomy 21)</p> <p>Down's Syndrome Association www.downs-syndrome.org.uk</p> <p>Down Syndrome Education International (DSE) www.downsed.org</p> <p>Downs Heart Group www.dhg.org.uk</p> <p>SOFT UK www.soft.org.uk</p>	<ul style="list-style-type: none"> • Chromosomal disorder/impairments • Individuals have three copies of chromosome 21 instead of two 	<p>movements and breathing malformations, e.g. face, limbs</p> <ul style="list-style-type: none"> • Specific facial characteristics e.g. upward slanting eyes, flat nasal bridge, small mouth • Delays in language and communication • Hearing impairments • Cognitive development slowing after age 2 yrs • Slower rate of development of motor skills • Behaviour that challenges • Very sociable 	<ul style="list-style-type: none"> • Behaviours that challenge, emotional and psychiatric impairments • Learning difficulties/impairments • OCD • Anxiety • Depression • Seizures • Other medical conditions 	<ul style="list-style-type: none"> • Early intervention • Behaviour analysis • Occupational or • Physiotherapy for motor impairments • Speech therapy • Communication aids
<p>Dyslexia</p> <p>British Dyslexia Association www.bdadyslexia.org.uk</p> <p>Dyslexia Action www.dyslexiaaction.org.uk</p>	<ul style="list-style-type: none"> • 40-60% genetically heritable • A number of theories posed regarding cause 	<ul style="list-style-type: none"> • Noticeable during early school years • Difficulties processing written information • Difficulties arising with reading, writing and spelling • No effect on intelligence 	<ul style="list-style-type: none"> • Dyspraxia • ADHD • Aphasia 	<ul style="list-style-type: none"> • Educational interventions such as teaching style e.g. <ul style="list-style-type: none"> – Multisensory – Structured – Thorough – Use of phonics – Computer software • Coloured overlays/ glasses

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
Dyspraxia Dyspraxia Foundation www.dyspraxiafoundation.org.uk	<ul style="list-style-type: none"> • Little known • Thought that neurons responsible for motor control not developed properly • Electrical signal not transmitting signals effectively 	<ul style="list-style-type: none"> • Affects movement and co-ordination • Clumsiness • Language impairments • Perception and thought problems • No effect on intelligence but affects learning 	<ul style="list-style-type: none"> • Dyslexia • ADHD • Asperger's syndrome • Hypotonia 	<ul style="list-style-type: none"> • No cure • Improvement of symptoms sought • Occupational therapist • Speech and language therapist • Physiotherapy
Encephalitis The Encephalitis Society www.encephalitis.info	<ul style="list-style-type: none"> • Inflammation of the brain • Infection • Immune system attacks the brain 	<ul style="list-style-type: none"> • Flu like symptoms • Fever • Headache • Deteriorates quickly • Seizures • Confusion • Drowsiness • Unconsciousness • Coma possible 	<ul style="list-style-type: none"> • Memory problems • Personality/ behaviour change • Speech and language impairment (Aphasia) • Epilepsy 	Three steps: 1. Antiviral medication 2. Control seizures/dehydration 3. Prevent long-term consequences like memory loss or epilepsy
Epilepsy Epilepsy Society www.epilepsysociety.org.uk Epilepsy Action www.epilepsy.org.uk Epilepsy Foundation www.epilepsyfoundation.org Joint Epilepsy Council www.jointepilepsycouncil.org.uk Young Epilepsy	Symptomatic epilepsy Known cause such as brain injury, tumour, cerebral palsy, birth defects, infections Ideopathic epilepsy No apparent cause Cryptogenic epilepsy No apparent cause but likely due to brain damage	Partial seizure <ul style="list-style-type: none"> • Simple: Person remains conscious • Complex –no awareness or memory of event • Changes in perception, tingling in body part/s, intense emotion, stiffness in body part/s, twitching • Inability to respond to others during seizure 	Brain damage can occur if seizure lasts more than 30 minutes (status epilepticus)	<ul style="list-style-type: none"> • Anti-epileptic drugs (AED), which changes the electrical activity of the brain • Vagus nerve stimulation (Sends electrical simulation into nerve and can reduce likelihood of seizure) • Ketogenic diet (Can cause other

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
<p>www.ncype.org.uk Fable www.fable.org.uk David Lewis Centre www.davidlewis.org.uk Epilepsy Bereaved www.sudep.org</p>		<p>Generalised seizures Abscences (petit mal)</p> <ul style="list-style-type: none"> • Common in children – loss of awareness for around 20 seconds • No memory of event • Can occur several times a day <p>Clonic seizure</p> <ul style="list-style-type: none"> • Limbs jerk or twitch • Can lose consciousness <p>Tonic seizure Muscles become stiff and can lose balance and fall over</p> <p>Tonic clonic seizure (grand mal)- Two stages:</p> <ul style="list-style-type: none"> • Body become stiff and limbs twitch/jerk • Lose consciousness • 1-3 minutes or more 		<p>health complications</p> <ul style="list-style-type: none"> • Surgery • Medication (To treat status epilepticus e.g. Diazepam and buccal midazolam)
<p>Fetal Alcohol Spectrum Disorders (FASD)</p> <p>FASawareUK www.fasaware.co.uk FASD Trust www.fasdtrust.co.uk</p>	<p>Exposure to alcohol before birth</p> <p>Umbrella term for a range of diagnosis, including:</p> <ul style="list-style-type: none"> • Fetal alcohol 	<ul style="list-style-type: none"> • Learning impairments/difficulties attention and behaviours that challenge • Speech and language impairments 	<ul style="list-style-type: none"> • Mental health problems • Neural tube defects (e.g. spina bifida) • Many of the symptoms listed are termed as 'disorders/conditions in 	<ul style="list-style-type: none"> • Early intervention can improve symptoms/presenting features • Medication • Behaviour and

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
<p>NOFAS-UK www.nofas-uk.org</p>	<p>syndrome</p> <ul style="list-style-type: none"> • Partial foetal alcohol syndrome • Alcohol related neurodevelopmental disorders/impairments • Alcohol related birth defects <p>Fetal alcohol effects</p>	<ul style="list-style-type: none"> • Autistic type features • Sleep difficulties • Mood issues • Sensory problems • Facial disfigurements • Organ damage • Cerebral palsy • Hormone disorders/conditions 	<p>their own right'</p>	<p>education therapy</p> <ul style="list-style-type: none"> • Parent training • Alternative and complementary medicine approaches • Physiotherapy
<p>Fragile X syndrome or Martin-Bell syndrome</p> <p>The Fragile X Society www.fragilex.org.uk</p>	<p>Genetic: caused by the mutation of the FMRI gene on the X chromosome</p>	<ul style="list-style-type: none"> • Learning and intellectual difficulties/impairments • Elongated facial features • Large ears, high palate • Large testes • Low muscle tone • OCD 	<ul style="list-style-type: none"> • Hyperactivity • Anxiety • Phobias • Variations include ataxia and autism 	<ul style="list-style-type: none"> • Deactivation of mGluR5 and RNA-binding proteins are currently being investigated • Therapies for physical impairments and special education
<p>Global Developmental Delay</p> <p>Contact a Family www.cafamily.org.uk/medical-information/conditions/global-developmental-delay/</p>	<p>Symptomatic of chromosomal and genetic conditions such as Down syndrome, Cerebral palsy, Fragile X, Spina bifida or prematurity</p>	<ul style="list-style-type: none"> • Underweight at birth • Comparably not on par development, physically and mentally <p>Late, or no further development in:</p> <ul style="list-style-type: none"> • Motor skills (sitting up, walking etc.) • Speech and language • Cognitive skills • Social and emotional skills 	<ul style="list-style-type: none"> • Learning difficulties/impairments • Impulsive • Aggression • Inattentive 	<ul style="list-style-type: none"> • Physiotherapy, behaviour and education therapy

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
Guillain-Barré syndrome Guillain-Barré Syndrome Support Group www.gbs.org.uk	<ul style="list-style-type: none"> • Immune system causes inflammation of peripheral nerves • May follow a viral infection 	<ul style="list-style-type: none"> • Tingling • Numbness • Progressive weakness in muscles 	<ul style="list-style-type: none"> • Inability to walk • Total paralysis requiring ventilation 	<ul style="list-style-type: none"> • Lesser infections respond to physiotherapy for improving circulation and muscle tone
Hydrocephalus Shine www.shinecharity.org.uk Ability www.ability.org.uk Action Medical Research www.action.org.uk	<ul style="list-style-type: none"> • Genetic, congenital or acquired by stroke, trauma or injury, subarachnoid haemorrhage (sometimes before birth) • Tumour • Meningitis or infection 	<ul style="list-style-type: none"> • In children, large head size due to excess cerebrospinal fluid causing intracranial pressure • Headache • Nausea-vomiting • Problems with balance and co-ordination • Unusual eye movements • Convulsions 	<ul style="list-style-type: none"> • Walking difficulties/impairments • Longer cognition and growth development in children • Drowsiness • Irritability • Incontinence • Lethargy • Memory loss 	<ul style="list-style-type: none"> • Surgical implant of a shunt to divert excess cerebrospinal fluid for absorption in another part of the body • Rehabilitation therapies
Learning disability Mencap www.mencap.org.uk ENABLE (Scotland) www.enable.org.uk	<ul style="list-style-type: none"> • Genetic (e.g. Down syndrome) • Congenital • Infections • Hypoxia • Alcohol • Physical injury • Profound neglect 	<ul style="list-style-type: none"> • Speech and language impairments • Learning impairment • Cognitive impairment • Coordination/balance • Emotional difficulties and behaviours that challenge 	<ul style="list-style-type: none"> • Lack of self-care and life skills • Sensory impairments 	<ul style="list-style-type: none"> • Special education • Speech therapy • Physiotherapy • Psychological issues addressed
Megalencephaly Climb National Information Centre for Metabolic Diseases www.climb.org.uk	A disturbance in the regulation of cell production before or after birth, resulting in an enlarged head	<ul style="list-style-type: none"> • Seizures • Partial paralysis • Developmental delay, abnormalities in brain-related functions 	<ul style="list-style-type: none"> • Brain cortex and spinal cord dysfunction • Alexander's disease • Tay Sachs 	Therapies or medication for individual disabilities within the syndrome

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
<p>Microcephaly</p> <p>Microcephaly Support Group www.microcephaly.co.uk</p>	<ul style="list-style-type: none"> Genetic-abnormality in one of the microcephalin genes causing inhibition of brain growth and a small head Exposure to toxins or drugs during development Associated with other diseases such as fetal alcohol syndrome Chickenpox and German measles 	<ul style="list-style-type: none"> Neurological deficits Developmental delay Small body size for age Facial development but skull does not grow at the same speed 	<ul style="list-style-type: none"> Seizures Motor function deficits Quadriplegia (rare) Hyperactivity Coordination difficulties 	<ul style="list-style-type: none"> Symptoms/conditions and impairments may be alleviated by therapies Medication to control seizures
<p>Multiple Sclerosis</p> <p>Multiple Sclerosis Society www.msociety.org.uk MS Resource Centre www.msrc.co.uk</p>	<p>Unproven, genetic, viral or environmental causes indicated, leading to degeneration of nerve-insulating myelin</p>	<ul style="list-style-type: none"> Blurred vision Tingling and numbness Muscle weakness and co-ordination/balance difficulties Cognitive challenges in concentration, memory, judgement & attention Headaches Depression Apathy 	<ul style="list-style-type: none"> Spasticity due to loss of muscle tone Occasionally, paralysis Hearing impairments 	<ul style="list-style-type: none"> No known cure, but beta interferons have been shown to slow progress Muscle relaxants may reduce spasticity Myelin substitutes, antibodies and immunosuppressants Therapies to maintain physical functions
<p>Muscular Dystrophies</p> <p>(e.g. Duchenne, Myotonic, Facioscapulohumeral, Becker) Muscular Dystrophy Campaign</p>	<ul style="list-style-type: none"> Genetic Impaired or absence of the protein dystrophin, which maintains muscle integrity 	<ul style="list-style-type: none"> Progressive weakness and degeneration of skeletal muscle Spasticity Later stage - breathing difficulties 	<ul style="list-style-type: none"> Heart muscle problems Endocrine abnormalities Seizures 	<ul style="list-style-type: none"> Physiotherapies Anticonvulsants for seizures Orthoses for support

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
<p>www.muscular-dystrophy.org</p> <p>Prada-Willi syndrome</p> <p>Prader-Willi Syndrome Association UK www.pwsa.co.uk</p>	<p>Genetic: Deletion on chromosome 15</p>	<ul style="list-style-type: none"> • Feeding difficulties from birth to infancy • Lethargy • Hypotonia • Learning impairments. • When feeding difficulties end, overeating begins • Intellectual difficulties/impairments • Obesity • Short stature, small hands and feet, almond eyes • Obsessive behaviours 	<ul style="list-style-type: none"> • Diabetes • Squint • Scoliosis • Hypogonadism • Breathing difficulties 	<ul style="list-style-type: none"> • Diet management • Special education • Behaviours that challenge addressed • Exercise
<p>Rett syndrome</p> <p>Rett UK www.rettsyndrome.org.uk Office for Advice Assistance Support and Information on Special Needs www.oaasis.co.uk</p>	<ul style="list-style-type: none"> • Not genetic, but arises from a mutation of the gene MECP2 possibly on the male X chromosome • Abnormalities in neurodevelopment causing loss of motor function 	<ul style="list-style-type: none"> • Slow growth development post-birth • Loss of motor function • Non-verbal • Autistic traits such as wringing of hands, eye contact avoidance or mouthing • Gastrointestinal disorders/conditions • Constipation • Epilepsy 	<ul style="list-style-type: none"> • Scoliosis • Learning difficulties • Breathing problems • Sensory problems • Swallowing difficulties leading to malnutrition • Ataxia • Spasticity • Dystonia 	<ul style="list-style-type: none"> • Medication to control epilepsy and gastrointestinal difficulties • Physiotherapy • Speech therapy and occupational therapies • Aids to maintain posture

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
<p>Sleep apnoea</p> <p><i>Obstructive</i></p> <p>The Sleep Apnoea Trust www.sleep-apnoea-trust.org</p> <p>Obstructive SA in Children at Patient.co.uk www.patient.co.uk</p> <p>Central sleep apnoea or Cheyne-Stokes respiration at Patient.co.uk www.patient.co.uk</p> <p><i>Congenital Central Hypoventilation Syndrome</i></p>	<ul style="list-style-type: none"> • Relaxing and collapse of muscles supporting airway during sleep, causing blockage stopping air entering momentarily (problem worse if overweight) • Enlarged tonsils and tongue (micrognathia) • Lack of oxygen causing brain tissue loss • Neurological controls to breathe malfunction • Failure to respond to chemoreceptors 	<ul style="list-style-type: none"> • Snoring • Fatigue • Learning/memory difficulties, mood swings • Irritability • Depression <ul style="list-style-type: none"> • As in <i>Obstructive</i> plus epilepsy • Cardiovascular problems • Turning blue <p>Inability to breathe naturally, requiring mechanical ventilation</p>	<ul style="list-style-type: none"> • High blood pressure • Stroke • Arrhythmias • Diabetes <ul style="list-style-type: none"> • Angina • Metabolic acidosis <p>Sudden infant death syndrome (cot death)</p>	<ul style="list-style-type: none"> • Changing sleeping position • Losing weight • Surgery to remove tonsils or widen airway passage <ul style="list-style-type: none"> • Life style changes including avoiding alcohol and tranquilisers • Respiratory stimulants <ul style="list-style-type: none"> • Tracheotomy • Diaphragmatic pacemaker
<p>Spina bifida</p> <p>Spina Bifida at Patient.co.uk www.patient.co.uk</p>	<p>Incomplete development of brain, spinal cord and/or their protective coverings caused by fetal failure to close spine during first month of development</p>	<ul style="list-style-type: none"> • Paralysis in lower limbs • Poor physical health • Lack of mobility • Bowel and bladder difficulties • Learning difficulties/impairments 	<ul style="list-style-type: none"> • Hydrocephalus • Rarely, total paralysis 	<ul style="list-style-type: none"> • Surgery to restore coverings • Physiotherapy to maximise physical potential and orthoses to support limbs in a good position

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
<p>Tay Sachs disease</p> <p>National Tay-Sachs and Allied Diseases www.ntsad.org</p>	<p>Genetic: Inheritance of 2 recessive genes on chromosome 15 leading to inability to produce the HEX-A enzyme which breaks down fatty acids</p>	<p>Infantile: Child becomes deaf, blind and unable to swallow, atrophy of muscles and paralysis.</p> <p>Juvenile</p> <ul style="list-style-type: none"> • Cognitive • Motor and speech impairments • Ataxia and spasticity 	<p>In late onset-</p> <ul style="list-style-type: none"> • Psychiatric illness • Schizophrenia • Psychosis 	<p>Palliative care</p>
<p>Tourette's syndrome</p> <p>Tourettes Action UK www.tourettes-action.org.uk</p> <p>Tourettes info www.tourettes.info</p>	<ul style="list-style-type: none"> • Largely unknown • Thought to arise due to problems with the (basal ganglia) in the brain • This can lead to imbalances of neurotransmitters in the brain • Possible genetic susceptibility • Childhood infection (controversial) 	<p>Tics:</p> <ul style="list-style-type: none"> • Physical (simple) e.g. blinking, jerking, grinding teeth etc • Phonological simple e.g. grunting, screaming, blowing • Physical (complex) e.g. hitting, kicking, jumping, shaking, touching, copying • Phonological (complex) e.g. repeating, shouting obscene words 	<ul style="list-style-type: none"> • Obsessive Compulsive Disorder • ADHD 	<ul style="list-style-type: none"> • Medication is usually only given if some behaviours interfere with normal functioning • Clonidine suppresses tics • Antidepressants, Prozac, Zoloft, Luvox • Neuroleptics, Haldol, Risperdal, Geodon • Cognitive Behaviour Therapy • Relaxation techniques
<p>West syndrome</p> <p>Epilepsy Action www.epilepsy.org.uk</p> <p>West Syndrome Support Group www.wssg.org.uk</p>	<ul style="list-style-type: none"> • Prematurity • Epilepsy before 12 months of age may indicate another underlying condition • Tuberous sclerosis • Stress (Inability to regulate GABA is suspected) 	<ul style="list-style-type: none"> • Spasms lasting one to fifteen minutes • Convulsions • Lethargy • Irregular heart rhythms • Learning difficulties/impairments • Growth restriction 	<ul style="list-style-type: none"> • Hydrocephalus • Microcephaly • Sturge-Weber syndrome • Tuberous sclerosis • Genetic syndromes • Brain damage • Congenital infections • Encephalitis 	<ul style="list-style-type: none"> • Anticonvulsant drugs for epilepsy • Management of associated disorders accordingly

Condition Information and Support	Causes	Potential symptoms	Potentially co-existing conditions/disorders	Treatment options
			<ul style="list-style-type: none"> • Meningitis • Brain haemorrhage • Phenylketonuria 	
<p>Williams syndrome</p> <p>Williams Syndrome Foundation www.williams-syndrome.org.uk</p>	<p>Genetic: Deletion of 24+ genes on chromosome 7</p>	<ul style="list-style-type: none"> • Learning difficulties/impairments • Elfin features with spaced teeth • Cardiovascular problems • Cognitive deficits • Hypercalcemia • Loose joints and muscle problems 	<ul style="list-style-type: none"> • Auditory and visual problems • Over friendly • Phobias or no fears • Sensitive hearing • Kidney stones 	<ul style="list-style-type: none"> • Avoiding calcium and vitamin D • Frequent monitoring of growth and blood pressures
<p>The following conditions are not considered to be neurological conditions, although they may affect behaviour. They are included because they are good examples of particular genetic conditions and are referred to in the text.</p>				
<p>Di-George Syndrome</p> <p>Max Appeal! www.maxappeal.org.uk</p>	<p>Genetic: Deletion of chromosome 22q11.2</p>	<ul style="list-style-type: none"> • Congenital heart defects • Abnormal facies, • Hypoparathyroidism • Hypocalcaemia • Lack of resistance to infection 	<ul style="list-style-type: none"> • Short stature • Mild to moderate cognitive behaviour and learning difficulties • Some palatal clefts and speech impairment 	<ul style="list-style-type: none"> • Surgery for heart and cleft problems • Immune problems treated through medication • Speech therapy can help with speech problems
<p>Turner syndrome</p> <p>Turner Syndrome Support Society www.tss.org.uk</p>	<p>Genetic: Missing or partially missing X chromosome in females</p>	<ul style="list-style-type: none"> • Shorter than average height • A lack of development of the ovaries leading to infertility 	<ul style="list-style-type: none"> • Heart, kidney and thyroid problems • Bone disorders and ear problems • Behaviour problems and learning disability can be present 	<ul style="list-style-type: none"> • Most are able to lead relatively normal healthy lives

Early Support

for children, young people and families

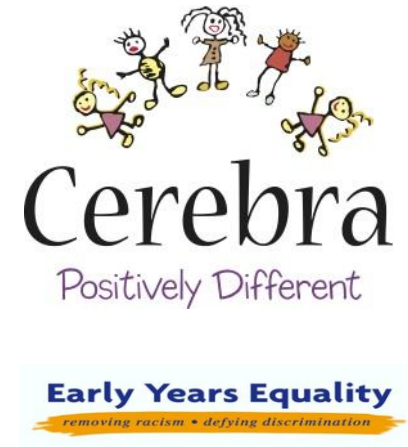
www.ncb.org.uk/earlysupport

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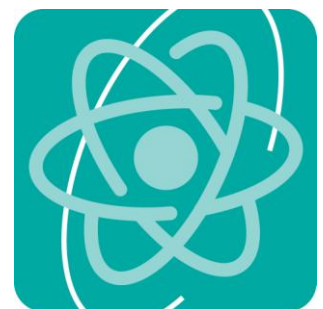
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2nd edition

Information about neurological disorders

Part 3 – Useful organisations and websites



Useful organisations and websites

There are a range of support organisations for specific disorders in the Guide to neurological disorders (Part 2 of the neurological disorders resources). Additional organisations and contacts, together with further details of some of those mentioned in Part 2 of these resources, are provided here.

Neurological disorders

Ataxia UK

Support for people with problems with movement, balance and speech.

Web: www.ataxia.org.uk

Helpline: 0845 644 006

Tel: 020 7582 1444

Association of Paediatric Chartered Physiotherapists (APCP)

APCP aims to bring together the skills, knowledge, research and innovative developments of paediatric physiotherapists for the benefit of its members, the profession, and the wider health community.

Web: www.apcp.org.uk

Brain and Spine Foundation

Information and resources for people with neurological conditions.

Web: www.brainandspine.org.uk

Tel: 0808 808 1000

The Disabilities Trust/Brain Injury Rehabilitation Trust (BIRT)

Helps people regain skills following a brain injury.

Web: www.thedtgroup.org

Tel: 01444 239123

BIRT - Tel: 01924 896100

The Chartered Society for Physiotherapy

Founded in 1894, the Chartered Society of Physiotherapy has grown to become the profession's largest membership organisation for physiotherapists.

Web: www.csp.org.uk

Tel: 020 7306 6666

The Children's Mitochondrial Disease Network (CMDN)

Information and support for families of children with a mitochondrial disease.

Web: www.emdn-mitonet.co.uk

Tel: 01606 43946

Climb

Support for children living with a metabolic disorder.

Web: www.climb.org.uk

Tel: 0800 652 3181

Genetic Alliance UK

A membership of over 150 patient organisations, which support children, families and adults with genetic conditions.

Web: www.geneticalliance.org.uk

24-hour helpline: 0808 80 10 388

National Institute of Neurological Disorders and Stroke (NINDS)

Provides information on a variety of neurological disorders and stroke, including an A-Z of different types of disorders.

Web: www.ninds.nih.gov

Tel: America (800) 3529424 or (301) 496 571

The Neurological Alliance

Information about a range of neurological conditions.

Web: www.neural.org.uk

Tel: 020 7584 6457

Meningitis Trust

Financial, practical and emotional help and information for anyone affected by meningitis.

Web: www.meningitis-trust.org

Free phone helpline: 0800 028 1828

Tel: 01453 768001

The National Society for Phenylketonuria (NSPKU)

Provides information on PKU and the PKU diet.

Web: www.nspku.org

SOFT

Support Organisation for Trisomy 13/18 and related disorders.

Web: www.soft.org.uk

Tel: 01213 513122

Spinal Injuries Association (SIA)

The leading national charity for spinal cord injured people.

Web: www.spinal.co.uk/index

Free phone advice line: 0800 980 0501

Unique

Rare chromosome disorder support group.

Web: www.rarechromo.co.uk

Helpline: 01833 330 766

Little Yellow Book – It gives information on chromosomes and rare chromosome disorders.

Web: www.rarechromo.org/html/LittleYellowBook.asp

Vision and hearing

National Deaf Children's Society (NDCS)

Supports deaf children and their families and provides information on all aspects of childhood deafness.

Web: www.ndcs.org.uk

Free helpline: 0808 800 8880

Tel: 020 749 8656

Minicom: 020 749 8656

Deaf Parenting UK

Resource of information for parents of deaf children.

Web: www.deafparent.org.uk

Tel: 07789 027186

RNIB

Provides a range of services for children and adults who are visually impaired including those who have additional needs.

Web: www.rnib.org.uk

Helpline: 0303 123 9999

Tel: 020 7388 1266

Royal Association for Deaf people (RAD)

Promotes the welfare and interests of deaf people.

Web: www.royaldeaf.org.uk

Tel: 0845 688 2525

Minicom: 0845 688 2527

Action on Hearing Loss

Aims to achieve a better quality of life for deaf and hard of hearing people. Provides a range of information, advice and support.

Web: www.actiononhearingloss.org.uk

Tel : 020 7296 8000

Textphone: 020 7296 8001

Sense

The major UK voluntary organisation for children and adults born with multi-sensory impairment (MSI) and their families. They provide information, advice and support.

Web: www.sense.org.uk

Tel: 0845 127 0060

Textphone: 0845 127 0062

Support for children, young people and families

General information

Action for Advocacy (A4A)

A4A is the central point of information on independent advocacy.

Web: www.actionforadvocacy.org.uk

Tel: 0207 921 4395

Barnardo's

Works with vulnerable children, young people and families and helps children with additional needs in a variety of ways, including promoting inclusion, providing short breaks and offering parenting support.

Web: www.barnardos.org.uk

Tel: 020 8550 8822

Carers UK

A registered charity that provides support to anyone who is a carer. They offer information and advice, provide a range of publications and also campaign for carers' rights. Carers run the organisation.

Web: www.carersuk.org

Adviceline: 0808 808 7777

Tel: 0207 378 4999

Cerebra

This is a unique charity set up to help improve the lives of children with brain related conditions through researching, educating and directly supporting children and their carers.

Web: www.cerebra.org.uk

Parent support line: 0800 328 1159

The Challenging Behaviour Foundation

Provides information and support to parents and carers of individuals who have severe learning difficulties and are described as having 'challenging behaviour'.

Web: www.challengingbehaviour.org.uk

Support from Family Support worker: 0845 602 7885

Tel: 01634 838 739

Child Brain Injury Trust UK (CBIT)

Offers support and information on childhood acquired brain injury.

Web: www.childbraininjurytrust.org.uk

National Helpline: 0303 303 2248

Tel: 01869341075

Contact a Family

This is a UK- wide charity providing support, advice and information for families with disabled children. They can also help you get in touch with other parents of disabled children living near you and/or who have a child with the same diagnosis.

Web: www.cafamily.org.uk
www.makingcontact.org

Helpline: 0808 808 3555

Tel: 020 7608 8700

Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations. CDC is the only national body that brings together the diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice.

Web: www.councilfordisabledchildren.org.uk

Tel: 0207 78436313

Carers Trust

Crossroads and the Princes Royal Trust for Carers have merged to form Carers Trust.

Works with individuals and their families, helping carers make a life outside of caring, providing flexible services to people of all ages and with a range of impairments and health conditions.

Web: www.carers.org

Tel: 0844 800 4361

Dial UK

Dial provides a range of location-specific disability information, run by disabled people. Scope provide support to the network.

Web: www.dialuk.info

GOV.UK (Replaces directgov)

A range of information for parents from finances to education. Provides an A-Z of government departments, public bodies and local councils. A general source of government based information.

Web: www.gov.uk

Equality and Human Rights Commission

The Equality and Human Rights Commission has a statutory remit to promote and monitor human rights; and to protect, enforce and promote equality across the nine "protected" grounds - age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment.

Phone: 0800 444 205

Textphone: 0800 444 206

Web: www.equalityhumanrights.com

Early Years Equality

Provides disability equality and other protected characteristic equality support , guidance, advice, discrimination casework and training to children, young people, young adults, families, organisations, providers and policy makers across the UK.

Tel: 0114 2700214

Email: enquiries@earlyyearesequality.org.uk

Web: www.earlyyearesequality.org.uk

Early Support

Early support aims to enable services to co-ordinate their activity better and provide families with a single point of contact and continuity through key working. It focuses on ensuring that service delivery is child, young person and family centered and that services and practitioners work in partnership with children, young people and their families. Early support provides a range of resources for families.

Web: www.ncb.org.uk/earllysupport

Tel: 0207 843 6350

Family Rights Group

Provides information on free access to legal advice from a solicitor.

Web: www.frg.org.uk

Tel: 0808 801 0366

Headway

Provides support following a brain injury.

Web: www.headway.org.uk

Helpline: 0808 800 2244

Tel: 0115 924 0800

Home-Start

Offers support, friendship and advice to parents carers in situations as diverse as isolation, bereavement, multiple births, illness, impairments or who are just finding parenting a struggle. They provide non- judgmental practical and emotional support and help to build the family's confidence and ability to cope.

Web: www.home-start.org.uk

Tel: 0800 068 6368

Tel: 0166 2587900

Include Me Too

Include Me Too supports disabled children, young people and their families from Black, ethnic minority and other marginalised backgrounds and aims to promote and support all disabled children and young people's rights.

Tel: 019023999888

Web: www.includemetoo.org.uk

Mencap

Offers services and advice to adults and children with a learning difficulty, for example, advice with benefits, housing, employment, leisure and recreational, residential holidays, etc.

Web: www.mencap.org.uk

Helpline: 0808 808 1111

Tel: 0207 454 0454

Mumsnet

Provides opportunities for contacting and talking to other parents about special educational needs.

Web: www.mumsnet.com

NHS Choices Carers Direct

A range of information and support for carers.

Web: www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx

Tel: 0808 802 0202

NHS Direct

A 24- hour advice and health information service, providing confidential information on what to do if you or your family are feeling ill, have particular health conditions, or need local health care services or self- help and support organisations.

Web: www.nhsdirect.nhs.uk

Tel: 0845 4647

Text phone: 0845 606 4647

National Parent Partnership Network

Information and advice for parents of children with additional needs, including special educational needs. Parent Partnership can put you in touch with local organisations.

Web: www.parentpartnership.org.uk

Tel: 0207 843 6058

National Portage Association

Portage is a home-visiting educational service for early years children with additional support needs and their families.

Web: www.portage.org.uk

Tel: 0121 244 1807

Rethink Mental Illness

Mental health charity that provides information and services for young people who are experiencing mental health issues and their families.

Web: www.rethink.org

Tel: 0300 5000 927

Royal College of Psychiatrists

Professional and educational body for psychiatrists.

Web: www.rcpsych.ac.uk

Tel: 020 7235 2351

Scope

The UK's leading disability charity. Their focus is on children and adults with cerebral palsy and people living with other severe and complex impairments.

Web: www.scope.org.uk

Tel: 0808 800 3333

Text: SCOPE plus message to 80039

Scope - Face to Face service

Offers a befriending service to help parents come to terms with their child's diagnosis.

Web: www.scope.org.uk/face2face

Tel: 0844 800 9189

The Children's Trust: Brain injury hub

A new source of information and practical help for families of children with acquired brain injury.

Web: www.braininjuryhub.co.uk

Working Families

Helping working parents and carers achieve work life balance.

Web: www.workingfamilies.org.uk

Helpline: 0300 012 0312

Young Minds

Committed to improving the emotional well being and mental health of children and young people and empowering their parents and carers. Support for anyone worried about the emotional or behaviour problems of a child or adolescent.

Web: www.youngminds.org.uk

Parents helpline: 0808 802 5544

Tel: 020 7336 8446

Childcare

4Children

Provides support for the delivery of childcare in and around schools, and information and support to parents.

Web: www.4children.org.uk

Tel: 0207 512 2112/100

The Pre-school Learning Alliance

An organisation that manages a range of childcare options throughout England.

Web: www.pre-school.org.uk

Tel: 020 7697 2500

Family Information Service

Provides information about the full range of childcare and other services for children, families and young people in your area

Web: www.daycaretrust.org.uk/nafis

Communication

Afasic

A parent-led organisation representing children and young people with speech, language and communication impairments.

Web: www.afasicengland.org.uk

Helpline: 0845 355 5577

Tel: 020 7490 9410

Association of Speech and Language Therapists in Independent Practice (ASLTIP)

Professional body for speech and language therapists who work independently. They provide information on independent speech and language therapy throughout the UK

Web: www.helpwithtalking.com

Tel: 01494 488 306

I CAN

I Can Help is a range of information services that provide help and advice to parents and practitioners about speech, language and communication.

Web: www.ican.org.uk

Tel: 0845 225 4073 or 020 7843 2552

Royal College of Speech and Language Therapists

Professional body of, and for, speech and language therapists (SLTs) in the United Kingdom and Ireland.

Web: www.rcslt.org

Tel: 020 7378 1200

Talking Point

Information and support on children's communication.

Web: www.talkingpoint.org.uk

Tel: 0845 225 4071

The Communication Trust

The Communication Trust is a coalition of about 50 voluntary and community organisations with expertise in speech, language and communication.

Web: www.thecommunicationtrust.org.uk

Tel: 0207 843 2564

The Makaton Charity

Provides access to education, training, resources and public information through the use of symbols and signs with speech.

Web: www.makaton.org

Tel: 01276 606 760

The National Autistic Society

This is a charity for people with autism, including Asperger syndrome, their parents and carers. It provides more information about the TEACCH method in the UK and information on the Early Bird parent training program.

Web: www.autism.org.uk

Helpline: 0845 070 4004

Parent to parent helpline: 0800 9520 520

Tel: 020 7833 2299

Web: www.nas.org.uk/earlybird

Tel: 01226 779218

Education

Bullying UK

Advice and support for anyone being bullied.

Web: www.bullying.co.uk

Helpline: 0808 800 2222

Contact a Family

Special educational needs advice service.

Web: www.cafamily.org.uk/advice-and-support/sen-national-advice-service/

Tel: 0808 808 3555

Department for Education

The Department for Education is responsible for education and children services.

Web: www.education.gov.uk

Family Information Services

Family Information Services (FIS) provide information about the full range of childcare and other services for children, families and young people available in your area. You can contact the FIS through your local authority offices or the National Association of Family Information Services (NAFIS). NAFIS is a charity that supports, links and promotes FIS in the UK.

Web: www.daycaretrust.org.uk/nafis

Independent Parental Special Education Advice (IPSEA)

Advice and support on all aspects of special education, including help with second options on children's educational needs. Also provides information about changes to SEN law.

Web: www.ipsea.org.uk

Helpline: 0800 018 4016

Tribunal support: 0845 6029579

nasen

Promotes the development of children and young people with additional needs and those with special educational needs and supports those who work with them.

Web: www.nasen.org.uk

Tel: 01827 311 500

Network 81

A registered charity and an umbrella organisation of parent support groups who aim to improve education for children with additional needs and those with special educational needs.

Web: www.network81.org

Helpline: 0845 077 4055

Parents for Inclusion

A national charity who work to enable disabled children to learn, make friends and have a voice in ordinary school and throughout life.

Web: www.parentsforinclusion.org/

Tel: 0800 652 3145

Special Educational Needs and Disability Tribunal (SENDIST)/ First-tier Tribunal and Upper Tribunal

SENDIST provides informal help for resolving disputes. It was also an independent body that heard appeals against decisions made by local authorities on SEN assessments and statements. It has now been replaced by a two tier tribunal. Existing judges and non-legal members of the Special Educational Needs and Disability Tribunal have all transferred into the new two-tier system and continue their work in much the same way as they did before.

Web: www.justice.gov.uk/tribunals/send

Transition Information Network (TIN)

Provides information about the transition process into adulthood that is useful to professionals and parents/carers

Web: www.transitioninfonetwork.org.uk/home1.aspx

Equipment

AbilityNet

Offers advice and information on computers, the internet and software for disabled children. They also advise on adjusting and adapting technology.

Web: www.abilitynet.org.uk

Tel: 0800 269545

Minicom: 01926 312847

Action For Kids

Provides mobility aids.

Web: www.actionforkids.org

Helpline: 0845 300 0237

Tel: 020 8347 8111

Minicom: 020 8347 3486

Assist UK

Leaders of a network of locally- situated disability living centres that can advise on equipment needs.

Web: www.assist-uk.org

Tel: 0161 238 8776

Cerebra

Provides grants for all kinds of equipment including computers, trikes, sensory toys and wheelchairs.

Web: www.cerebra.org.uk

Helpline: 0800 328 1159

Disabled Living Foundation

A national charity that provides information and advice on daily living aids.

Web: www.dlf.org.uk

Helpline: 0845 130 9177

Textphone: 020 7432 8009

Switchboard: 0207 289 6111

Do2learn

Do2learn provides thousands of pages of social skills and behavioural regulation activities and guidance, learning songs and games, communication cards, academic material, and transition guides for employment and life skills.

Web: www.do2learn.com

Inclusive Technology

Offers a range of inclusive technology devices such as software, switches and computer access devices, and communication aids.

Web: www.Inclusive.co.uk

Tel: 01457 819 790

Living made easy

Provides a comprehensive database of equipment from a range of companies, with advice and information.

Web: www.livingmadeeasy.org.uk

Tel: 0845 130 9177

Motability

The Motability website contains in-depth advice and information on the Motability scheme.

Web: www.motability.co.uk

Tel: 0845 456 4566

Textphone: 0845 675 0009

The Family Fund

Provides information and grants to families caring for a severely disabled child up to the age of 18. These grants can be used for a range of items, including beds, special baths and computers.

Web: www.familyfund.org.uk

Tel: 08449 744 099

Whizz-kidz

Provides disabled children and young people with mobility equipment not available through the NHS.

Web: www.whizz-kidz.org.uk

Tel: 0207 233 6600

Family relationships

Contact a Family

Provides information and support for families.

Web: www.cafamily.org.uk

Tel: 0808 808 3555

Textphone: 0808 808 3556

Relate

Provides relationship counselling.

Web: www.relate.org.uk

Tel: 0300 100 1234

Relate for Parents & Families

Useful information and advice for parents, or anyone in a family, to help with the most important of relationships - the ones you have with your family.

Web: www.relateforparents.org.uk

Helpline: 0300 100 1234

Sibs

For brothers and sisters of children and young people with additional needs, including special educational needs and chronic illness. Their purpose is to make a positive difference to the lives of siblings to make growing up with someone who has additional needs and who has special educational needs a bit easier.

Web: www.sibs.org.uk

Tel: 01535 645 453

The Couple Connection

A self-help website.

Web: www.thecoupleconnection.net

Finances

Benefit Enquiry Line (BEL)

A confidential telephone service for people with disabilities. General advice is provided on the range of benefits, forms and leaflets that are available.

Web: www.direct.gov.uk/disability-money

Tel: 0800 882 200

Citizens Advice Bureau

Helps people resolve their legal, money and other problems by providing free, confidential and impartial information and advice.

Web: www.citizensadvice.org.uk or www.adviceguide.org.uk

Contact a Family

Have a number of publications, which provide information on the common benefits families of a child with disabilities are entitled to.

Web: www.cafamily.org.uk

Helpline: 0808 808 3555

Text phone: 0808 808 3556

Tel: 020 7608 8700

GOV.UK

Provide information on financial support for carers.

Web: www.gov.uk/browse/benefits

Turn2us

A charitable organisation that helps people access the money available to them, including welfare benefits, grants and other help.

Web: www.turn2us.org.uk

Health

British Association of Occupational Therapists and College of Occupational Therapists

Professional body for occupational therapists and OT staff in the United Kingdom. Offers resources and services to members and information about the profession.

Web: www.cot.co.uk

Tel: 020 7357 6480

Department of Health

The department of health leads public health, the NHS and social care in England.

Web: www.dh.gov.uk

NHS Choices

The online front door to the NHS.

Web: www.nhs.uk

NHS A-Z Conditions and treatments

A-Z of conditions – gives an excellent description of many conditions, symptoms, causes, diagnoses and treatment.

Web: www.nhs.uk/conditions/Pages/hub.aspx

NHS Medicines A-Z

The NHS provide comprehensive information about medicines, including possible known side effects, interactions and dosages.

Web: www.nhs.uk/medicine-guides/pages/default.aspx

NHS Directory of Complementary and Alternative Medicine

Provides information on different therapies as well as a service to find NHS registered therapists in the UK.

Web: www.nhsdirectory.org

National Institute for Health and Clinical Excellence (NICE)

Independent organization responsible for creating guidelines on good health and prevention and treatment of ill health. Provides a national formulary of medicines.

Web: www.nice.org.uk

Tel: 0845 003 7780

Holidays and short breaks

3H Fund (Helping Hands for Holidays)

Helps to organise and fund holidays for children and adults with physical impairments.

Web: www.3hfund.org.uk

Tel: 01892 860207

Break

A charity that provides holidays and respite care for children with additional needs and adults and their families.

Web: www.break-charity.org

Tel: 01263 822 161

Kids

Offers a direct short breaks service for children, young people and families.

Web: www.directshortbreaks.org.uk/?gclid=CJ6jkvPojLMCFcPHtAodYkcA3w

Tel: 0845 453 1000

Scope (residential short breaks)

Provides opportunities for short breaks.

Web: www.scope.org.uk/services/short-breaks-and-leisure

Tel: 0808 800 333

Short Breaks Network

They aim to increase the quality, diversity and availability of short breaks for disabled children and young people. The network can help you to locate a short break service in your area and publishes a directory of family- based, short term care services in the UK.

Web: www.shortbreaksnetwork.org.uk

Tel: 0117 941 5361

The Children's Trust

Provides a range of services including short breaks for children with multiple impairments, complex health needs and acquired brain injury.

Web: www.thechildrenstrust.org.uk

Tel: 01737 365 000

Personal care

Cry-sis

Offers support to parents and carers of excessively crying, sleepless and demanding babies.

Web: www.cry-sis.org.uk

Helpline: 08451 228 669

Education and Resources for Improving Childhood continence (ERIC)

Provides advice, support and information for children and their families on childhood bedwetting, daytime wetting, constipation and soiling.

Web: www.eric.org.uk

Helpline: 0845 370 8008

Tel: 01179603060

PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy)

PINNT is a support group for patients receiving parenteral or enteral nutrition therapy.

Web: www.pinnt.com

Recreation

English Federation of Disabled Sports

Information and advice about sport for disabled people with impairments.

Web: www.efds.co.uk

Tel: 01509 227 750

Get Kids Going

Helping to get disabled children into sport.

Web: www.getkidsgoing.com

Tel: 020 7481 8110

National Children's Bureau (NCB) – Play Matters

The National Association of Toy and Leisure Libraries in England and Northern Ireland merged with the National Children's Bureau and is now known as Play Matters.

Web: www.playmatters.org.uk

Phab

A range of clubs around the UK offering activities such as arts and crafts, games, discos, days out and group holidays.

Web: www.phab.org.uk

Tel: 020 8667 9443

Playwork Partnerships

Play activities for disabled children.

Web: www.playwork.co.uk

Tel: 01242 714 601

Riding for the Disabled Association

Information on horse riding for therapy, achievement and enjoyment.

Web: www.riding-for-disabled.org.uk

Tel: 0845 658 1082

Special Needs Kids

Provides a list of suggestions for days out suitable for children with additional needs, including special educational needs.

Web: www.special-needs-kids.co.uk

Sensory

Sensory Developments

Offer a range of multisensory equipment, as well as the maintenance of sensory equipment.

Web: www.sensorydevelopments.co.uk

Tel: 01284 826012

SensoryPlus

Provides sensory products and advice.

Web: www.sensoryplus.co.uk

Tel: 0800 212709

SpaceKraft

Offers a range of sensory and interactive equipment.

Web: www.spacekraft.co.uk

Tel: 01274 581 007

Special Needs Toys

Offer a range of special needs toys.

Web: www.specialneedstoys.com/uk/

Tel: 01299 827820

The Sensory Company

Offers a vast range of sensory equipment.

Web: www.thesensorycompany.co.uk

Tel: 0845 838 22 33

Single parents

Dads UK

Provide information and support for single dads.

Web: www.dads-uk.co.uk

Tel: 07092 391 489

Gingerbread

A national charity that works to support single parents to improve their lives. Gingerbread has a good list of organisations that can help.

Web: www.gingerbread.org.uk

Helpline: 0808 802 0925

Tel: 020 7428 5400

Sleep

Cerebra Sleep Service

Cerebra has a team of sleep practitioners who can offer help and advice on overcoming sleep problems such as anxiety at night and not being able to get to sleep, bedwetting, nightmares and repetitive movement disorders. Mostly this is done through the post and over the phone but in some cases a sleep counsellor can come out and visit you.

Web: www.cerebra.org.uk

Scope

Provides a one-to-one sleep practitioner service in England, as well as an online/telephone sleep service for families nationwide.

Scope response helpline: 0808 800 33 33

Web: www.scope.org.uk/help-and-information/families-and-parenting/sleep-difficulties-children/sleep/one-one-sleep-practiti

Sleep Scotland

A charity offering support and advice for parents on sleep related issues in children and young people, with additional support needs. It offers a support line, sleep clinics, access to counsellors, etc.

Web: www.sleepscotland.org

Tel: 0131 651 1392

Children's sleep centre, Guy's and St Thomas' Hospital

Specialist assessment, diagnosis and treatment.

Telephone: 0207 1884649

Web: www.guysandstthomas.nhs.uk/our-services/childrens/services/childrens-sleep-centre

Early Support

for children, young people and families

www.ncb.org.uk/earllysupport

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Cerebra
Positively Different

Early Years Equality
removing racism • defying discrimination

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