

# Early Support

Helping every child succeed

## Information for parents

### Neurological disorders



## About this publication

The booklet has been developed with the help of families who have a child with a **neurological** disorder and contains the information that they say it's useful to know. It was developed by the Early Support programme in partnership with **Cerebra**, in response to requests from families, professional agencies and voluntary organisations for better standard information. Families were consulted about the content and the text reflects what parents who have 'been there before' say they would have liked to have known in the early days of finding out about their child's situation.

To find out more about **Early Support** and to download copies of other **Early Support** materials, visit [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport)

Where words are printed in colour and italics, *like this* it means that a parent of a child with a learning disability said it. Where a word or phrase appears in colour, **like this**, it means you can find an explanation of the word in the text that surrounds it, that the contact details for the organisation or agency identified are listed in the Useful contacts section or that you can find out more in the Meeting professionals section.



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# Introduction

## The aim of this booklet

The aim of this booklet is to provide you with information about the many things you may want to know as a parent of a child with a **neurodevelopmental disorder (NDD)**. You might not want to read it all at once – there is a lot of information to take in and it might be worth considering just looking at the particular sections you are most concerned about just now and come back to it over time. Just use it in a way that is most useful to you and your family.

The term **neurodevelopmental disorder (NDD)** is an umbrella term for any condition that is caused by a dysfunction in part of the **brain** or nervous system, resulting in physical and/or psychological symptoms as a child develops.

A huge range of conditions fall under this heading. Some of the most common are **autistic spectrum disorders (ASDs)**, **attention deficit hyperactivity disorder (ADHD)**, **traumatic brain injury**, **brain tumour**, **communication disorders**, and **cerebral palsy**, as well as a vast range of genetic conditions such as **Fragile X syndrome** and **Down syndrome**.

There is a quick reference table at the back of this booklet explaining the causes, symptoms and potential therapies for a range of disorders, with details of support organisations that may be able to offer help and advice. Also, there are three other **Early Support Information for parents booklets** in this series which provide more detail about **Autistic spectrum disorders**, **cerebral palsy** and **Down syndrome**. If your child has been diagnosed with one of these conditions then you might want to read this booklet alongside one of those.

This booklet has been devised with the help of parents of children with an NDD, in order to inform you of:

- the types and causes of [neurodevelopmental disorders](#)
- their diagnosis and treatment
- what you can do to help your child
- the potential therapies available
- information about the issues you may face in daily life
- the management of services
- where you can gain further information and support
- the perspective of families who have a child with a [NDD](#).

A range of support is available to help you understand your child's condition and what it means for the future. Support can come from friends and family, statutory services provided by the government, and many voluntary organisations. This booklet is designed to help you make contact with, and have a record of, all the sources of support that are available for your family at different stages of your lives.

Most sections of this booklet have details about organisations that can provide you with further information and support. There is a website and telephone number given for each organisation. If you do not have access to the internet, you should be able to gain access from your local library or a local internet cafe. You may also ask a professional you are in contact with to print any information you require.

If you would like any further information about [neurodevelopmental disorders](#), or want more information about the contents of this booklet, please contact [Cerebra](#). The contact details are provided at the end of this booklet.



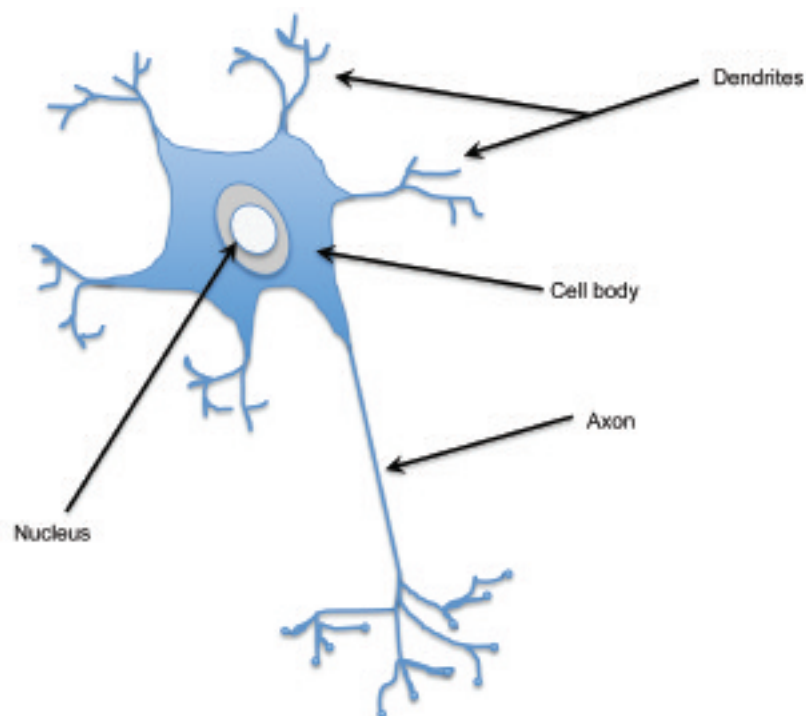
# Symptoms of Neurodevelopmental Disorders

## How does the human brain develop?

The development of the human **brain** is a complex process beginning during pregnancy and continuing through infancy, childhood and adolescence. Most brain cells (up to 100 billion) are formed before birth. However, the trillions of connections between the nerve cells (**neurons**) are not developed until infancy.

The **brain** is made up of both **grey matter** (**neurons** and immediate connections, i.e. **cells** and **dendrites**) and white matter (fibres that connect the various regions of the brain, i.e. **axons**). The structure of a **neuron**, showing the cell body, dendrites and axon is shown below:

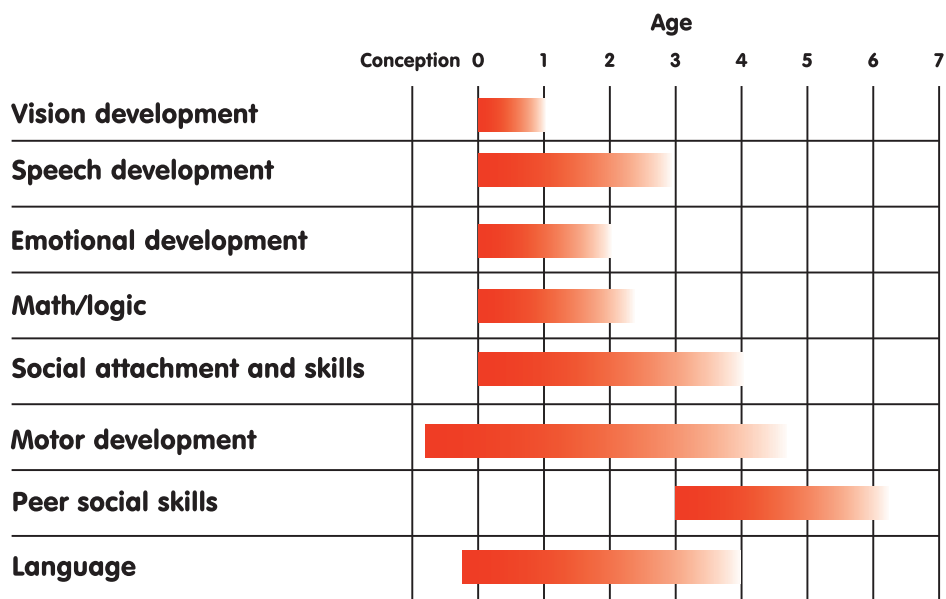
**Diagram showing the basic structure of a neuron**



The **brain** is a self-organising system and actually selects information to forward its growth and development. The brain also adapts to work within its environment. Children's brains are highly influenced by their environment, and the connections in the brain develop through their experiences. This is mainly achieved through the child's five senses: touch, smell, sight, taste and hearing.

Table 1 shows the range of brain developmental stages expected in a healthy child

**Table 1: Stages of brain development in an infant**



(taken from <http://factoidz.com/how-to-nurture-the-brain-development-of-your-child>, accessed March 2010)





## What are neurodevelopmental disorders?

All **NDDs** result from damage to the nervous system. Any neurodevelopmental symptoms are dependent on where the damage occurs, but may affect areas that control movement, communication, vision, hearing or thinking and information processing (see Table 1).

NDDs are a very wide-ranging group of disorders. They have many and various causes, complications and **prognoses**. 'Prognosis' is a medical term that means the expected or predicted outcome of an illness or a disorder.

The majority of NDDs begin to emerge during the early years of a child's life and severe developmental disorders often require ongoing care from family members and specialised professionals. The disorder may be diagnosed at birth (e.g. **Down syndrome**) or might not become apparent until later in life. NDDs emerging later might become apparent:

- When the child misses developmental milestones and has difficulties with day-to-day activities – for example, this can happen when the child has **ADHD** or an **ASD**.
- Following an infection or disease, such as meningitis
- After an accident that causes brain injury.

## What is the range of symptoms amongst the NDDs?

**NDDs** involve a variety of symptoms. Children with NDDs often have a variety of physical, cognitive (to do with thinking and processing information), emotional and behavioural strengths and difficulties.

Many children will have more than one clinical diagnosis and children's symptoms don't always follow the textbook description of the disorder. Each child is unique, with their individual strengths and weaknesses, rehabilitation, recovery and outcomes.

The broad ranges of symptoms that can be present in a child diagnosed with an NDD are outlined below. Please note:

- Individual conditions have particular clusters of these symptoms
- Some conditions are more physical in nature (e.g. [cerebral palsy](#))
- Some conditions have more effect on behaviour (e.g. [ADHD](#)).

### Physical effects

These may include:

- Communication problems
- Mobility problems - difficulties in moving around
- Psychomotor deficits - problems carrying out tasks that involve combining perception, thinking and movement, such as a young child's ability to turn over, sit, control bladder and bowel functions
- Fatigue – creating difficulties for the child in doing everyday tasks because they are too tired
- Sensory impairment – difficulties with sight and/or hearing
- [Epilepsy](#)
- [Spasticity](#) – causing stiff or rigid muscles which can interfere with movement and sometimes speech
- Weakness or paralysis
- [Ataxia](#) - co-ordination and balance problems
- Tics – sudden, repetitive movements or sounds.

### Cognitive effects

These may include:

- Intellectual disability - leading to difficulties in learning and thinking
- Memory problems
- Motivation problems
- Reduced concentration
- Reduced speed of information processing
- Reduced problem solving ability
- Impaired reasoning and judgement
- Lack of insight
- Impairments in visual perceptual skills, where visual images can be seen but not interpreted correctly.



## Emotional and behavioural effects

These may appear as:-

- Loss of confidence
- Mood swings
- Depression
- Anxiety
- Frustration and anger
- **Disinhibition** - lack of restraint - or impulsiveness, where a child might do things without thinking them through first
- Obsessive behaviour
- Repetitive behaviours
- Hyperactivity
- Aggression
- Anti-social behaviour
- Difficulties with social interaction
- Self-injury.

# What causes NDDs?

NDDs can be present at birth (**congenital**) or can develop after birth (**acquired**), for a variety of reasons. Sometimes the cause of the disorder is unknown.

## Congenital causes of NDDs

**Congenital** (present at birth) does not necessarily mean caused by a genetic defect. The causes can be due to a variety of reasons, as outlined below:

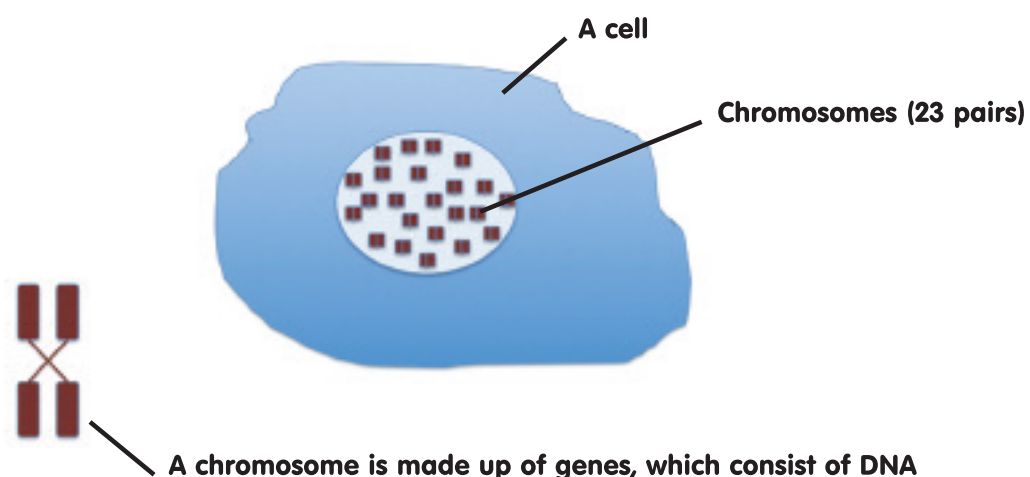
### Genetic

There's lots of evidence to suggest that genetic factors can influence the development of a variety of NDDs, for example **ADHD**, **Tourette's syndrome**, **ASD** and **dyslexia**. These conditions can be passed from one generation to the next. A family history of a particular disorder indicates an increased risk of its development in future generations.

### Chromosomal abnormalities

**Chromosomes** are found in the centre (nucleus) of the cells (see diagram below) that make up our bodies and are long strands of **DNA**. The role of DNA is to hold the genes that make us who we are; DNA is the 'building block' of the body. The human body has 46 chromosomes (23 pairs), half inherited from the mother and half from the father. Every chromosome in our bodies has a precise pattern of bands that is the same in all human beings. Any difference from this 'normal' pattern, in terms of the number of chromosomes or structure, represents a chromosome abnormality.

### Diagram showing chromosomes





- **Number:** abnormalities to do with the number of chromosomes are the most severe. The term **monosomy** means the individual has lost one chromosome in a pair (eg. Turner's syndrome). The term **trisomy** means the individual has gained an extra chromosome (eg. **Down syndrome**).
- **Structure:** abnormalities to do with structure are where fragments (varying amounts) of the chromosome are different from the 'normal' chromosome structure. These differences are called **microdeletions** (genes lost), or **microduplications** (genes gained). Some common forms are **Cri-du-chat syndrome**, **Prader-Willis/Angelman's syndrome** and **Di-George syndrome**.

### Metabolic Disorders

'**Metabolism**' is the term given to the many chemical processes that occur in the body. These processes can go wrong in a variety of ways. Most metabolic disorders are identified from a blood or urine sample. It is important that the disorder is spotted as soon as possible so its effects can be managed (via diet or the replacement of hormones or missing chemicals) to reduce the likelihood of any lasting damage.

**Phenylketonuria (PKU)** is an example of an inherited metabolic disorder that increases the level of a substance called phenylalanine in the body. If this disorder is not treated it can cause intellectual disability in the individual. Neurodevelopmental damage can also arise from too high or too low glucose levels caused by diabetes, if the condition is not well controlled. The frequency of these problems is associated with the severity of the diabetes.

### Structural disorders/congenital malformation/birth defects

**Congenital** malformation/birth defects are caused by **brain** cells not working as they should, leading to abnormalities of the brain and sometimes other body parts. These are believed to be the result of a complex interaction between **genes**, environment and behaviours. An example is **tuberous sclerosis**, where children have growths in different organs of the body (brain, heart, eyes, skin, kidneys, lungs) and may have **epilepsy**, learning difficulties, **ASD** and kidney problems.

## Immune disorders

Immune disorders/reactions in the mother and developing baby can lead to NDDs. One such immune disorder is the **Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infection (PANDAS)**. This can cause emotional problems, abnormal body movements, **obsessive compulsive disorder (OCD)** and tic disorders including **Tourette's syndrome**. These symptoms come on suddenly or worsen following an infection such as scarlet fever. What causes this is not known, but experts believe that an area of the brain thought to be involved in movement and behaviour is affected by **PANDAS**.

## Pre/perinatal (before birth/around the time of birth)

There are a range of **pre/perinatal** causes of NDDs, including:

- Toxins and environmental factors (teratogens) - the brain and nervous system develop in a highly complex way. We come into contact with thousands of chemicals during our lifetime and at least ten of these are highly toxic and pose a great neurological risk. **Toxins** can enter a child's developing system through the placenta during fetal development, or after they are born. If a child has been exposed to such environmental toxins, there is a higher risk that they may develop intellectual and behavioural problems. Effects of some of the toxins are:
  - **Alcohol** - because their nervous system is still developing, babies may be more susceptible to damage from alcohol than adults. For example, a pregnant woman who drinks alcohol excessively may suffer a hangover, whilst the developing child inside her may suffer irreversible brain damage. Brain damage caused in this way is known as **fetal alcohol syndrome**.
  - **Lead** - this is a known neurotoxin, and there are no safe levels for children. Lead contamination leads to problems with intelligence, learning and memory and has been linked to **ADHD**, even at really low levels.
  - **Mercury** - this also causes learning and developmental disorders, however, there is much controversy surrounding the amount of mercury that is considered toxic. There is mercury in our environment - eg. in coal, in amalgam fillings in our teeth, and a form of mercury named methyl-mercury can accumulate in the flesh of fish and can then be eaten by humans. Many countries advise on safe levels of fish consumption, especially for women and children.
  - **Polychlorinated biphenyls (PCBs)** - these compounds were previously used in cooling and insulating fluids in a range of electrical devices such as fridges. PCB use has been banned since 1970, but they are still present in the environment. It has been well documented that exposure can lead to deficits in motor skills, learning and memory.



- **Tobacco** - smoking during pregnancy and environmental tobacco smoke (passive smoking) have been linked to behavioural disorders and developmental delay.
- **Food additives** – we can be exposed to many artificial food colourings and additives in our diet and these are suspected of causing behaviour related problems. For example, food additives and colourings can cause a greater rate of **ADHD** in young children.
- **Nutritional deficiencies** - There are certain chemicals we need to live and grow – these are **nutrients**. If we don't get enough **nutrients** we are considered to have nutritional deficiencies, which can cause a number of problems. Nutritional deficiencies during the last three months of pregnancy and the first few months of life can have effects on the brain, with a decrease in the number of brain cells and a lower brain weight. Most nutrients are easy to get if you have a varied and balanced diet. Some nutrients need to be taken as supplements – for example, women are encouraged to take folic acid (a B vitamin) before conception and during the early stage of pregnancy, to reduce the likelihood of the development of a **neural tube defect (NTD)**. **NTDs** are defects of the brain and spine, such as spina bifida, 'open spine', and less commonly, anencephaly (fatally underdeveloped brain and skull).
- **Infections** - Toxoplasmosis, **Other** infections (hepatitis B, syphilis, Varicella-Zoster virus, HIV and Parvovirus B19), **Rubella**, **Cytomegalovirus**, and **Herpes simplex virus** are known as **TORCH** infections (because of their initial letters). **TORCH** infections can be passed from mother to baby during pregnancy. These infections can cause developmental abnormalities in the unborn child, or miscarriage. Sexually transmitted infections can also be dangerous and infections that only occur in pregnancy (eg. chorioamnionitis) can cause disorders such as **cerebral palsy**.
- **Hypoxia/asphyxia** - Perinatal asphyxia is a common cause of newborn neurological injury and can progress into **hypoxic-ischemic encephalopathy (HIE)**. **HIE** occurs in around 6/1000 births, however, the rate is much higher in premature babies. Many infants who develop **hypoxic ischaemia** (insufficient blood flow causing reduced blood oxygen content) do not develop **HIE** because lasting injury is determined by the severity and length of the asphyxia. The effects of severe **HIE** can include **cerebral palsy**, intellectual disability and

**epilepsy**, but if therapies such as mild hypothermia (cooling) are used within one to three days then the effects might not be so severe.

- **Complications during childbirth** (birth injury/**trauma**) - During labour, the baby may suffer a physical injury or trauma that is due to the stress of being born and the complications that can sometimes arise. This can happen for a number of reasons.
- **Prematurity/low birth weight** - Low birth weight (LBW) is thought to be a potential risk factor for the later development of a range of problems. This is because it may indicate growth problems in the womb and has been associated with risk factors prior to birth, complications during childbirth, and newborns' diseases. There is a greater likelihood of developing cognitive difficulties including speech and language problems, problems with attention, social difficulties, hyperactivity and learning disabilities.
- **Interaction effects** - A range of factors including heredity (inheriting **genes** from parents), gene expression (how the gene reacts to life circumstances), environment, infectious disease, poor nutrition, stress, and drug and chemical exposure can contribute to the development of a range of **NDDs** in complex ways. For example, there are genetic risk factors that can influence the likelihood of a child having **ADHD** and that affect its developmental course. However, it is believed that there are additional factors (genetic and environmental) that do not necessarily influence the origins of ADHD, but affect the course and **prognosis**. A range of environmental factors have been associated with **ADHD**, including smoking during pregnancy, low birth weight, and prematurity. These factors can interact with a genetic predisposition, where the genes affect the person's sensitivity to, or response to, environmental factors. The importance of gene-environment interaction has only recently been realised and there is still a long way to go in understanding these complex interactions for a range of disorder development, course and outcomes.





## Sensory issues

The senses include things we take for granted such as touch, movement, body position, hearing, vision, taste and smell. We describe the brain's processing of this information as sensory integration. Sensory integration is very important for the development of learning and behaviour. A problem with the integration of sensory information is named sensory processing disorder (SPD) or dysfunction in sensory integration (DSI), and can be characterised by problems in learning, behaviour and motor skills.

Sensory integration problems are common in children with a variety of neurodevelopmental conditions such as [autism](#), [ADHD](#), [Fragile X syndrome](#), and [Down syndrome](#), amongst others.

*'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 symptoms include:

- Being particularly sensitive to touch, sounds, movements, tastes and smells
- Dislike of particular clothing fabrics, waistbands etc
- Avoiding a variety of foods
- Limited body awareness
- Poor development of personal care skills
- Poor attention and concentration
- Dislike of social settings
- Level of activity being particularly high or low
- 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 more angry about it. He would even do this on the way to school on the pavement'.*

## What should you do if you suspect your child is suffering from a sensory dysfunction?

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

## Acquired causes of NDDs

These are less common than congenital causes of NDDs.

### Postnatal infections

- **Encephalitis** (inflammation of the brain) usually shows as flu-like symptoms, but over hours or days more severe symptoms follow, including a temperature, nausea, mental state changes, drowsiness, **seizures**, problems with speech, movement difficulties, stiffness in the neck and generally unusual behaviour. Many types of infection (usually viral) can cause encephalitis. The majority of people have some protection from viral infections from their blood-brain barrier, which protects the brain from infections carried in the blood. Encephalitis occurs in individuals who have an inadequate blood-brain barrier. Around two out of three people may develop some neurological long-term consequences following encephalitis, including memory problems, behavioural changes, speech problems, and **epilepsy**.
- **Meningitis** is caused by an infection that inflames the **meninges** (protective membranes that surround the brain and spinal cord). The inflammation and swelling that takes place can damage the brain and nerves. There are two types of infection that can cause meningitis - a bacterial infection or a viral infection. Thankfully, vaccination programmes have been very successful in reducing the number of bacteria and **viruses** that can cause meningitis (e.g. the measles, mumps and rubella vaccination (MMR) provides protection against mumps, a previously common cause of meningitis). The blood-brain barrier in some individuals does not manage to keep the infection from entering the brain **meninges** (membrane) and **cerebro-spinal fluid (CSF)** that protects the spinal cord. The infection causes the **meninges** to swell and the **CSF** to cause greater pressure within the brain. Complications are more likely following bacterial meningitis (15-25% people), compared with viral meningitis (very rare). Potentially lasting symptoms following meningitis can include hearing problems, memory and concentration difficulties, co-ordination and balance problems, learning difficulties (temporary or lasting), **epilepsy**, **cerebral palsy**, speech problems, and also some, or complete loss of vision.



## Postnatal trauma

**Traumatic brain injury (TBI)** occurs when an individual receives a sudden trauma to the head that results in damage to the brain. In incidents that involve the head hitting an object with force, or when the skull is pierced with an object that enters the brain, the likelihood of obtaining a significant TBI is high. There are three main types of TBI including:

- Closed head injuries – where no damage is visible. Common in car accidents where the brain hits the skull with force during impact.
- Open wounds – in which the brain is exposed and damaged by an object.
- Crushing injuries – where the head is crushed and brain damage occurs.

The disabilities that may result from a TBI can range depending on the severity of the injury, the location of the injury, and the age and health of the person can also have an impact. There is evidence to suggest that children's brains are more susceptible to lasting damage from TBI. Because children are still developing, injury at an early age may have an impact on the full development of the range of skills expected, due to a disruption of the **nervous system** during this crucial time.

## Neoplasm

**Neoplasm** is an abnormal mass of tissue – a tumour. Every year around 350 children are diagnosed with a tumour of the brain or spinal cord. Tumours can be benign (non-cancerous) or malignant (cancerous). Malignant tumours are the most dangerous, so early diagnosis is very important. Benign tumours seem to grow more slowly, but can have neurological consequences as they increase pressure on other parts of the brain, damaging healthy tissue. The symptoms of a tumour are dependent on where the tumour arises but can include **seizures**, limb weakness, difficulty walking, speech and swallowing difficulties, strange sensations, learning or behavioural difficulties, vision and hearing problems.

## Toxins

As discussed previously, exposure to environmental chemicals and toxins can lead to neurological impairment during childhood.

# Issues around diagnosis

## What to expect

The process to enable you to get a diagnosis for your child's condition is not always an easy one. It throws up lots of questions that can't always be answered easily. Some NDDs are 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](#)).

Even if you do receive a diagnosis at birth, it is not always possible for professionals to know exactly how the disorder may develop. To find out what the outcomes will be you may have to wait for developmental milestones such as speaking, walking etc to be achieved or not achieved.

Following a diagnosis, it can still be difficult to foresee how the diagnosis will affect your child in the future (from adolescence into adulthood). However, doing as much as possible as early as possible is vitally important in working towards the best outcome.

*'Our son got a diagnosis of a rare chromosome disorder when he was 6 months old. The neurologist who gave us the results couldn't explain any more about the diagnosis which was very frustrating, we were just told he might not walk. The charity Unique were a marvellous source of information and support'.*

## Meeting professionals

There are a range of professionals that you may come into contact with to help your child and family. You may often find yourself having to repeatedly state your child's problems and history to professional after professional. You are the expert on your child and professionals will need all of the information you can give them. There may be a range of professionals involved in the process of your child's diagnosis, treatment and management, all of whom will have different information to offer you. This can be overwhelming at times.

The [Early Support Family file](#) may be helpful if your child is receiving a number of different support services. It is designed to provide a simple way of sharing information with others about what is happening, including family, friends and particularly the range of people involved in the care of your child. It can save you having to repeat the same information time and time again. The [Family file](#) is also useful to help you make sense of what is happening, help you keep track of the professionals you have been in contact with, what they have said and what the next steps may be. Professionals should always explain what they are doing and why, and it is a good idea to ask for copies of reports and assessments for your records. You



can get more information and a copy of the [Early Support Family file](#) from the [Early Support](#) website – [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport)

The following list describes the role of the many health professionals you may come into contact with. You can find further information about other professionals in the [Early Support Background information booklet: People you may meet](#) (ref ES20):

### Audiologist

An audiologist carries out hearing tests and explains the results of those tests. If your child needs hearing aids they will identify the best type and arrange for you to get them. They also monitor your child's hearing, to make sure that any hearing aids supplied are appropriate. An audiologist usually refers you to a doctor who works with deaf children. Depending on where you live, this doctor can be called an audiological physician, a community [paediatrician](#) in audiology, or an ear, nose and throat (ENT) surgeon.

### Consultant

A consultant is the most qualified and experienced member of the medical team. In complex cases, a number of consultants may be involved in the care of your child.

### Child and Adolescent Psychiatrist

A medical doctor that specialises in dealing with problems in the way your child thinks, feels and behaves. They are responsible for the prescription of medication and can refer your child on to a [clinical psychologist](#).

### Clinical Psychologist

A clinical psychologist helps people with a range of difficulties – they can help children with specific problems with learning or with overcoming behaviour difficulties.

### Clinical Neuropsychologist

A neuropsychologist specialises in brain functioning and has in-depth knowledge of how behaviour and skills relate to the brain. A neuropsychologist may undertake an assessment with your child, identifying their strengths and weaknesses.

## Dietician

A dietician is a health professional who gives advice about nutrition and swallowing or feeding difficulties. Sometimes children need **nasogastric** or **gastrostomy** feeding to receive the nutrition they need. This means liquid feed is given through a tube that is inserted directly through the abdominal wall or through a narrow tube that is passed through the nose, down the food pipe and into the stomach. A dietician makes a full nutritional assessment before feeding begins in this way. They can advise you, the hospital and community health staff about the feed type, the amount, the method of administration, the feeding regimen and any equipment required for your child. Dietitians are often responsible for ordering supplies and equipment and will make sure you have a regular supply of the things you need to feed your child.

## Educational Psychologist (E/P)

Educational psychologists tackle the problems encountered by children and young people in education, which may involve learning difficulties and social or emotional problems. They carry out a wide range of tasks with the aim of enhancing children's learning and enabling teachers to become more aware of the social factors affecting teaching and learning.

## General practitioner (GP)

A GP is a family doctor who works in the community. They may be your first point of contact if you are at all worried about your child's development. They deal with your child's general health and can refer you on to clinics, hospitals and **specialists** when needed. They may also support welfare benefit applications and/or other types of help.

## Geneticist

Geneticists are medical doctors who specialise in genetics. They can provide information about the genetic aspects of a condition, the likelihood of a genetic condition occurring in a family, and can advise on the medical management of a particular genetic condition.

## Health Visitor

A health visitor is a qualified nurse or midwife with additional special training and experience in child health. They visit family homes in the early years to check on children's health and development. They give help, advice and practical assistance to families about the care of very young children, normal child development, sleep patterns, feeding, behaviour and safety. You should automatically receive a visit from a health visitor, as all families are visited in the early years. If you don't, they can be contacted through your **GP**. Health visitors can help you contact doctors, hospitals and other services in your area. Some areas have specialist health visitors who have particular experience and expertise supporting families with very young children with an identified condition or disability or who need extra help.



### Key worker

Key workers provide disabled children and young people and their families with a system whereby services from different agencies are co-ordinated. A key worker is a source of support – they will maintain regular contact with your family and take responsibility for checking that you have all the information you need, that services are well-coordinated and that information about your child is shared efficiently with everyone who is working with your family. Key worker services are not available in all areas.

### Learning support assistant (LSA)

A learning support or teaching assistant is someone who works in early years settings alongside teachers, supporting individual children or small groups to help them learn effectively, participate and fulfil their potential.

### Occupational Therapist (OT)

An occupational therapist (OT) helps children improve their developmental function by therapeutic techniques, environmental adaptations and the use of specialist equipment. OTs are concerned with difficulties that children have in carrying out the activities of everyday life. This could include sitting in a chair, holding a spoon and fork or drinking from a cup. They can also advise on how you as a parent can carry your child up and down stairs safely. OTs work for both the health service and social services. Paediatric OTs working for the health service assess children for things like specialist chairs or cups. Social services OTs pay for the equipment. You may also come across health service OTs once your child starts nursery or school (see Therapies section for more information).

### Paediatrician

A paediatrician is a doctor who specialises in working with babies and children. They are often the first point of contact for families who find out their child has an impairment or disability very early on in hospital and can offer advice, information and support about any medical condition(s) a child has. Paediatricians sometimes work in hospitals and sometimes within community health. It's usually a paediatrician who refers your child on to any other [specialists](#) that they need to see.

## Physiotherapist

A physiotherapist is a health professional specialising in physical and motor development. They are concerned with maximising children's potential. This means they will assess your child and develop a plan that might include helping your child control their head movement, sit, roll over, crawl or walk. Physiotherapists can also teach you how to handle your child at home for feeding, bathing and dressing, and advise on equipment that might help your child's mobility. A physiotherapist may see your child at home, or in other settings such as a nursery placement or child development centre (CDC). They work closely with families, with other healthcare professionals and anyone else involved in caring for children. Some families meet a physiotherapist for the first time very early on, when their child is in a Special Care Baby Unit or on a hospital ward (see Therapies section for more information).

## Social worker

A social worker is a professional who supports children and families by advising on appropriate services and introducing families to some of the services they need. They are normally employed by a local authority. Social workers provide practical help and advice about counselling, transport, home helps, and other services. They may also be able to help you with claiming welfare benefits or obtaining equipment you need at home. They help families to access other services, such as family sign language classes, parents' groups or play schemes. In some areas, social care services have specialist social workers who have particular knowledge and experience of working with people who have learning disabilities, blind or deaf people. In other areas, social workers work within teams supporting a range of disabled children.

## Special educational needs co-ordinator (SENCO)

A SENCO is a teacher in a school or early years setting who has responsibility for identifying children with special educational needs and making sure they receive appropriate support. This may involve working directly with the child, supporting mainstream staff in assessing a child's needs or a combination of both of these. SENCOs also work with external support services at [Early Years Action](#) or [Early Years Action Plus](#).

## Specialists

[Paediatricians](#) often specialise in particular areas, for example, a paediatric neurologist treats neurological symptoms in children under 18, the [paediatric neurologist](#) may then specialise in a particular condition, for example, epilepsy or another neurodevelopmental condition.





## Speech and Language Therapist (SALT)

A speech and language therapist specialises in speech, language and communication problems. They assess, diagnose and develop programmes of care to help children develop communication skills. They offer support and advice to parents and to other professionals about developing communication that may be verbal (i.e. using speech) or non-verbal, using signs, symbols or communication aids. Some speech and language therapists also specialise in feeding, eating or swallowing disorders. There are many causes of speech and language difficulties. Some speech and language therapists specialise in working with particular populations of children - for example, deaf children or children with cleft lip and palate. They work with children of all ages. Speech and language therapists work as members of teams in many different settings including health clinics, hospitals, nurseries, Sure Start Children's Centres and schools. They work closely with families, medical and health staff, teachers and social workers, depending on children's needs and circumstances (see Therapies section for more information).

## What to do if you are worried about the neurodevelopmental health of your child.

If you are at all concerned about the health of your child, you should seek medical advice as soon as possible. This will usually mean a visit to your [GP](#). However, if any change occurs very quickly (e.g. suspected meningitis or a head injury) you may want to go straight to the accident and emergency department at the hospital for immediate treatment. For some neurodevelopmental conditions, you will be referred on to a [specialist](#). You should see a specialist within two to three months. The government states that the maximum waiting time to see a specialist is 13 weeks. Often an initial diagnosis will be given and then a confirmed diagnosis will follow once all specific test procedures have been completed.

## Why a diagnosis is important.

It is important to get a diagnosis so that you and the professionals helping you can begin to understand why your child's symptoms are occurring and identify their specific needs. By pinpointing your child's condition, professionals are much more able to design effective treatment strategies to help manage any symptoms. By fully realising what is at the root of any symptoms, the access to support services can be much easier.

*'Some health specialists may be reluctant and say – we don't like to label children – well we don't like to label them as parents either, but we have to. Getting that label is the first step to getting some help and you want to know what it is you are dealing with – you just want to know'.*

## Difficulty getting a diagnosis.

In some cases, it can be a very complex process for **paediatricians** to identify a cause for a condition. This is because some children have a variety of symptoms that make it difficult to pin it down confidently to one condition. Also, a number of conditions have similar symptoms and some children have a large range of problems that make accurate diagnosis difficult.

Individual children experience conditions differently. Some features of a specific condition may not become apparent until your child gets older and develops further. This can lead to a late diagnosis, or even a change in diagnosis.

Also health professionals are not with your child all the time, and have a small window of time to make an assessment of their condition. Remember that you are with your child more than anyone else and know them better than anyone else does. If there are things that worry you about your child, try to make sure that you describe your worries in as much detail and as accurately as you can – that will help the professionals working with you.

It may be someone quite unexpected that notices there is a problem that needs attention.

*'Our GP didn't pick up autism, my child wasn't going through the stages and it was his nursery nurse who referred for diagnosis.'*



## What to do if you can't get a diagnosis.

It is possible that it may take a long time to get a diagnosis or that your child may never get a diagnosis, despite having symptoms. Your child may have a condition there is still little known about and in such circumstances, a diagnosis may not be possible at all. However, this does not mean there are no treatment options for your child. There are still many options for the treatment of specific symptoms, with or without a diagnosis, and a range of services, information and advice is available.

'I was told to get on with it and learn through my child (he has a rare condition there is not much known)... I now help other families come to terms with a similar diagnosis'.

Ask your [GP](#) and local social services department what services are available for your child and your particular situation. There are two other booklets in this series that might help – the [Early Support Information for parents booklets: If your child has a rare condition](#) (ref. ES18) and [When your child has no diagnosis](#) (ref. ES16).

## Diagnostic techniques

Depending on your child's suspected condition, you may be referred for a range of assessments to identify what is causing any symptoms.

Some children with a suspected **NDD** may need a neurological assessment, neuropsychological assessment, or brain scan. Not all children with NDDs will need further assessment, apart from traditional assessments at an educational level. However, some conditions do require a specialist to investigate.

New technologies allow non-invasive brain mapping and observation of brain processes during set tasks. By sequencing scanned sections of the brain, the activity between **neurons** in different parts of the **brain** can be observed and monitored. These techniques are expensive and are only used for the diagnosis of conditions affecting the central nervous system. Some common forms of brain scanning techniques are:

- **Computerised tomography (C/T)** – this uses X rays to show the structure of the brain, giving a 3D image which can reveal underdeveloped parts of the brain or sites of injury from impact, tumours, lesions or infections.
- **Magnetic Resonance Imaging (MRI)** – this uses a strong magnetic field and radio waves to create pictures of the tissues and other structures inside the brain on a computer. It can give a clear, detailed pictures of the structure of the brain and can detect any abnormalities or tumours. The process of having a MRI scan is painless and safe, and there is no exposure to radiation. The scan can take from 15-40 minutes.
- **Functional magnetic resonance imaging (fMRI)** – this can show which part of the brain is active or functioning, in response to the patient performing a given task, by recording the movement of blood flow. It is painless and harmless.
- **Diffusion tensor imaging (DTI)** – this is used so that functions in the brain can be observed as they occur. It can detect tumours, which would not show up on any other MRI scan. DTI can also be used to study the way in which information is processed to control muscles and development during childhood. This procedure is painless and harmless, but involves remaining still for half an hour whilst the images are processed. It's a new technique and there are few scanners in the UK at present.
- **Positron Emission Tomography (PET)** – this produces a 3D image of functional processes in the brain (not just the structure). It requires the patient to receive a small injection of radio-active material, into their bloodstream. A patient may only have one PET scan, due to the radiation dosage regulations. PET has proved to be particularly useful in monitoring visual problems, tumours and metabolic processes.



- **Single Photon Emission Computerised Tomography (SPECT)** – this produces a scan that is slightly less clear than a PET image. It allows assessment of brain functions. The patient will have to remain absolutely still for 15 to 20 minutes in a scanner. A tracer will be injected via a catheter in the arm. The amount of radiation the patient will be exposed to is very small, the procedure is painless and the patient may resume normal activities immediately afterwards.

### Other assessments of physical changes.

Some additional measures to investigate any physical changes include:-

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

## Clinical assessments (cognitive/emotional abnormalities)

- **Neurological evaluation** - A neurological evaluation is undertaken when meningitis or **encephalitis** is suspected, also in cases of potential seizures, sudden motor clumsiness, motor weakness and head trauma. It involves an:
  - in-depth review of medical and developmental history
  - assessment of mental status
  - assessment of capacity of the **Central Nervous System (CNS)**
  - investigation of motor systems
  - assessment of sensory functions
  - assessment of autonomic functions – these are involuntary vital functions such as heart, digestive and glandular functioning.
- **Neuropsychological assessment** - Neuropsychological tests are used to assess the brain-behaviour relationship to identify whether cognitive, academic and psychiatric disorders are a result of abnormal functioning of the brain. Neuropsychological evaluations can be used to diagnose a range of **NDDs** including learning disabilities, brain injuries, and **CNS** diseases. They can also be used to measure the effectiveness of any intervention and to monitor rehabilitation. Neuropsychological assessments may look into a range of functions, including your child's **cognitive ability** (intellectual functioning), academic functioning, executive functioning (organisational ability, flexibility of thinking, working memory etc), attention, language, memory, visual perception, visual motor functioning, motor functioning, and behaviour.
- **Assessments specific to disorders** – such as:
  - **ASD** – A range of standardised measures are often used in the diagnosis of ASD including the Childhood Autism Rating Scale (CARS), the Autism Diagnostic Observation System (ADOS) and the Autism Diagnostic Interview - revised (ADI-R).
  - **ADHD** – The techniques used in the diagnosis of ADHD include a range of behavioural techniques and approaches, such as interviews with the child's parents and teachers, behaviour rating scales, and observational techniques.



## Once you have a diagnosis

There will be a huge range of information you might want once your child has been diagnosed. Some common types of information that you may need include:

- General information about the condition
- A description of potential symptoms
- Information on the management of any symptoms
- Safety information
- Details of treatment options and any risks of treatment
- Information on the expected course of the condition (if possible)
- Information for the rest of the family (to help them understand and come to terms with the diagnosis).

*'You can be confident that what you feel is daunting now, you will actually look back on and find you can deal with easily. There are always going to be challenges, but you will be amazed at the level of expertise you will gain'.*

## Getting accurate information about your child's diagnosis

Be careful about sources of information taken from the internet. It is important to bear in mind that anyone can set up a website and the information they display is not always accurate and up-to-date. Some tips are outlined below to help you ensure you get good quality information when accessing sources on the internet:

- University sites, government sites and hospital sites will usually have up-to-date and accurate information. (e.g. [National Institute of Clinical Excellence \(NICE\)](#), [NHS Choices](#) and the [Royal College of Psychiatry](#)).
- Sources of information should give details of the author and the date the information was written. Check the qualifications of the author.
- Check any medical information taken from the internet with a qualified professional.
- It is important to realise that information from other countries (e.g. America) may not be applicable in the UK.





## Tips when meeting your child's paediatrician or health professional.

1. Don't be afraid to ask questions, find out as much as you can about the needs of your child.
2. Write down some potential questions you may want to ask your paediatrician before you attend. This may prevent you from forgetting something important. You can use the [Early Support Family file](#) for this.
3. Take another family member with you for support.
4. Take some time to digest the information given to you.
5. Ask if there is any written information about the diagnosis (including medical details) that you can take with you and read when you get home.
6. Arrange another meeting with the paediatrician or health professional. This will give you an opportunity to ask some further questions once you have had time to digest the information. You can use your [Early Support Family file](#) to record details about this.
7. Ask the professional to explain any information provided to another family member so you can discuss it further at home.
8. You may have many questions about how the diagnosis is going to affect your child and day-to-day life. Your specialist should be able to give you information on other services that can help.

*'I was shocked at the time and couldn't take in all the information. Parents need further information at different stages'.*

## Coming to terms with a diagnosis

If your child has a neurodevelopmental disorder you will probably experience a range of emotions and challenges along the way. It is important to realise you are not alone in this - there are many other parents or carers who have similar experiences to you and who have feelings similar to yours. There is a range of feelings you might experience following the diagnosis of your child's condition:

- shock, denial and disbelief
- anger and rage (why us?)
- stress and depression
- grief and fear - for your child and the family as a whole and for how life may change
- acceptance and adjustment - the realisation that it is not hopeless and there is a lot that can be done to make life easier and more enjoyable for your child and family
- fight and hope – you may begin to enjoy the different challenges you may face and gain hope from making progress, and may begin to appreciate the positive differences in your child.

*'He is unique and wonderful. His different way of looking at the world can make us laugh'.*

It is important to note that not all families experience all of these emotions, but it is interesting to understand the possible reactions that could occur and to realise these are totally normal reactions. Every family is different and may progress through the stages in completely different ways (or may skip some stages completely).

*'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'.*



## Support for you as a parent

*'As a parent I needed lots of support to deal with the diagnosis, I felt there wasn't enough practical help available for parents to help them get their life back on track'.*

You might have a variety of feelings and emotions about your child's diagnosis - it is important to talk about them with people you can trust to give you good advice, such as a partner, family, close friend, professionals involved in your child's care, other parents in the same situation.

*'Supporting each other helped us a lot, learning to know what battles to fight'.*

*'Before our daughter was born with Down syndrome, I had no first-hand experience with children with disabilities. After the shock of having Alissa, we began to meet other families who shared the same experience as ourselves. This opened a whole new world for my wife and me'.*

Contact a Family provide a free 'making contact' service to enable you to get in touch with other families who have a child with the same diagnosis. The website for this is [www.makingcontact.org](http://www.makingcontact.org). Many voluntary organisations, such as Contact a Family, provide a free helpline to help you through times that you find difficult – contact details are provided towards the end of this booklet.

# Therapies

There are lots of physical, psychological and educational therapies outlined below that can be useful for many conditions. A health professional should be able to advise you on suitable therapies that could help your child.

It is important to consider whether therapy is intended to be palliative (treating symptoms to provide relief) or therapeutic (dealing with the improvement/cure of the condition). This will help you to be realistic about the outcome of any therapy.

## Physical Therapies

Please ask your doctor about access to any of the following physical therapies. They are available on the NHS but resources may be limited.

### Speech and Language Therapy (SALT).

See the section 'Meeting professionals' above for a description of what **SALTs** do. A recent review into speech and language services stresses the importance of the early identification of children with any language and communication difficulties. Speech and language therapy should be available from the NHS, however, funds and provision can vary in different areas.

*'We pay for speech and language therapy. Although our son is statemented to get SALT, due to lack of funding, he gets very little. There is no doubt this has helped our son who didn't make any noise and now has about 20 words and over 50 signs'.*

- **The Royal College of Speech and Language Therapists** is the professional body for **SALT**. They offer a range of information about the therapy and can direct you to a qualified speech and language therapist in your area.
- **The Association of Speech and Language Therapists in Independent Practice** are able to provide you with more information about **SALT** in the private sector and provide a searchable database of speech and language practitioners that are able to offer services in a private practice.
- **Afasic** are a charity who aim to help children with speech, language and communication impairments. They have a range of printed information available, a helpline and a range of local groups to assist with more information about how you can help your child.



## Alternative communication methods

Many children with NDDs have varying degrees of communication impairments, which can be very frustrating for them. This frustration can contribute to a range of behavioural problems such as tantrums, self-harming behaviours and aggression. It can help to use alternative communication methods, such as:

- **Sign language** - this can be a great tool to help children communicate their needs more effectively. This technique involves using hand gestures to represent words, and can also be used in conjunction with some speech to accompany the signs (signed speech). This method is not suitable for all children with communication difficulties as some children also have difficulty in imitating motor patterns. You will need to discuss this with your speech and language therapist. You can find out more information about it from [The National Deaf Children's Society \(NDCS\)](#) or [The Royal National Institute for Deaf people \(RNID\)](#).
- **Picture Exchange Communication System (PECS)** –instead of using gestures, PECS focuses on using picture cards. For example, if the child is hungry and wants some food, they will take the picture of some food to an adult, who will then get them some food. Children can also learn how to construct simple sentences, as well as asking and responding to questions. [Pyramid Educational Consultants](#) are the UK providers of PECS.
- **Makaton** – this is a language programme that uses speech, gesture, facial expression, eye contact and body language. Makaton signs and symbols provide a visual representation when communicating. This method combines both sign language and PECS, encouraging children to learn a variety of techniques that have been shown to promote understanding and aid communication. [The Makaton Charity](#) can provide training, lists of approved tutors and access to resources and materials for Makaton use.
- **Signalong** – its aim is to aid communication for those who suffer communication problems associated with learning difficulties. Signalong is based on British Sign Language and uses signs, symbols and pictures to aid communication. For more information ask your speech and language therapist, or visit the [Signalong Group](#).

**There is more information about getting equipment to aid communication in the Equipment and the Useful contacts sections later in this booklet.**

## Occupational Therapy

See the section 'Meeting professionals' above for a description of what **Occupational Therapists (OTs)** do. An OT's main role is to promote independence.

*'Some OTs are good and some are not so good and provision depends on the OT and the area'.*

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 include:

- **British Association of Occupational Therapists** and **College of Occupational Therapists** are the professional bodies for occupational therapy. They are able to provide you with more information about the occupational therapy service.
- **Occupational Therapy Direct** provide a range of information about occupational therapy and links to useful organisations.

There is more information about getting equipment to aid daily living in the **Equipment** and the **Useful contacts** sections later in this booklet.

## Physiotherapy

Your child may have difficulties with day-to-day activities, due to loss of movement, sensation, balance or co-ordination. See the section 'Meeting professionals' above for a description of what **physiotherapists** do to help.

- **NHS Choices** provide information about physiotherapy, how it is used, what it is used for and how to access a physiotherapist ([www.nhs.uk/conditions/physiotherapy](http://www.nhs.uk/conditions/physiotherapy))
- **The Chartered Society of Physiotherapists (CSP)** is the governing body for physiotherapy, working towards excellence in practice. All reputable physiotherapists should be a member of the CSP.

## Neurophysiotherapy.

Neurophysiotherapy differs from physiotherapy in that it will specifically assess the problems that result from a neurological disorder. These may include spasticity, weakness, walking problems, balance problems and altered movement patterns.

Your **GP** should refer your child for physiotherapy if they think it will be of benefit. Some primary care trusts may refuse to pay for physiotherapy due to funding reasons - if this is the case, you can appeal via the **Patient Advice and Liaison Service (PALS)**. If you want to pay for private physiotherapy, it is important that you ensure the practitioner is registered with the **Chartered Society of Physiotherapists (CSP)**.

**There is more information about getting equipment to aid mobility in the **Equipment** and the **Useful contacts** sections later in this booklet.**



## The Bobath Concept

The Bobath Concept was developed by Dr Karel and Mrs Berta Bobath in the 1940s. The therapy was designed to incorporate physiotherapy, occupational therapy, speech and language therapy, and family support for the treatment of cerebral palsy. Bobath Therapy aims to help children move more effectively, in a more co-ordinated fashion and help them overcome postural difficulties to achieve a more functional quality of life. Handling techniques are utilised to promote the use of 'normal' movement as much as possible in the child, whilst undertaking daily activities. Bobath therapists work with the child's family to encourage continuation of the therapy techniques at home. For more information, please contact [The Bobath Centre](#). If you are interested in finding out about other kinds of support for children with cerebral palsy then you can find further information in another [Early Support](#) booklet in this series – [Information for parents: Cerebral palsy](#) – this is available to download from [www.dcsf.gov.uk/everychildmatters/earlysupport](http://www.dcsf.gov.uk/everychildmatters/earlysupport) or order by calling 0845 602 2260, quoting reference ES10.

## Educational and Behavioural Therapies

### Applied Behavioural Analysis (ABA)

ABA is an educational programme used with children with autistic spectrum disorders and behavioural disorders. It is based on the principals of [operant conditioning](#), which involves rewarding desired behaviours through praise, tokens and food rewards, and reducing or eliminating problem behaviours by ignoring or redirecting them. The intervention is recommended to be extremely intensive, requiring around 30-40 hours per week of one-to-one therapy time, for a minimum of two years. For further information please contact:

- [UK Young Autism Project](#) – this provides centre-based services in London, Birmingham and Bristol and can offer consultancy-based services elsewhere in the UK.
- [Parents for the Early Intervention of Autism in Children \(Peach\)](#)- a parent-led charity that is committed to promoting early interventions (particularly ABA).

## Conductive Education (CE)

Conductive Education was developed to assist in the rehabilitation of children with cerebral palsy, but can be applied to a range of conditions that involve poor control of movement and co-ordination (e.g. [dyspraxia](#) and head injury). Conductive Education techniques can help with skills such as head control, moving around independently, sitting unaided, walking, dressing, feeding, washing and communication skills. CE has been described as a learning process that helps manage problems relating to movement and learning – it is described as a way of life, rather than a set of exercises. The technique involves hours of commitment per day and extensive parental training- it is not promoted as a treatment, therapy or cure. For further information and advice contact the [National Institute of Conductive Education](#) and have a look at the [Early Support Information for parents booklet: Cerebral Palsy](#).

## Neurofeedback/biofeedback

Neurofeedback (also named biofeedback or neurotherapy) is a form of modification of electrical brain activity. It involves rewarding desirable brain activity and discouraging undesirable brain activity. Neurofeedback aims to teach the brain to help improve its ability to regulate all bodily functions, and to look after itself. The procedure undertaken during neurofeedback training sessions involves the following:-

- The therapist applies electrodes to the child's scalp
- The child's brainwave activity is compiled by a computer
- Any change in brain activity is fed back to the child via the computer, sometimes visually via a monitor, or as sounds through headphones
- If the child's brain activity adjusts in the desired direction specified by the neurofeedback practitioner, a positive 'reward' feedback is given to the individual.

For example, a game will not continue unless the child produces a specific brainwave signal. Once the brainwaves reach a desired level, the child is rewarded because the game carries on. Through this method, the child actually learns to change their brainwave activity. This method is used for the treatment of a range of conditions. For more information you could contact either [Peakmind](#) a neurofeedback centre, based in Swansea or [EEG Neurofeedback](#) a provider of neurofeedback training, based in Cornwall. Most neurofeedback practitioners belong to the [Society of Applied Neuroscience](#).





### Social Stories™

The use of Social Stories™ was developed by Carol Gray, for use with children, adolescents and adults with autism. Social Stories™ was developed with the aim of helping those with autism to develop the skills necessary to improve their social interaction abilities and to improve their understanding of the perspectives of others. The stories are designed with the interests and problems of the child in mind. Social stories are used with children with a variety of conditions by teachers, psychologists, speech therapists, occupational therapists and other child care professionals. [The Gray Centre for Social Learning and Understanding \(USA\)](#) is the founder of Social Stories™.

### Sensory Integration Therapy (SIT).

Sensory Integration Therapy aims to improve the effectiveness and efficiency of processing and co-ordinating sensory information input from touch, movement sense, sense of body position, and vision, hearing, smell, and taste systems. The therapy is designed specifically for the child's needs, according to their abilities, and involves intensive physical and mental exercises. The therapy is recommended for [Sensory Integration Disorder](#), [ASD](#), [Dyspraxia](#), [Asperger's syndrome](#), developmental delay, [Down syndrome](#), [Global Delay](#), [Fragile X](#), specific learning disorders such as [dyslexia](#), [dyspraxia](#), [cerebral palsy](#), [ADHD](#) and [ADD](#). SIT is not funded by the NHS. Further information on Sensory Integration Therapy is available from [Sensory Integration UK](#).

## Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH).

TEACCH was developed in the 1970s by Eric Scopler, a psychologist from the University of Carolina. It aims to provide a programme of education and advocacy for individuals with autism to function more effectively in the home, school and community environment. TEACCH believe in promoting a culture of 'being autistic', instead of pushing autistic individuals to conform to societal norms. TEACCH focuses on developing an individual's unique potential, whatever that may be, focusing on this, rather than correcting any perceived problems. TEACCH is very wide-ranging in its methods and utilises a structured educational environment, parental involvement, and behavioural techniques (usually using functional rewards, rather than tokens or food), to create an individualised holistic programme of education, in order to promote the wellbeing of the autistic individual. [The National Autistic Society](#) provides more information about the TEACCH method in the UK and the [Early Support Information for parents booklet: Autistic spectrum disorders and related conditions](#) has further details – this is available to download from [www.dcsf.gov.uk/everychildmatters/earlysupport](http://www.dcsf.gov.uk/everychildmatters/earlysupport) or order by calling 0845 602 2260, quoting reference ES12.

## Parent Training Skills

### Early Bird (NAS)

The Early Bird programme is a three-month programme aimed at the parents of children under 5 years with a diagnosis of autism. It is promoted by the [National Autistic Society \(NAS\)](#) in various parts of the UK. The programme promotes parental involvement and enrolls up to six families on each group. The families meet for group sessions and are also visited at home. During the home visits, a video is made, which is then reviewed at the next meeting, in order to monitor progress of behaviours and skills. This programme's ultimate aim is to help parents understand their child's autism, develop their child's communication and social skills, and to learn strategies to manage their child's challenging behaviours. Parents must commit to a two and a half hour training session or a home visit each week, and to ongoing work with their child at home over the three-month programme duration.

### Incredible Years

The Incredible Years programme is a parent training programme designed for children with conduct disorder and early onset conduct problems, for example, [oppositional defiant disorder](#) (where children have disruptive and oppositional behaviour that is particularly directed towards authority figures, such as parents or teachers). This programme is designed to tackle conduct problems in children aged 3-10 years, by reducing challenging behaviours through promoting social, emotional, and academic



skills at home and at school. The programme does this by enhancing positive parenting and promoting teachers' classroom management skills, encouraging parents and teachers to work together to tackle any problem behaviours. Incredible Years has three dimensions – child-based, parent-based and teacher-based. These training programmes use modelling (via film clips), role playing, rehearsal and homework tasks in groups of 8-14 parents. For more information contact [Incredible Years Cymru](#).

## Medication

What follows is a very brief description of some common medications – if you would like to know more about any of these, or any other medications, you could ask your [paediatrician](#), [GP](#) or [health visitor](#). For more information on specific medications, see the [Electronic Medicines Compendium](#), which provides UK approved information on a variety of medications. A combination of behavioural treatments and medication are sometimes used with some conditions to achieve better results.

### [Antidepressants \(but used in a range of conditions\).](#)

Depression, [Obsessive Compulsive Disorder \(OCD\)](#) and anxiety can be treated with antidepressants. These medications can reduce the intensity of repetitive behaviour and behavioural problems, but can have side-effects such as headaches, dizziness, and insomnia, amongst others. Some medication names include Fluvoxamine (Luvox), Fluoxetine (Prozac), Clomipramine (Anfranil), Bupropion (Wellbutrin) and Amitriptyline (Elavil).

### [Antiepileptic drugs](#)

Antiepileptic drugs (AEDs), such as Carbamazepine, Phenytoin, Valproic acid and Phenobarbitone are the most common drugs used to treat epilepsy. The one chosen by the physician for a particular patient is based on the type of epilepsy the patient has, the suitability for that patient, and the side-effects the medication may cause. Different AEDs will be tried initially to find the one most suitable, and the lowest possible dose to control the onset of seizures, which may take some time to evaluate. Side-effects of AEDs may include nausea, fatigue, changes in vision, weight gain, fever, rashes, easy bruising, sore throats and swollen glands, and sometimes increased seizures.

## Antipsychotic medication

Antipsychotic medication is sometimes used to treat behavioural problems, hyperactivity, and aggression. Some examples of these medications include Clozapine (Clozaril), Risperidone (risperdal) and Olanzapine (Zyprexa). However, these medications have side-effects including anxiety, drowsiness, and headaches.

## Benzodiazepines

Behavioural problems can be treated with benzodiazepines - but these are not given lightly, as they have a number of side-effects and withdrawal effects. Some examples are Diazepam (Valium) and Lorazepam (Ativan).

## Melatonin

Sleep disorders are common in children and can be a huge source of stress for the whole family. Melatonin is a hormone that is secreted by the pineal gland, mainly at night. It has been found that some individuals with insomnia have lower levels of melatonin in their systems in the evening. Melatonin is a prescription medication, thus, for further information speak with your [GP](#). Melatonin is also discussed in the [Early Support Information for parents booklet: Sleep](#).

## Psychostimulants

Psychostimulants or central nervous system (CNS) stimulants are used to reduce the symptoms of ADHD, by increasing the activity of chemicals in areas of the brain controlling attention and behaviour. Some examples of these medications include Methylphenidate (Ritalin, Equasym and Concerta XL), Dexamphetamine and Atomoxetine. Stimulants are also used to increase focus and reduce hyperactivity in people with high functioning autism. However, risk of dependence is high, as are side-effects of stomach pain, insomnia, reduced appetite, increased heart rate and hypertension, amongst others.



## Dietary and nutritional therapies

**BEFORE STARTING ANY DIET, IT IS EXTREMELY IMPORTANT YOU SEEK THE ADVICE OF YOUR GP OR THE PROFESSIONAL RESPONSIBLE FOR YOUR CHILD'S MEDICAL CARE.**

You should be able to see a registered dietician within the NHS. You will need a referral from a GP, health visitor or other health care professional. Dieticians Unlimited provides a national search service for those who want to see a dietician privately.

### Dietary supplements

The term '[dietary supplements](#)' is used to describe vitamins, minerals, fatty acids or amino acids that are thought to be deficient in a person's diet. Through eating a varied, balanced diet, most people can gain all the vitamins and minerals they need. However, in some cases this is not possible, perhaps due to a medical condition, and then vitamin and mineral supplementation may be needed. It is important you seek the advice of your [GP](#) before you start supplementing your child's diet.

### Elimination Diets

There are various elimination diets for different NDDs, for example:

- [Attention Deficit Hyperactivity Disorder \(ADHD\)](#) - the role of additives (such as sugar, artificial colourings and preservatives) in contributing to ADHD has been a controversial subject. However, some parents see an improvement in symptoms after the removal of some substances from their child's diet. These include caffeine (chocolate, some fizzy drinks and coffee); artificial colourings, especially yellow (Tartrazine) and red (Erythrocine B); and food additives (E numbers). Dietary supplementation with fish oils has also been found to help ease ADHD symptoms in some children. If a link is suspected between a food type and your child's behaviour, it may be a good idea to keep a food diary and to take it to your child's doctor. For further information contact the [Hyperactive Children's Support Group \(HACSG\)](#), a leading charity providing information on the dietary approach to ADHD.

- **Autistic Spectrum Disorders (ASD)** - a gluten-free, casein-free (GFCF) diet is the most common diet recommended for children with autism but is also recommended for children with other behavioural problems. Gluten is the protein found in barley (malt), wheat, oats and rye grains, which make up a range of products including bread, pasta, cakes, biscuits, porridge and many processed (ready made) foods. Casein is a protein found in all products made from cows' milk. For further information on dietary choices and supplements for autistic children, the **National Autistic Society** has an information paper, which you can access on their website at [www.nas.org.uk/nas/jsp/polopoly.jsp?d=1385&a=3368](http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1385&a=3368)
- **Epilepsy** – the Ketogenic Diet is based on 'fasting to prevent seizures' since 'burning fat for energy' has reduced the number of seizures for some children. It is sometimes offered to children with 'hard to control' epilepsy, and is available at some medical centres and institutions. However, it is important to ensure that this diet is only tried under strict professional guidance, to ensure correct nutrition for your child. Further help and information can be found via the **Epilepsy Foundation's** website at [www.epilepsyfoundation.org/about/treatment/ketogenicdiet](http://www.epilepsyfoundation.org/about/treatment/ketogenicdiet)
- **Phenylketonuria (PKU)** – the main method of treatment is a very low protein diet, and use of an amino acid supplement that contains 20 of the 21 amino acids that protein is constructed from. The final amino acid, phenylalanine, is removed because individuals with PKU cannot process this amino acid. PKUexchange can provide further information on PKU and the PKU diet.

For general information about diet, food groups, vitamins and minerals:

- Go to the NHS Choices website at [www.nhs.uk/Conditions/Diet](http://www.nhs.uk/Conditions/Diet). The **British Association of Nutritional Therapists** is the regulatory body for nutritional therapy practitioners, and provides information and help to find a registered nutritional therapist.
- **Action Against Allergy** provides information about diagnosis and treatment of allergies in the National Health Service (NHS).
- **Dieticians Unlimited** is a database of registered independent dieticians where you can search for a dietician in your area.



## Complementary therapies

Complementary and alternative medicines are becoming more readily available on the NHS, but they may still be available only in certain areas of the country. It is worth asking your GP about availability on the NHS if you are interested in this type of treatment, as private practices can be costly. For further information contact the [British Complementary Medicine Association](#), who offer a variety of resources on many complementary and alternative medicines, signposting to accredited therapists and training. Also, the [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.

- **Acupuncture** involves the use of very fine stainless steel needles, which are inserted into specific areas of the skin, known as acupuncture points. Acupuncture is sometimes combined with the use of heat and herbal remedies. Western medics cannot explain the effectiveness of acupuncture in a scientific way yet, as more research is needed. Scientifically, acupuncture has been found to be most effective in treating pain-related symptoms, but may have limited effect in other conditions. If you decide to use acupuncture, it is advisable that you inform your G.P. [The British Acupuncture Council](#) is the main regulatory body for acupuncture in the UK and the [British Medical Acupuncture Society](#) is a charity consisting of around 2700 medical doctors promoting the use and scientific knowledge of acupuncture alongside more conventional techniques. These organisations can provide you with more information and direct you a qualified and registered practitioner in your area.
- **Homeopathic** treatment is based on the principle that a substance that can cause symptoms in a healthy person, can be used to treat the same symptoms in an unwell person. Homeopaths call this 'like cures like'. The second principle of homeopathy is the more you dilute the substance, the more it is able to treat any symptoms, this is called **potentisation**. Treatment using homeopathic principles involves the use of homeopathic remedies that correspond to the person's symptoms, their constitution and emotional state. Most remedies are made up of herbal or plant substances, or sometimes mineral or animal substances. Drugs such as antibiotics are also sometimes used. Homeopathic remedies are used for a variety of medical problems, and in the treatment of autism and ADHD to improve the behavioural symptoms. [The British Homeopathic Association](#)

promotes the use of homeopathy in the NHS, and can provide you with information about homeopathy and how to access this treatment. [The Society of Homeopaths](#) is the organisation of professional homeopaths in Europe and can provide you with more information about homeopathy and direct you to a qualified practitioner.

- [Osteopathy](#) is a holistic therapy that focuses on the musculo-skeletal system, to include the bones, joints, muscles, ligaments and connective tissues and nerves. An osteopath may perform a variety of manipulation techniques including stretching soft tissue, massage, joint movements, thrust techniques (known as cracking), with the aim of improving movement in the joints. The theory behind the practice of osteopathy is that the structure and function of the body are interconnected, for example, any pain in the structure of the body can have a negative effect on the organs of the body. It is believed that treating problems of the musculoskeletal system helps the body to utilise its natural recuperative capability generally. Osteopathy is recognised by the medical profession, despite having little evidence in its favour. Osteopathy can be used for a variety of symptoms including pain, bad posture, carpal tunnel syndrome (problem with nerves affecting the hands and fingers), and back and neck pain, including sciatica. Osteopathy is also used in the treatment of sleeplessness and health problems such as ear, nose and throat problems and digestive problems. Side-effects from osteopathic treatment are very rare. [British School of Osteopathy](#) is the largest school of osteopathy in the UK. They can provide information and direct you to a qualified osteopath. The General Osteopathic Council is the regulator of osteopathy practice in the UK, and by law all practicing therapists must be registered. [The General Osteopathic council](#) can provide details of registered UK osteopaths and information about NHS and private access to therapy.
- A [chiropractor](#) is a complementary and alternative therapist who focuses on improving health through the manipulation of vertebrae and joints. Chiropractors believe that if the spine, skull or pelvis structures are out of position they can cause entrapment of the nerves, leading to health problems and pain. A chiropractic treatment aims to treat these misalignments, easing the pressure on the spine and central nervous system, and relieving pain and other problems using manipulation techniques called adjustments. This is generally considered a safe intervention, but is not recommended for individuals with certain conditions such as spinal tumours/inflammation, recent bone fractures, or osteoporosis. [The General Chiropractic Association](#) sets the standards for chiropractors and can help you find a registered chiropractor in your area.
- [Herbal medicine](#), also called herbalism, involves the use of plant-based remedies to treat a range of problems. Herbal medicine takes a holistic approach to treat a person, looking at the spectrum of signs and symptoms, and working from there. Herbal remedies are often designed for a person, dependent on their





individual symptoms. [The National Institute of Medical Herbalists](#) offers information on herbalism and a service to locate a registered herbal practitioner.

- [Reflexology](#) is a form of massage that aims to bring about the body's natural healing abilities, by applying pressure to various areas of the hands or feet (usually feet). It is based on the idea that there are energy zones running through the body - though there is no scientific proof for this at present. It has been used in children with hyperactivity, bed-wetting and eating problems as well as with children with oversensitivity in conditions such as autism. [The British Reflexology Association \(BRA\)](#) is the representative body for reflexology practitioners and [The Association of Reflexologists \(AOR\)](#) is an independent professional body for reflexologists. These organisations can tell you more about reflexology and help you find a registered practitioner.
- [Aromatherapy](#) is the use of essential oils (plant-based) to improve health and wellbeing. Aromatherapy is often combined with massage, and is believed to aid emotional wellbeing by acting on the parts of the brain responsible for emotional regulation. This method has been used to reduce stress and improve attention in a variety of disorders, such as autism and learning disabilities. The Aromatherapy Council offers information on aromatherapy and can direct you to a registered local practitioner.
- [Massage](#) involves the rubbing, pressing and general manipulation of muscles in order to increase the sense of wellbeing, relieve pain and for other health benefits. Massage can be useful in children with NDDs to reduce stress and anxiety, improve behaviour, help sleep patterns and ease tense muscles. Massage is often used by therapists such as physiotherapists as part of a holistic treatment. The [General Council for Massage Therapy](#) provides information on massage and offers signposting to registered masseurs. The [International Association of Infant Massage \(IAIM\)](#) provides information and training in the use of baby massage.
- [Meditation](#) is an age-old practice to induce a state of relaxation. Transcendental meditation is one form of meditation that has received recent interest as a potential treatment for children with [ADHD](#), [Asperger's syndrome](#) and other conditions, to improve symptoms associated with inattention, hyperactivity and impulsiveness. The organisation Transcendental Meditation (TM) offers information and advice on the practice of TM.

**If you are going to use a complementary or alternative therapy, then:**

- **Make sure you consult your doctor first**
- **Ensure the practitioner is an accredited member of the appropriate governing body/organisation.**

## Charitable organisations offering combined treatment approaches.

These organisations offer therapies that are not funded by the NHS and are described here only briefly. You will need to contact the providers for more information about what they can offer and about funding options.

### Bibic

Bibic are a charitable organisation that provide an assessment, coaching and mentoring programme for families of children with a range of neurodevelopmental conditions, and even children with no confirmed diagnosis. Bibic consists of a range of qualified developmental therapists with expertise in areas such as childcare, social work, and physiotherapy, amongst others. Bibic aim to help children reach their full potential and develop the skills necessary to be as independent as possible, empowering parents and carers to promote this concept in day-to-day activities. Therapists are on hand to help you work through any concerns you may have regarding your child and to advise on practical solutions that may be able to help.

### Brainwave

The Brainwave organisation consists of therapists qualified in physiotherapy, psychology and education and who have undergone further training in cognitive and communication methods. Brainwave offers a therapy service in which a two-day assessment will be conducted with your child. Following assessment, an exercise programme is devised specific to your child's needs. This programme is taught to parents to be undertaken at home. A recording of exercises is provided, as well as an information sheet and any equipment required. The exercises are designed to improve children's physical, cognitive and developmental progress. Continued support is provided by the Brainwave team, by phone, email and through re-assessments every 4-6 months. This service is available for children with a range of neurodevelopmental conditions.

*'We take our son for therapy at Brainwave, following an initial assessment they make a specific activity programme for you to do with your child at home. Initially our son could not sit or crawl, but as soon as we started the programme there were significant changes in our son, it was lovely to see his confidence grow'.*



## Some things to consider

It is difficult to decide if a therapy will be suitable for your child, with a range of pros and cons to take into consideration. It is important that you speak with your [GP](#) or your child's main health care professional before you undertake any therapy. The following questions are provided to help you think about the things you may want to know, in order to make the best decision for your child.

- Is there research on the benefits of the treatment for your child's condition?
- Are there any conditions that should not receive this treatment?
- What conditions have been found to gain the most benefit from the treatment?
- What is the average amount of treatment needed to see a positive result?
- Do you need a referral from a professional?
- What does treatment involve?
- How much will the therapy cost?
- Where can I access the treatment?
- What training is the practitioner required to have and are they officially registered?
- How long have they been practising?
- Does this therapy conflict with any other drugs, therapies and treatments?
- Are there any side-effects?
- Can you speak with another family who has used this treatment with their child?

In general, it is a good idea to think about the questions you have that are specific to your child, before you contact a practitioner, as things can easily be forgotten in the moment.

There is an excellent description of many conditions symptoms, causes, diagnosis and treatment in the [NHS Choices A-Z of conditions](#). Also, the [Henry Spink Foundation](#), a charity that helps families to learn more about varying diagnoses and to find alternative methods of treatment, might be able to help.

# Managing day-to-day life

## Stress

Raising and caring for a child with disabilities is a very demanding experience. Not only do you have to manage the daily care of your child, but you have to negotiate the health, social care and education systems, often meeting with lots of different professionals. On top of this, you are sure to have worries about the future of your child. All of these factors can impact on your relationships with your partner, other children, family members and friends.

As a result of all these things, it is not surprising that sometimes you may feel unable to cope. This is not something to be ashamed of, everyone gets stressed sometimes and you are likely to have lots of things to deal with.

*‘Just take a deep breath and if you can, do one thing a day. If it’s one phone call that has left you with another ten to do, then still you have done something. And doing something makes you feel better’.*

## Dealing with stress

The simple way to prevent stress is to remove whatever is causing the stress. However, this is not always possible and you will not always be able to avoid stressful situations.

There are lots of things you can do to help you cope with stress and anxiety. For example, because stress can impact on your immune system, you should try and make sure you eat a healthy, well-balanced diet and get enough exercise. It is also important to try and get some time for yourself. It may be difficult to arrange this, but time to relax will help you care for your child- if you are relaxed and happy then they are more likely to be.

## Don’t be afraid to ask for help

When you are stressed or anxious, it is often your partner, closest family member or friend who you turn to. They are also going to be the people who bear the brunt of your temper!

It is important to try and find different people to talk to, particularly if they can offer you real and practical support. You may find it helpful to join a local support group or to find time to spend with other parents who have children with disabilities. They may have found ways of dealing with situations and issues that you find particularly stressful.



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

- Call a support line such as [Cerebra's Stress Helpline](#), [Contact a Family's Helpline](#) or [Parentline Plus](#). There are a range of other support organisations listed in the back of this booklet.
- Contact your [GP](#) who should be able to inform you of the location and contact details of your local counselling service.
- Have a look at some self-help books – for example, Professor Ann Edworthy, a Chartered Psychologist, has written a book, 'Managing Stress for Carers'. You can download a copy for free: [www.cerebra.org.uk/parent\\_support/support/stress.htm](http://www.cerebra.org.uk/parent_support/support/stress.htm), or request one by telephoning the [Cerebra Parent Support Helpline](#).

## Relationships

### Couple relationships

Managing the changes that take place in your life when having a child with any form of disability 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 parental 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 inevitably 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 re-assure 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'.*

There is a range of support available to help you through difficult times in your relationship and to help you understand what may be going wrong:

- [Relate](#)
- [Relate for parents and families](#)
- [The Couple Connection](#)
- [Contact a Family](#) have put together a booklet on 'relationships and caring for your disabled child' – see [www.oneplusone.org.uk/Publications/relationshipsguide.pdf](http://www.oneplusone.org.uk/Publications/relationshipsguide.pdf)

### Sibling relationships

Having a brother or sister with a disability can have many positive aspects. However, many siblings are raised in a family where a lot of the family's time and resources, mum's and dad's attention, and the attention of professional services are given to their sibling with disabilities. Therefore, their needs can sometimes appear less important than their brother's or sister's, due to their disability.

It is important that siblings get information about their brother's or sister's condition at different stages. This can help prevent them from coming to inappropriate reasoning about their situation. Without appropriate information the sibling/s can develop a sense of self-blame, guilt and damaging views that may affect them into adulthood.

*'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'.*

Siblings have specific needs that require attention at different stages. There is an organisation whose focus is on siblings - [Sibs](#) provide information, advice and support for brothers and sisters of a child with a disability.

### Fathers

Being informed that your child has a disability can affect mothers and fathers differently. For more information on support for you as a father you could get in touch with:

- [Fatherhood Institute](#) – [www.fatherhoodinstitute.org](http://www.fatherhoodinstitute.org)
- [Contact a Family](#) - [www.cafamily.org.uk/families/familyissues/dads/index.html](http://www.cafamily.org.uk/families/familyissues/dads/index.html).
- [Dads UK](#) – [www.dads-uk.co.uk](http://www.dads-uk.co.uk).



## Single parent families

**Gingerbread** is a national charity working to support single parents to improve their lives. They aim to empower single parents by providing them with the knowledge, skills and confidence to achieve what they want from life. **Gingerbread** has a further list of organisations that can help.

## Sleep

Children with neurological conditions often have problems with sleep and this can impact on their wellbeing during the daytime. You may find that your child cannot 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 you don't get enough sleep it will be more difficult for you to care for your child and meet other responsibilities you may have. Parents 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 that you get the support you need 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 for parents booklet** on **Sleep**. You can download a copy from [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport). Or you can order a copy by calling 0845 602 2260, quoting reference ES82.

## Daily Care

When your child is very young their care needs may be no different from those of non-disabled children. If the child with a condition is your first child you 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 with disabilities, such as [Contact a Family](#) or [Cerebra](#).

### Routine

Having a routine is good for you and your child. Many children with neurological conditions will gain a sense of security from a daily routine. This does not mean you have to do everything at the same time every day, just that you have regular activities.

### Getting dressed

If your child has severe physical disabilities then as they grow older, getting dressed can sometimes be difficult. However, wherever possible you should try and encourage them to do things for themselves.

Some practical tips are included in the [Early Support Information for parents booklet](#) on [Cerebral Palsy](#).

### Difficulties with motor skills

It is possible that your child may have problems 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 your child may see a [physiotherapist](#) who will do various exercises with them. They may also give you exercises to do with your child at home to help improve their movement.

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.

### Health and Safety

As your child grows and gains some freedom of movement, you may have concerns that they will injure themselves. You can't watch them every second for 24 hours a day!

An [occupational therapist](#) should be able to help you to make sure your home is safe. Some neurological conditions can result in children having no sense of danger, so you may need to secure cupboards and doors and make sure that radiators are covered.

Some children have tendencies to rock and repeatedly bang their heads. You can arrange special safe spaces within your home to help prevent them injuring themselves.





## Feeding

### Babies

If your child has problems feeding then it can make you feel very anxious and upset. Lots of children with neurological conditions begin life with difficulties that affect the feeding process. If your child has had problems with feeding since they were born, then you should have been given advice and support from staff in the hospital. This may include using a special 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 you will be able to feed them some food by mouth as well. You should talk to professionals about this, or you can contact the support group [PINNT](#) who can offer advice.

### Weaning

As your 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 your 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 your child, it can cause damage if left untreated for a long time. If your child is vomiting regularly after eating try not to worry too much. It may be that if you alter your child's sitting position and ensure they do not lie down immediately after food, the vomiting will stop. If it does continue then you should seek medical advice.

*'Our son is 5 and still cannot eat solid food. He eats 4 month baby purees, custards, yoghurts 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 – wish we had been told about it by a professionals earlier!'*

## Independent feeding

Just because your child has a disability 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.

## Food fads and fussy eaters

Some children are 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. You can get more information and advice from [Contact a Family](#) who provide information on feeding and eating - see [www.cafamily.org.uk/pdfs/paptFeeding.pdf](http://www.cafamily.org.uk/pdfs/paptFeeding.pdf)

## Toileting

Many children with neurological conditions can develop the skills needed for toilet training but may find them more difficult 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.

### Before you start

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 a disability 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.



## Getting started

Don't expect it to work right away, and try not to pressure your child too much. If you are anxious, they will be too. Every time they are successful, offer them some praise.

If your child is anxious or restless, you may want to sing them a song or read a bit of a story to them. However, don't leave them on a potty or toilet too long.

If you have been trying for a while and are having little success, it may be best to wait a few weeks and start again before the experience becomes too stressful for both of you.

You can get more detailed advice from healthcare providers as well as organisations such as [Contact a Family](#) and the [National Autistic Society](#). [Resources for improving childhood Continence \(ERIC\)](#) can be useful if you particular continuing problems.

## Behaviour problems

Some children with disabilities will exhibit problematic behaviour which is often linked to their condition. 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 their physical disability.

With some children, disruptive or defiant behaviours can be directly linked to their condition, such as [ADD](#) and [Oppositional Defiant Disorder \(ODD\)](#).

*'I was frequently asked to remove my son, at any time during a school day, because they did not have trained staff to deal with his requirements'.*

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](#). There is an [Early Support Information for parents booklet](#) on [Behaviour](#). You can download a copy from [www.dcsf.gov.uk/everychildmatters/earlysupport](http://www.dcsf.gov.uk/everychildmatters/earlysupport) or you can order a copy by calling 0845 602 2260, quoting reference ES81.

## Communication

Some children with **NDDs** have difficulties in communicating. Your child may have delayed development which means it will 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** who will probably organise a hearing test and may refer your child for speech and language therapy.

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.

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. 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 booklet.

## Equipment and adaptations

As your child grows up, you may find that you need to make changes to your home or to acquire special 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 your **Primary Care Trust** 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 facilitate your child's disability, then you should contact your **social worker** or **occupational therapist** who can explain to you how to get an assessment.

It is very important that any assessment takes into account the impact that your child's disability, and any adaptations, has on the rest of the 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 for example:

- [Whizz-kidz](#) provides mobility equipment.
- [Action for Kids](#) provides mobility aids.
- [Disabled Living Foundation](#) is a national charity that provides information and advice on daily living aids.
- [The Disability Equipment Register \(DER\)](#) is a database of specialist equipment for people with disabilities, with items either for sale privately, or wanted.
- [Abilitynet](#) is a charity helping both adults and children with disabilities use computers and the internet, by adjusting and adapting technology.
- [Inclusive technology](#) offer a range of inclusive technology devices such as software, switches and computer access devices, communication aids etc,
- [Assist](#) are leaders of a network of locally situated disabled living centres that can advise on equipment needs.
- [Living made easy](#) provide a comprehensive database of equipment from a range of companies with advice and information.

If your child has sensory problems there are organisations that can offer sensory equipment, including:

- [Spacecraft](#) offers a range of sensory and interactive equipment
- [Special needs toys](#) offer a range of appropriate toys
- [Sensory UK](#) provides sensory equipment for sale
- [Sensory Plus](#) provides sensory products and advice
- [The Sensory Company](#) offers a vast range of sensory equipment
- [Sensory developments](#) offer a range of multisensory equipment, as well as maintenance of sensory equipment.

# Managing services and accessing support

## Education

Choosing an early years setting or a school for any child can be difficult, but when the child has special educational needs the decision can be even harder. As there are extra factors and arrangements that may need to be taken into account, as a parent of a child with additional support needs, you may want extra information and help in choosing a suitable setting for your child.

There is a lot of information that you might find useful about your rights as a parent, your child's rights and the kinds of additional support you can access. [Early Support](#) have produced two [background information booklets](#) that provide a great deal of information and ideas about where you can get additional support and further information resources: [Education](#) and [Statutory Assessment: Education](#) can be downloaded from [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport). You can order copies by calling 0845 602 2260, quoting reference ES24 (for the Education booklet) and ES26 (for the Statutory Assessment: Education booklet).



## Social services

Every social services department has a duty to provide you with an assessment of your child's needs should you request one. This could result in services for your child or services to help you as the main carer of your child. A **social worker** will usually conduct this assessment and co-ordinate any resulting service provision. The types of services the social services can provide include:

- help around the home
- recreational activities inside and outside of the home
- travel assistance
- home adaptations and equipment
- holidays and respite.

The best way to contact your local social services department to request an assessment is to look up the number in your local telephone directory. You can also speak to your GP or other health professional to make a referral for an assessment on your behalf.

**Early Support** have produced a **background information booklet** that provides further information about **Social Services**. It can be downloaded from [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport). You can order copies by calling 0845 602 2260, quoting reference ES25A.

## Recreational activities

Children with disabilities have the same need 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 also depend on the extent of any disability, the child's age and the family's circumstances.

Children and young people with disabilities often miss out on leisure and play activities. As a parent trying to access facilities for your child, you 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 can be off-putting.

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

### Why is play important?

Play is a very important part of development, and this is no different for a child with a neurodevelopmental disorder. Play can aid your child's development by:

- Giving them a sense of self-esteem
- Helping your child to deal with difficulties and setbacks
- Providing an opportunity to be in control of the situation
- Allowing the practice of co-ordination skills
- Enabling your child to meet other children
- Teaching them the many social aspects of interacting with others
- Aiding the development of an active imagination and improving concentration
- Providing bonding time for you and your child
- Teaching your child crucial family values.

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

- 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, play and learning about food, playdough and paint, music and movement games, and relaxation time, perhaps reading a story).





- Provide opportunities for your child to play near a child who is doing something similar- they can learn through one another.
- Choose suitable equipment for play that meets your child's needs.
- Keep verbal instructions simple, using descriptive words such as long, short, big and 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.
- Avoid over stimulation, limit the amount of materials/toys out at once.

**Other useful organisations that may be able to offer information and support:**

- **KIDS** works towards an inclusive approach for disabled children, particularly in play.
- **Playwork Partnerships** offer play activities for children with disabilities.
- **Action for Leisure** provides information and advice on play and leisure activities for children and adolescents with disabilities.
- **Special Needs Kids** provides a list of suggestions for days out suitable for children with special needs.
- **Family activities**
- **Play England**
- **English Federation of Disabled Sports**
- **Get Kids Going** - helping to get children with disabilities into sport.
- **School sports and disabled children**

## Childcare, holidays and short breaks

*'I have started a ski club for disabled young people in our county. I am a parent rep on 3 different committees in our county. Just recently we have become family link workers providing short breaks to other disabled children. In short our daughter's birth has changed the direction of our lives. It has brought great satisfaction being able to help other families'.*

Your child and the family as a whole can benefit from the opportunities that short breaks, short-term childcare, play and leisure facilities can offer. They can provide a well-deserved break for you, and the chance for your child to make more friends and experience other environments.

It is important that you explore all avenues to ensure you get a regular break from caring, because without a break, things can become too much and you are likely to burn out.

Finding adequate childcare for children with disabilities can be problematic, because it is often too expensive, scarce or patchy, not appropriate for their needs, and can be rationed, where available. [Early Support](#) have produced a [background information booklet](#) that provides further information about [Childcare](#). It can be downloaded from [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport). You can order copies by calling 0845 602 2260, quoting reference ES22.

There is 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 your child. 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 (respite) services. You can contact your local authority for more information. The Government has given Local Authorities a large amount of additional funding to increase the provision of short breaks. Additional information about this and about other kinds of breaks for children and families is available from:

- [www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/shortbreaks/shortbreaks](http://www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/shortbreaks/shortbreaks)
- There are Early Support background information booklets on [Childcare](#) (mentioned in the previous paragraph) and [Social Services](#) (mentioned in the 'Social Services' section above).
- [Shared Care Network](#) is a charity that shares information and promotes good practice in short break services.
- [Break](#) is a charity that provides holidays and respite care for children and adults with disabilities and their families.



- **Scope** (residential short breaks) provides opportunities for short breaks.
- **The Children's Trust** provides short breaks for children with multiple disabilities, complex health needs and acquired brain injury.

## Financial issues

As a parent of a child with a disability, you may face more expense caring for your child, compared to parents of non-disabled children. You may experience increased costs for a variety of things such as adaptations to help independence, clothing, equipment, childcare, utilities, recreation and transport. You may find yourself bearing the bulk of costs relating to the care of your child. However, there is financial support out there for you. **Early Support** have produced a **background information booklet** that provides further information about **Financial help**. It can be downloaded from [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport). You can order copies by calling 0845 602 2260, quoting reference ES23.

# A quick reference guide to some neurodevelopmental 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 booklet but if you would like to know more about anything in this table that is not explained elsewhere in the booklet 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.

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>ADHD/ADD</b>  <a href="#">Adders</a> <a href="http://www.adders.org">www.adders.org</a>  <a href="#">ADDISS</a> <a href="http://www.addiss.co.uk">www.addiss.co.uk</a>	<ul style="list-style-type: none"> <li>• Unknown definitively</li> <li>• Likely multi-factorial i.e. genetic predisposition and environment factors may contribute eg. toxins or food additives</li> <li>• Brain injury</li> </ul>	3 types <ul style="list-style-type: none"> <li>• Hyperactive-impulsive</li> <li>• Inattentive</li> <li>• Combined hyperactive-impulsive and inattentive</li> </ul>	<ul style="list-style-type: none"> <li>• Learning disability</li> <li>• Oppositional defiant disorder (ODD)</li> <li>• Conduct disorder</li> <li>• Anxiety</li> <li>• Depression</li> <li>• Bipolar disorder</li> <li>• Tourette's syndrome</li> <li>• Sleep disorder</li> </ul>	<ul style="list-style-type: none"> <li>• Focus on reducing symptoms and improving function</li> <li>• Medication</li> <li>• Psychotherapy</li> <li>• Education/training</li> <li>• Combination of treatments</li> </ul>
<b>Agenesis of the corpus callosum</b>  <a href="#">Contact a Family</a> information paper <a href="http://www.cafamily.org.uk/Direct/a27.html">www.cafamily.org.uk/Direct/a27.html</a> <a href="#">Corpal</a> <a href="http://www.corpal.org.uk">www.corpal.org.uk</a>	<ul style="list-style-type: none"> <li>• Genetic: Recessive gene abnormalities on chromosomes 18,13,8</li> <li>• Prenatal infections</li> <li>• Cysts or tumours</li> </ul>	<ul style="list-style-type: none"> <li>• Learning difficulties</li> <li>• Poor muscle tone</li> <li>• Cognitive delays</li> <li>• Social and behavioural problems</li> <li>• Hydrocephalus</li> <li>• Cerebral palsy</li> </ul>	<ul style="list-style-type: none"> <li>• Aicardi-Goutieres -</li> <li>• Meckel-Gruber,</li> <li>• Apert's Syndrome - Walker-Walburg syndrome</li> <li>• Arnold-Chiari Malformation</li> </ul>	Dependant upon disability, services from: <ul style="list-style-type: none"> <li>• Neuropsychologist</li> <li>• Physiotherapist</li> <li>• Educationalists</li> <li>• Occupational therapists</li> <li>• Speech and language therapist</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Angelman's syndrome</b>  <b>Epilepsy Action</b> <a href="http://www.epilepsy.org.uk/info/angelman.html">www.epilepsy.org.uk/info/angelman.html</a> <b>ASSERT</b> <a href="http://www.angelmanuk.org">www.angelmanuk.org</a>	Neuro-genetic- deletion of genes on maternal chromosome 15	<ul style="list-style-type: none"> <li>• Learning disabilities</li> <li>• Seizures</li> <li>• Coordination problems (jerky movements)</li> <li>• Excessive laughter</li> </ul>	<ul style="list-style-type: none"> <li>• Prominent jaw</li> <li>• Sleep disorders</li> <li>• Oral problems, swallowing, tongue projection</li> <li>• Irregular heart rhythms</li> <li>• Microcephaly</li> </ul>	<ul style="list-style-type: none"> <li>• Anticonvulsant medication</li> <li>• Therapies for speech, sleep &amp; behaviour</li> <li>• Physiotherapy</li> </ul>
<b>Aphasia</b>  <b>Speak Ability</b> <a href="http://www.speakability.org.uk">www.speakability.org.uk</a> <b>Talking point</b> <a href="http://www.ican.org.uk/talkingpoint">www.ican.org.uk/talkingpoint</a> <b>Connect</b> <a href="http://www.ukconnect.org">www.ukconnect.org</a>	<ul style="list-style-type: none"> <li>• Brain damage</li> <li>• Degeneration</li> <li>• Stroke</li> <li>• Cerebral tumours</li> </ul>	Difficulties in: <ul style="list-style-type: none"> <li>• Speech</li> <li>• Comprehension</li> <li>• Reading and writing</li> <li>• Pronunciation</li> <li>• Forming sentences</li> <li>• Naming objects</li> <li>• Spontaneity in talking</li> </ul>	<ul style="list-style-type: none"> <li>• Cerebrovascular disorders</li> <li>• Seizure disorders</li> <li>• Deafness</li> </ul>	Depending on severity: <ul style="list-style-type: none"> <li>• Speech therapy</li> <li>• Melodic intonation therapy</li> </ul>
<b>Arnold Chiari Malformation</b>  <b>Chiari support</b> <a href="http://www.chiari.co.uk">www.chiari.co.uk</a> <b>The Ann Conroy Trust</b> <a href="http://www.theannconroytrust.org.uk/index.htm">www.theannconroytrust.org.uk/index.htm</a>	Downward displacement of the cerebellar vermis and medulla through the foramen magnum	<ul style="list-style-type: none"> <li>• Learning disabilities</li> <li>• Seizures</li> <li>• Coordination problems (jerky movements)</li> <li>• Excessive laughter</li> </ul>	<ul style="list-style-type: none"> <li>• Prominent jaw</li> <li>• Sleep disorders</li> <li>• Oral problems, swallowing, tongue projection</li> <li>• Irregular heart rhythms</li> <li>• Microcephaly</li> </ul>	<ul style="list-style-type: none"> <li>• Anticonvulsant medication</li> <li>• Therapies for speech, sleep &amp; behaviour</li> <li>• Physiotherapy</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Asperger's Syndrome</b>  <b>National Autistic Society</b> <a href="http://www.nas.org.uk">www.nas.org.uk</a>	<ul style="list-style-type: none"> <li>• Still under investigation</li> <li>• Likely multi-factorial eg. genetic and environmental factors may contribute to changes in brain development</li> </ul>	<ul style="list-style-type: none"> <li>• Social communication/ interaction difficulties</li> <li>• Social imagination difficulties</li> <li>• Particular about routines - sensory difficulties</li> </ul>	<ul style="list-style-type: none"> <li>• Sensory processing disorder (SPD)</li> <li>• OCD</li> <li>• ADHD</li> <li>• Anxiety</li> <li>• Depression</li> <li>• Dyspraxia</li> <li>• Tourette's syndrome</li> </ul>	<ul style="list-style-type: none"> <li>• Treatments to improve an individual's quality of life</li> <li>• Communication-based interventions</li> <li>• Behavioural therapy</li> <li>• Nutritional approaches</li> </ul>
<b>Autism</b>  <b>National Autistic Society</b> <a href="http://www.nas.org.uk">www.nas.org.uk</a> <b>Tree House</b> <a href="http://www.treehouse.org.uk">www.treehouse.org.uk</a>	<p>Still under investigation. Likely multi-factorial - genetic and environmental factors may contribute to changes in brain development, the exact nature differing from child to child.</p>	<ul style="list-style-type: none"> <li>• Social communication/ interaction difficulties.</li> <li>• Social imagination difficulties</li> <li>• Language difficulties</li> <li>• Particular about routines</li> <li>• Sensory difficulties</li> <li>• Learning disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Seizures.</li> <li>• Tourette's syndrome</li> <li>• ADHD</li> <li>• Anxiety</li> <li>• Mood disorders (e.g. depression)</li> </ul>	<ul style="list-style-type: none"> <li>• Early intervention</li> <li>• Educational/ Behavioural interventions</li> <li>• Family counselling</li> <li>• Nutritional approaches</li> <li>• Medications to treat allied symptoms e.g. seizures/ anxiety, behaviour problems</li> </ul>
<b>Brain Injury</b>  <b>Cerebra</b> <a href="http://www.cerebra.org.uk">www.cerebra.org.uk</a> <b>BIBIC</b> <a href="http://www.bibic.org.uk">www.bibic.org.uk</a> <b>Brainwave</b> <a href="http://www.brainwave.org.uk">www.brainwave.org.uk</a> <b>Headway</b> <a href="http://www.headway.org.uk">www.headway.org.uk</a>	<ul style="list-style-type: none"> <li>• Trauma e.g. road accident or fall</li> <li>• Tumour</li> <li>• Stroke</li> <li>• Haemorrhage</li> <li>• Infection</li> <li>• Hypoxic/anoxic brain injury</li> <li>• Medical accidents</li> </ul>	<ul style="list-style-type: none"> <li>• Dependent on brain region affected</li> <li>• Cognitive deficits e.g. memory, understanding, concentration, problem-solving, language abilities</li> <li>• Emotional and behavioural changes</li> <li>• Physical problems</li> </ul>	<ul style="list-style-type: none"> <li>• Epilepsy</li> <li>• Anxiety</li> <li>• OCD</li> <li>• Impulsiveness</li> <li>• Aphasia</li> <li>• Ataxia</li> <li>• Spasticity</li> <li>• Sensory impairment</li> </ul>	<p>Rehabilitation – to help re-gain former skills</p>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Brain Tumour</b>  <a href="http://www.cancer.gov">www.cancer.gov</a> <a href="http://www.braintumouraction.org.uk">Brain Tumour Action www.braintumouraction.org.uk</a> <a href="http://www.braintumouruk.org.uk">Brain Tumour UK www.braintumouruk.org.uk</a> <a href="http://www.braintumourtrust.co.uk">Samantha Dickson Brain Tumour Trust www.braintumourtrust.co.uk</a>	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"> <li>• Headaches</li> <li>• Nausea and vomiting</li> <li>• Seizures</li> <li>• Changes in hearing, vision and speech</li> <li>• Changes in mood, concentration, memory or personality</li> <li>• Jerkiness or twitching</li> <li>• Numbness or tingling in arms and legs</li> <li>• Balance and walking problems</li> </ul>	<ul style="list-style-type: none"> <li>• Hydrocephalus</li> <li>• Circulatory problems</li> <li>• Learning difficulties</li> </ul>	<ul style="list-style-type: none"> <li>• Surgery</li> <li>• Chemotherapy</li> <li>• Radiotherapy</li> </ul>
<b>Cornelia de Lange Syndrome</b>  <a href="http://www.cdls.org.uk">CdLS Foundation www.cdls.org.uk</a>	A mutation of genes on the 5th and 10th chromosomes	<ul style="list-style-type: none"> <li>• Developmental delay</li> <li>• Visual and hearing problems</li> <li>• Excess body hair</li> <li>• Microcephaly</li> <li>• Abnormalities in body size, limbs, hands and feet</li> </ul>	<ul style="list-style-type: none"> <li>• Cardiovascular malfunctions</li> <li>• Seizures</li> <li>• Cleft palate</li> <li>• Gastrointestinal problems</li> </ul>	<ul style="list-style-type: none"> <li>• Medication to control seizures and gastric problems</li> <li>• Therapies to address individual disabilities</li> </ul>
<b>Cri du Chat Syndrome</b>  <a href="http://www.criduchat.org.uk">Cri du Chat www.criduchat.org.uk</a>	A deletion on chromosome 5	<ul style="list-style-type: none"> <li>• Low birth weight</li> <li>• 'Cry of a cat'</li> <li>• Unusual facial features</li> <li>• Developmental delay</li> <li>• Behavioural difficulties</li> <li>• Constipation</li> </ul>	<ul style="list-style-type: none"> <li>• Microcephaly</li> <li>• Low set ears</li> <li>• Cardiovascular problems</li> <li>• Hypotonia</li> <li>• Renal problems</li> </ul>	<ul style="list-style-type: none"> <li>• Behavioural and feeding problems - interdisciplinary therapists</li> <li>• Heart dysfunctions - surgery</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Cerebral Palsy</b> <b>SCOPE</b> <a href="http://www.scope.org.uk">www.scope.org.uk</a> <b>Hemihelp</b> <a href="http://www.hemihelp.org.uk">www.hemihelp.org.uk</a> <b>Living with Cerebral Palsy</b> <a href="http://www.livingwithcerebralspalsy.com">www.livingwithcerebralspalsy.com</a>	<p>Oxygen deprivation during birth (5-10% cases)</p> <p>Damage to brain <b>before birth</b>:</p> <p>Reduced blood supply to fetus from:</p> <ul style="list-style-type: none"> <li>• Maternal infection.</li> <li>• Maternal low blood pressure</li> <li>• Premature birth (&lt;6 months gestation)</li> <li>• Cocaine use during pregnancy</li> <li>• Mutations of genes</li> <li>• Trauma to fetus</li> <li>• Fetal intracranial haemorrhage</li> </ul> <p>Damage to brain <b>after birth</b>:</p> <ul style="list-style-type: none"> <li>• Infection to brain e.g. meningitis or encephalitis</li> <li>• Traumatic brain injury (TBI)</li> </ul>	<p>Becomes apparent during first three years of life</p> <p><b>Spastic hemiplegia</b></p> <ul style="list-style-type: none"> <li>• Muscle stiffness (spasticity) on one side of body</li> <li>• May have curved spine</li> <li>• Speech problems</li> </ul> <p><b>Spastic diplegia</b> Muscle stiffness in legs.</p> <p><b>Ataxic CP</b></p> <ul style="list-style-type: none"> <li>• Clumsy/ uncoordinated</li> <li>• Tremors</li> <li>• Erratic speech</li> </ul> <p><b>Dyskinetic CP</b></p> <ul style="list-style-type: none"> <li>• Increased and decreased muscle tone (erratic movements)</li> <li>• Speech problems</li> <li>• Eating problems</li> <li>• Drooling</li> </ul> <p><b>Spastic quadriplegia</b></p> <ul style="list-style-type: none"> <li>• Most severe type</li> <li>• Stiffness in all limbs</li> <li>• Problems supporting head</li> <li>• Speech problems</li> <li>• Learning difficulties</li> <li>• Seizures common</li> </ul>	<ul style="list-style-type: none"> <li>• Epilepsy</li> <li>• Intellectual disability</li> <li>• Language delay</li> <li>• Pervasive developmental disorders</li> <li>• Behavioural problems</li> <li>• Sensory problems</li> </ul>	<ul style="list-style-type: none"> <li>• Physiotherapy</li> <li>• Speech and Language therapy</li> <li>• Occupational therapy</li> <li>• Medications e.g. muscle relaxant.</li> </ul> <p>Treatment for feeding/drooling:</p> <ul style="list-style-type: none"> <li>• Anticholinergic medications</li> <li>• Surgery</li> <li>• Devices for better tongue position</li> <li>• Biofeedback training.</li> </ul> <p>Orthopaedic surgery to improve posture and mobility</p> <ul style="list-style-type: none"> <li>• Selective Dorsal Rhizotomy (SDR)</li> <li>• Used as a last resort to ease muscle stiffness</li> <li>• Removal of nerves in spinal column which are causing muscle stiffness</li> <li>• Extensive physiotherapy required following SDR</li> </ul>



Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Dandy Walker Syndrome</b>  <b>Ability</b> <a href="http://www.ability.org.uk">www.ability.org.uk</a> <b>Assoc. for Spina Bifida and Hyrdrocephalus</b> <a href="http://www.asbah.org">www.asbah.org</a> <b>Contact a Family</b> <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>	Unknown congenital brain malformation	<ul style="list-style-type: none"> <li>• Slow movements</li> <li>• Lack of muscle co-ordination</li> <li>• Increasing head size</li> <li>• Signs of pressure within the skull</li> <li>• Convulsions, abnormal eye movements and breathing malformations, e.g. face, limbs</li> </ul>	<ul style="list-style-type: none"> <li>• Abnormal internal organs</li> <li>• Intracranial cysts irritability</li> <li>• Vomiting</li> </ul>	No overall specific treatment individual problems addressed as child grows
<b>Down syndrome (Trisomy 21)</b>  <b>Down's syndrome Association</b> <a href="http://www.downs-syndrome.org.uk">www.downs-syndrome.org.uk</a> <b>Down Education International (Downsed)</b> <a href="http://www.downsed.org">www.downsed.org</a> <b>Downs Heart Group</b> <a href="http://www.dhg.org.uk">www.dhg.org.uk</a> <b>SOFT UK</b> <a href="http://www.soft.org.uk">www.soft.org.uk</a>	<ul style="list-style-type: none"> <li>• Chromosomal disorder</li> <li>• Individuals have three copies of chromosome 21 instead of two</li> </ul>	<ul style="list-style-type: none"> <li>• Specific facial characteristics eg. upward slanting eyes, flat nasal bridge, small mouth</li> <li>• Delays in language and communication</li> <li>• Hearing difficulties</li> <li>• Cognitive development slowing after age 2 yrs</li> <li>• Slower rate of development of motor skills</li> <li>• Challenging behaviour</li> <li>• Very sociable</li> </ul>	<ul style="list-style-type: none"> <li>• Behavioural, emotional and psychiatric difficulties.</li> <li>• Learning difficulties</li> <li>• OCD</li> <li>• Anxiety</li> <li>• Depression</li> <li>• Seizures-amongst other medical conditions</li> </ul>	<ul style="list-style-type: none"> <li>• Early intervention.</li> <li>• Behaviour analysis</li> <li>• Occupational or physiotherapy for motor problems.</li> <li>• Speech therapy.</li> <li>• Communication aids</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Dyslexia</b> <a href="http://www.bdadyslexia.org.uk">British Dyslexia Association</a> <a href="http://www.bdadyslexia.org.uk">www.bdadyslexia.org.uk</a> <a href="http://www.dyslexiaaction.org.uk">Dyslexia Action</a> <a href="http://www.dyslexiaaction.org.uk">www.dyslexiaaction.org.uk</a>	<ul style="list-style-type: none"> <li>• 40-60% genetically heritable</li> <li>• A number of theories posed regarding cause</li> </ul>	<ul style="list-style-type: none"> <li>• Noticeable during early school years</li> <li>• Difficulties processing written information</li> <li>• Problems arising with reading, writing and spelling</li> <li>• No effect on intelligence</li> </ul>	<ul style="list-style-type: none"> <li>• Dyspraxia</li> <li>• ADHD</li> <li>• Aphasia</li> </ul>	<ul style="list-style-type: none"> <li>• Educational interventions such as teaching style e.g. <ul style="list-style-type: none"> <li>◦ Multisensory</li> <li>◦ Structured</li> <li>◦ Thorough</li> <li>◦ Use of phonics</li> <li>◦ Computer software</li> </ul> </li> <li>• Coloured overlays/glasses</li> </ul>
<b>Dyspraxia</b> <a href="http://www.dyspraxiafoundation.org.uk">Dyspraxia Foundation</a> <a href="http://www.dyspraxiafoundation.org.uk">www.dyspraxiafoundation.org.uk</a>	<ul style="list-style-type: none"> <li>• Little known</li> <li>• Thought that neurons responsible for motor control not developed properly</li> <li>• Electrical signal not transmitting signals effectively</li> </ul>	<ul style="list-style-type: none"> <li>• Affects movement and co-ordination</li> <li>• Clumsiness</li> <li>• Language problems</li> <li>• Perception and thought problems</li> <li>• No effect on intelligence but affects learning</li> </ul>	<ul style="list-style-type: none"> <li>• Dyslexia</li> <li>• ADHD</li> <li>• Asperger's syndrome</li> <li>• Hypotonia</li> </ul>	<ul style="list-style-type: none"> <li>• No cure</li> <li>• Improvement of symptoms sought</li> <li>• Occupational therapist</li> <li>• Speech and language therapist</li> </ul>
<b>Encephalitis</b> <a href="http://www.encephalitis.info">Encephalitis Society</a> <a href="http://www.encephalitis.info">www.encephalitis.info</a> <a href="http://www.cafamily.org.uk/Direct/a17.html">Contact a Family</a> <a href="http://www.cafamily.org.uk/Direct/a17.html">www.cafamily.org.uk/Direct/a17.html</a>	<ul style="list-style-type: none"> <li>• Inflammation of the brain</li> <li>• Infection</li> <li>• Immune system attacks the brain</li> </ul>	<ul style="list-style-type: none"> <li>• Flu like symptoms</li> <li>• Fever</li> <li>• Headache</li> <li>• Deteriorates quickly</li> <li>• Seizures</li> <li>• Confusion</li> <li>• Drowsiness</li> <li>• Unconsciousness</li> <li>• Coma possible</li> </ul>	<ul style="list-style-type: none"> <li>• Memory problems</li> <li>• Personality/ behaviour change</li> <li>• Speech and language problems (Aphasia)</li> <li>• Epilepsy</li> </ul>	<p>Three steps:</p> <ol style="list-style-type: none"> <li>1. Antiviral medication</li> <li>2. Control seizures/dehydration</li> <li>3. Prevent long-term consequences like memory loss or epilepsy</li> </ol>

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<b>Epilepsy</b>  <a href="http://www.epilepsysociety.org.uk">National Society for Epilepsy</a> <a href="http://www.epilepsysociety.org.uk">www.epilepsysociety.org.uk</a> <a href="http://www.epilepsy.org.uk">Epilepsy Action</a> <a href="http://www.epilepsy.org.uk">www.epilepsy.org.uk</a> <a href="http://www.epilepsyfoundation.org">Epilepsy Foundation</a> <a href="http://www.epilepsyfoundation.org">www.epilepsyfoundation.org</a> <a href="http://www.jointepilepsy.org.uk">Joint Epilepsy Council</a> <a href="http://www.jointepilepsy.org.uk">www.jointepilepsy.org.uk</a> <a href="http://www.ncype.org.uk">National Centre for Young People with Epilepsy</a> <a href="http://www.ncype.org.uk">www.ncype.org.uk</a> <a href="http://www.fable.org.uk">Fable</a> <a href="http://www.fable.org.uk">www.fable.org.uk</a> <a href="http://www.davidlewis.org.uk">David Lewis Centre</a> <a href="http://www.davidlewis.org.uk">www.davidlewis.org.uk</a> <a href="http://www.sudep.org">Epilepsy Bereaved</a> <a href="http://www.sudep.org">www.sudep.org</a>	<b>Symptomatic epilepsy</b> Known cause such as brain injury, tumour, CP, birth defects, infections  <b>Ideopathic epilepsy</b> No apparent cause  <b>Cryptogenic epilepsy</b> No apparent cause but likely due to brain damage	<b>Partial seizure</b> <ul style="list-style-type: none"> <li>• Simple – Person remains conscious</li> <li>• Complex – no awareness of event</li> <li>• Changes in perception, tingling in body part/s, intense emotion, stiffness in body part/s</li> <li>• Inability to respond to others during seizure</li> </ul> <b>Generalised seizures</b> <b>Absences</b> (petit mal) <ul style="list-style-type: none"> <li>• Common in children</li> <li>• No memory of event</li> <li>• Can occur several times a day</li> </ul> <b>Clonic seizure</b> <ul style="list-style-type: none"> <li>• Limbs jerk or twitch</li> <li>• Can lose consciousness</li> </ul> <b>Tonic seizure</b> <ul style="list-style-type: none"> <li>• Muscles become stiff and can lose balance and fall over</li> </ul> <b>Tonic clonic seizure</b> (grand mal) - Two stages: <ul style="list-style-type: none"> <li>• Body become stiff and limbs twitch/jerk</li> <li>• Loses consciousness</li> <li>• Can last 1-3 mins or more</li> </ul>	Brain damage can occur if seizure lasts more than 30 minutes (status epilepticus)	<b>General treatment.</b> Anti-epileptic drugs (AED), which changes the electrical activity of the brain  <b>Vagus nerve stimulation</b> <ul style="list-style-type: none"> <li>• Device wrapped around nerves in left side of neck under skin (vagus nerve)</li> <li>• Sends electrical simulation into nerve and can reduce likelihood of seizure</li> <li>• Used with AED</li> </ul> <b>Ketogenic diet</b> <ul style="list-style-type: none"> <li>• High in fats, low in protein and carbohydrates</li> <li>• Can cause other health complications</li> </ul> <b>Surgery</b> <ul style="list-style-type: none"> <li>• Last resort</li> <li>• Not all cases suitable</li> </ul> <b>Status epilepticus</b> <ul style="list-style-type: none"> <li>• Medication</li> <li>• Diazepam</li> <li>• Buccal midazolam – liquid administered on cheek</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<p><b>Fetal Alcohol Spectrum Disorders (FASD)</b></p> <p><b>FASAwareUK</b> www.fasaware.co.uk</p> <p><b>FASD Trust</b> www.fasdtrust.co.uk</p> <p><b>NOFAS-UK</b> www.nofas-uk.org</p>	<p>Exposure to alcohol before birth</p>	<p>Umbrella term for a range of diagnosis, including:</p> <ul style="list-style-type: none"> <li>• Fetal alcohol syndrome</li> <li>• Partial foetal alcohol syndrome</li> <li>• Alcohol related neurodevelopmental disorders</li> <li>• Alcohol related birth defects</li> <li>• Fetal alcohol effects</li> </ul> <p>Symptoms can include:</p> <ul style="list-style-type: none"> <li>• Learning, attention and behaviour disorders</li> <li>• Speech and language disorders</li> <li>• Autistic type symptoms</li> <li>• Sleep disorders</li> <li>• Mood disorders</li> <li>• Sensory problems</li> <li>• Facial defects</li> <li>• Organ damage</li> <li>• Cerebral palsy</li> <li>• Hormone disorders</li> </ul>	<ul style="list-style-type: none"> <li>• Mental health problems</li> <li>• Neural tube defects (e.g. spina bifida)</li> <li>• Many of the symptoms listed are disorders in their own right</li> </ul>	<p>No cure for FASD but early intervention can improve symptoms</p> <ul style="list-style-type: none"> <li>• Medication</li> <li>• Behaviour and education therapy</li> <li>• Parent training</li> <li>• Alternative and complementary medicine approaches</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Fragile X syndrome (or Martin-Bell syndrome)</b>  <a href="http://www.fragilex.org.uk">Fragile X Society</a> <a href="http://www.fragilex.org.uk">www.fragilex.org.uk</a>	Genetic disorder caused by the mutation of the FMRI gene on the X chromosome	<ul style="list-style-type: none"> <li>• Learning and intellectual difficulties</li> <li>• Elongated facial features</li> <li>• Large ears, high palate</li> <li>• Large testes</li> <li>• Low muscle tone</li> <li>• OCD</li> </ul>	<ul style="list-style-type: none"> <li>• Hyperactivity</li> <li>• Anxiety</li> <li>• Phobias</li> <li>• Variations include ataxia and autism</li> </ul>	<ul style="list-style-type: none"> <li>• No cure at present.</li> <li>• Deactivation of mGluR5 and RNA-binding proteins are currently being investigated</li> <li>• Therapies for physical disabilities and special education</li> </ul>
<b>Global Developmental Delay</b>  <a href="http://www.cafamily.org.uk">Contact a Family</a> <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>	Symptomatic of chromosomal and genetic conditions such as Down syndrome, CP, Fragile X. Spina Bifida or prematurity	<ul style="list-style-type: none"> <li>• Underweight at birth</li> <li>• Comparably slower development, physically and mentally.</li> </ul> <p>Late, or no further development in :</p> <ul style="list-style-type: none"> <li>• Motor skills (sitting up, walking etc.)</li> <li>• Speech and language</li> <li>• Cognitive skills</li> <li>• Social and emotional skills</li> </ul>	<ul style="list-style-type: none"> <li>• Learning disabilities</li> <li>• Impulsive</li> <li>• Aggression</li> <li>• Inattentive</li> </ul>	Depends on the cause – physiotherapy, behaviour and education therapy
<b>Guillain-Barré syndrome</b>  <a href="http://www.gbs.org.uk">Guillain-Barré syndrome Support Group</a> <a href="http://www.gbs.org.uk">www.gbs.org.uk</a>	<ul style="list-style-type: none"> <li>• Immune system causes inflammation of peripheral nerves.</li> <li>• The condition may follow a viral infection</li> </ul>	<ul style="list-style-type: none"> <li>• Tingling</li> <li>• Numbness</li> <li>• Progressive weakness in muscles</li> </ul>	<ul style="list-style-type: none"> <li>• Inability to walk</li> <li>• Total paralysis requiring ventilation</li> </ul>	<ul style="list-style-type: none"> <li>• No known cure</li> <li>• Lesser infections respond to physiotherapy for improving circulation and muscle tone</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Hydrocephalus</b>  <a href="http://www.asbah.org">Assoc..for Spina Bifida and Hydrocephalus</a> <a href="http://www.asbah.org">www.asbah.org</a> <a href="http://www.parent-plus.org">Hydrocephalus Parents Plus</a> <a href="http://www.parent-plus.org">www.parent-plus.org</a> <a href="http://www.ability.org.uk">Ability</a> <a href="http://www.ability.org.uk">www.ability.org.uk</a> <a href="http://www.actionmedicalresearch.org">Action Medical Research</a> <a href="http://www.actionmedicalresearch.org">www.action.org.uk</a>	<ul style="list-style-type: none"> <li>Genetic, congenital or acquired by stroke, trauma or injury, subarachnoid haemorrhage (sometimes before birth)</li> <li>Tumour,</li> <li>Meningitis or infection</li> </ul>	<ul style="list-style-type: none"> <li>In children, large head size due to excess cerebrospinal fluid causing intracranial pressure</li> <li>Headache</li> <li>Nausea-vomiting</li> <li>Problems with balance and co-ordination</li> <li>Unusual eye movements</li> <li>Convulsions</li> </ul>	<ul style="list-style-type: none"> <li>Walking difficulties</li> <li>Slow cognition and growth development in children</li> <li>Drowsiness</li> <li>Irritability</li> <li>Incontinence</li> <li>Lethargy</li> <li>Memory loss</li> </ul>	<ul style="list-style-type: none"> <li>Surgical implant of a shunt to divert excess CSF for absorption in another part of the body</li> <li>Rehabilitation therapies</li> </ul>
<b>Learning Disability</b>  <a href="http://www.mencap.org.uk">Mencap</a> <a href="http://www.mencap.org.uk">www.mencap.org.uk</a> <a href="http://www.enable.org.uk">ENABLE (Scotland)</a> <a href="http://www.enable.org.uk">www.enable.org.uk</a>	<ul style="list-style-type: none"> <li>Numerous specific biological causes:</li> <li>Genetic (eg. Down syndrome)</li> <li>Congenital</li> <li>Infections</li> <li>Hypoxia</li> <li>Alcohol</li> <li>Physical injury</li> <li>Profound neglect</li> </ul>	<ul style="list-style-type: none"> <li>Speech and language problems</li> <li>Intellectual impairment</li> <li>Cognition</li> <li>Coordination/balance</li> <li>Emotional and behavioural difficulties</li> </ul>	<ul style="list-style-type: none"> <li>Lack of self-care and life skills</li> <li>Sensory impairments</li> </ul>	<ul style="list-style-type: none"> <li>Special education</li> <li>Speech therapy</li> <li>Physiotherapy</li> <li>Psychological issues addressed</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Megalencephaly</b>  <a href="#">Centre for Metabolic Diseases</a> <a href="http://www.climb.org.uk">www.climb.org.uk</a> <a href="#">Contact a Family</a> <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>	<p>A disturbance in the regulation of cell production before or after birth, resulting in an enlarged head</p>	<ul style="list-style-type: none"> <li>• Seizures</li> <li>• Partial paralysis</li> <li>• Developmental delay, - abnormalities in brain-related functions</li> </ul>	<ul style="list-style-type: none"> <li>• Brain cortex and spinal cord dysfunction</li> <li>• Alexander's disease</li> <li>• Tay Sachs</li> </ul>	<p>Therapies or medication for individual disabilities within the syndrome</p>
<b>Microcephaly</b>  <a href="#">Microcephaly support group</a> <a href="http://www.microcephaly.co.uk">www.microcephaly.co.uk</a> <a href="#">Contact a Family</a> <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>	<ul style="list-style-type: none"> <li>• Genetic-abnormality in one of the microcephalin genes causing inhibition of brain growth and a small head</li> <li>• Exposure to toxins or drugs during development</li> <li>• Associated with other diseases such as fetal alcohol syndrome,</li> <li>• Chickenpox and German measles</li> </ul>	<ul style="list-style-type: none"> <li>• Neurological deficits</li> <li>• Developmental delay</li> <li>• Small body size for age</li> <li>• Face develops but skull does not grow at the same speed</li> </ul>	<ul style="list-style-type: none"> <li>• Seizures</li> <li>• Motor function deficits</li> <li>• Quadriplegia (rare)</li> <li>• Hyperactivity</li> <li>• Coordination problems</li> </ul>	<ul style="list-style-type: none"> <li>• Symptoms and disabilities may be alleviated by therapies,</li> <li>• Medication to control seizures</li> </ul>

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<p><b>Multiple Sclerosis</b></p> <p>Multiple Sclerosis Society  <a href="http://www.mssociety.org.uk">www.mssociety.org.uk</a>  MS Resource Centre  <a href="http://www.msresourcecentre.co.uk">www.msresourcecentre.co.uk</a></p>	<p>Unproven, genetic, viral or environmental causes indicated, leading to degeneration of nerve-insulating myelin</p>	<ul style="list-style-type: none"> <li>• Blurred vision</li> <li>• Tingling and numbness</li> <li>• Muscle weakness and co-ordination/balance problems</li> <li>• Cognitive problems in concentration, memory, judgement &amp; attention</li> <li>• Headaches</li> <li>• Depression</li> <li>• Apathy</li> </ul>	<ul style="list-style-type: none"> <li>• Spasticity due to loss of muscle tone</li> <li>• Occasionally, paralysis</li> <li>• Hearing impairments</li> </ul>	<ul style="list-style-type: none"> <li>• No known cure, but beta interferons have been shown to slow progress</li> <li>• Muscle relaxants may reduce spasticity</li> <li>• Myelin substitutes, antibodies and immunosuppressants</li> <li>• Therapies to maintain physical functions</li> </ul>
<p><b>Muscular Dystrophies</b>  (e.g. Duchenne, Myotonic, Facioscapulohumeral, Becker)</p> <p>Muscular Dystrophy Campaign  <a href="http://www.muscular-dystrophy.org">www.muscular-dystrophy.org</a></p>	<ul style="list-style-type: none"> <li>• Genetic</li> <li>• Impaired or absence of the protein dystrophin, which maintains muscle integrity</li> </ul>	<ul style="list-style-type: none"> <li>• Progressive weakness and degeneration of skeletal muscle.</li> <li>• Spasticity</li> <li>• Later stage - breathing problems</li> </ul>	<ul style="list-style-type: none"> <li>• Heart muscle problems</li> <li>• Endocrine abnormalities</li> <li>• Seizures</li> </ul>	<ul style="list-style-type: none"> <li>• No known cure, but beta interferons have been shown to slow progress.</li> <li>• Muscle relaxants may reduce spasticity.</li> <li>• Myelin substitutes, antibodies and immunosuppressants.</li> <li>• Therapies to maintain physical functions</li> </ul>

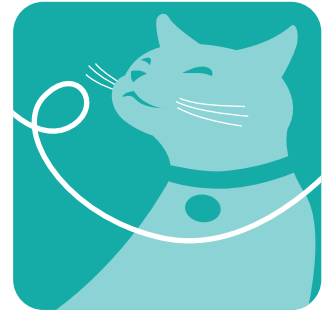


Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<p><b>Prada-Willi syndrome</b></p> <p>Prader-Willi Syndrome Association <a href="http://www.pwsa.co.uk">www.pwsa.co.uk</a></p>	<p>Gene deletion on chromosome 15</p>	<ul style="list-style-type: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

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Sleep Apnoea</b> <i>Obstructive</i>	<ul style="list-style-type: none"> <li>Relaxing and collapse of muscles supporting airway during sleep, causing blockage stopping air entering momentarily- problem worse if overweight</li> <li>Enlarged tonsils and tongue (micrognathia)</li> <li>Lack of oxygen causing brain tissue loss</li> </ul>	<ul style="list-style-type: none"> <li>Snoring</li> <li>Fatigue</li> <li>Learning/memory difficulties, mood swings</li> <li>Irritability</li> <li>Depression.</li> </ul>	<ul style="list-style-type: none"> <li>High blood pressure</li> <li>Stroke</li> <li>Arrhythmias</li> <li>Diabetes</li> </ul>	<ul style="list-style-type: none"> <li>Changing sleeping position</li> <li>Losing weight</li> <li>Surgery to remove tonsils or widen airway passage</li> </ul>
<b>Sleep Apnoea</b> <i>Central sleep apnoea or Cheyne-Stokes Respiration</i>	<ul style="list-style-type: none"> <li>Neurological controls to breathe malfunction</li> <li>Failure to respond to chemoreceptors</li> </ul>	<ul style="list-style-type: none"> <li>As in Obstructive plus epilepsy</li> <li>Cardiovascular problems</li> <li>Turning blue</li> </ul>	<ul style="list-style-type: none"> <li>Angina</li> <li>Metabolic acidosis</li> </ul>	<ul style="list-style-type: none"> <li>Life style changes including avoiding alcohol and tranquilisers</li> <li>Respiratory stimulants</li> </ul>
<b>Sleep Apnoea</b> <i>Congenital Central Hypoventilation Syndrome</i>		<ul style="list-style-type: none"> <li>Inability to breathe naturally, requiring mechanical ventilation</li> </ul>	<ul style="list-style-type: none"> <li>Sudden infant death syndrome (cot death).</li> </ul>	<ul style="list-style-type: none"> <li>Tracheotomy</li> <li>Diaphragmatic pacemaker</li> </ul>
<b>Sleep Apnoea Trust</b> <a href="http://www.sleep-apnoea-trust.org">www.sleep-apnoea-trust.org</a> <b>Obstructive SA in Children</b> <a href="http://www.patient.co.uk">www.patient.co.uk</a>				

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Spina Bifida</b>	<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"> <li>• Paralysis in lower limbs</li> <li>• Poor physical health</li> <li>• Lack of mobility</li> <li>• Bowel and bladder problems</li> <li>• Learning difficulties</li> </ul>	<ul style="list-style-type: none"> <li>• Hydrocephalus</li> <li>• Rarely, total paralysis</li> </ul>	<ul style="list-style-type: none"> <li>• Surgery to restore coverings</li> <li>• Physiotherapy and orthoses for muscle support</li> <li>• Special education</li> </ul>
<b>Tourette's syndrome</b>  <b>Tourettes Action</b> <a href="http://www.tourettes-action.org.uk">www.tourettes-action.org.uk</a> <a href="http://www.tourettes.info">www.tourettes.info</a>	<ul style="list-style-type: none"> <li>• Largely unknown.</li> <li>• Thought to arise due to problems with the <b>basal ganglia</b> in the brain.</li> <li>• This can lead to imbalances of neurotransmitters in the brain.</li> </ul> <p><b>Possible triggers</b></p> <ul style="list-style-type: none"> <li>• Genetic susceptibility</li> <li>• Childhood infection (controversial).</li> </ul>	<p>Tics:</p> <ul style="list-style-type: none"> <li>• Physical (simple) e.g. blinking, jerking, grinding teeth etc.</li> <li>• Phonological simple e.g. grunting, screaming, blowing.</li> <li>• Physical (complex) e.g. hitting, kicking, jumping, shaking, touching, copying.</li> <li>• Phonological (complex) e.g. repeating, shouting obscene words</li> </ul>	<ul style="list-style-type: none"> <li>• Obsessive Compulsive Disorder</li> <li>• ADHD</li> </ul>	<ul style="list-style-type: none"> <li>• Medication is usually only given if some behaviours interfere with normal functioning:</li> <li>• Clonidine suppresses tics</li> <li>• Antidepressants, Prozac, Zoloft, Luvox</li> <li>• Neuroleptics, Haldol, Risperdal, Geodon</li> <li>• Cognitive Behaviour Therapy</li> <li>• Relaxation Techniques</li> </ul>

Condition Information & Support	Causes	Potential Symptoms	Potentially co-existing conditions	Treatment Options
<b>Tay Sachs Disease</b>  <a href="http://www.cafamily.org.uk">Contact a Family</a> <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a> <a href="http://www.ntsad.org">National Tay-Sachs and Allied Diseases</a> <a href="http://www.ntsad.org">www.ntsad.org</a>	Genetic, inheritance of 2 recessive genes on chromosome 15 leading to inability to produce the HEX-A enzyme which breaks down fatty acids	<b>Infantile</b> - Child becomes deaf, blind and unable to swallow, atrophy of muscles and paralysis. <b>Juvenile</b> <ul style="list-style-type: none"> <li>• Cognitive</li> <li>• Motor and speech problems</li> <li>• Ataxia and spasticity.</li> </ul>	In late onset: <ul style="list-style-type: none"> <li>• Psychiatric illness</li> <li>• Schizophrenia</li> <li>• Psychosis</li> </ul>	Palliative care
<b>West syndrome</b>  <a href="http://www.epilepsy.org.uk">Epilepsy Action</a> <a href="http://www.epilepsy.org.uk">www.epilepsy.org.uk</a> <a href="http://www.ukselfhelp.info">UK Self-Help groups</a> <a href="http://www.ukselfhelp.info">www.ukselfhelp.info</a>	<ul style="list-style-type: none"> <li>• Prematurity</li> <li>• Epilepsy before 12 months of age may indicate another underlying condition</li> <li>• Tuberous sclerosis</li> <li>• Stress</li> <li>• Inability to regulate GABA is suspected</li> </ul>	<ul style="list-style-type: none"> <li>• Spasms lasting one to fifteen minutes</li> <li>• Convulsions</li> <li>• Lethargy</li> <li>• Irregular heart rhythms</li> <li>• Learning difficulties</li> <li>• Growth restriction</li> </ul>	<ul style="list-style-type: none"> <li>• Hydrocephalus</li> <li>• Microcephaly</li> <li>• Sturge-Weber synd.</li> <li>• Tuberous sclerosis</li> <li>• Genetic syndromes</li> <li>• Brain damage</li> <li>• Congenital infections</li> <li>• Encephalitis</li> <li>• Meningitis</li> <li>• Brain haemorrhage</li> <li>• Phenylketonuria</li> </ul>	<ul style="list-style-type: none"> <li>• Anticonvulsant drugs for epilepsy</li> <li>• Management of associated disorders accordingly</li> </ul>
<b>Tay Sachs Disease</b>  <a href="http://www.cafamily.org.uk">Contact a Family</a> <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a> <a href="http://www.ntsad.org">National Tay-Sachs and Allied Diseases</a> <a href="http://www.ntsad.org">www.ntsad.org</a>	Genetic, inheritance of 2 recessive genes on chromosome 15 leading to inability to produce the HEX-A enzyme which breaks down fatty acids	<ul style="list-style-type: none"> <li>• Learning difficulties</li> <li>• Elfin features with spaced teeth</li> <li>• Cardiovascular problems</li> <li>• Cognitive deficits</li> <li>• Hypercalcemia</li> <li>• Loose joints and muscle problems</li> </ul>	<ul style="list-style-type: none"> <li>• Auditory and visual problems</li> <li>• Over friendly</li> <li>• Phobias or no fears</li> <li>• Sensitive hearing</li> <li>• Kidney stones</li> </ul>	<ul style="list-style-type: none"> <li>• Avoiding calcium and vitamin D</li> <li>• Frequent monitoring of growth and blood pressures</li> </ul>



## Useful Contacts

There are a range of support organisations for specific disorders in the quick reference guide to neurodevelopmental disorders above. Additional organisations and contacts, together with further details of some of those mentioned above, are provided here.

### General

#### Ataxia UK

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

Web: [www.ataxia.org.uk](http://www.ataxia.org.uk)

Helpline: 0845 644 006

Tel: 020 7582 1444

#### Changing faces

Support for anyone affected by disfigurements of the face or body from any cause.

Web: [www.changingfaces.org.uk](http://www.changingfaces.org.uk)

Tel: 0845 4500275

#### The Children's Mitochondrial Disease Network (CMDN)

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

Web: [www.emdn-mitonet.co.uk](http://www.emdn-mitonet.co.uk)

Tel: 01606 43946

#### Climb

Support for children living with a metabolic disorder.

Web: [www.climb.org.uk](http://www.climb.org.uk)

Tel: 0800 652 3181

### The Dystonia Society

National charity providing advice and support for anyone affected by the neurological movement disorder dystonia.

Web: [www.dystonia.org.uk](http://www.dystonia.org.uk)  
Helpline: 0845 458 6322

### Genetic Interest Group

A membership of over 130 charities, which support children, families and adults with a genetic disorder.

Web: [www.gig.org.uk](http://www.gig.org.uk)  
Tel: 0207 704 3141

### Max Appeal

A support group for parents of children with DiGeorge syndrome, Velo-cardio facial syndrome (VCFS) and 22q11.2 deletion.

Web: [www.maxappeal.org.uk](http://www.maxappeal.org.uk)  
Tel: 0800 389 1049

### Meningitis Trust

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

Web: [www.meningitis-trust.org](http://www.meningitis-trust.org)  
Free phone helpline: 0800 028 1828  
Tel: 01453 768001

### PKU Exchange

Provide information on PKU and the PKU diet.

Web: [www.pkuexchange.co.uk](http://www.pkuexchange.co.uk)

### SOFT

Support Organisation For Trisomy 13/18 and related disorders.

Web: [www.soft.org.uk](http://www.soft.org.uk)  
Tel: 01213 513122



## Unique

Rare chromosome disorder support group.

Web: [www.rarechromo.co.uk](http://www.rarechromo.co.uk)

Helpline: 01833 330 766

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

Web: [www.rarechromo.org/html/LittleYellowBook.asp](http://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](http://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](http://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](http://www.rnib.org.uk)

Helpline: 0303 123 9999

Tel: 020 7388 1266

## Royal Association for Deaf People (RAD)

Promote the welfare and interests of deaf people.

Web: [www.royaldeaf.org.uk](http://www.royaldeaf.org.uk)

Tel: 0845 688 2525

Minicom: 0845 688 2527

## Royal National Institute Deaf People (RNID)

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.rnid.org.uk](http://www.rnid.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](http://www.sense.org.uk)

Tel: 0845 127 0060

Textphone: 0845 127 0062

# General Sources of Support

## Ableize

Directory of disability information aids and mobility services, and sports and holidays, as well as listings for groups, clubs and charities.

Web: [www.ableize.com](http://www.ableize.com)

## Barnardos

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

Web: [www.barnardos.org.uk](http://www.barnardos.org.uk)

Tel: 020 8550 8822





### Bibic

A charity promoting home based therapy for children with a range of neurodevelopmental disorders.

Web: [www.bibic.org.uk](http://www.bibic.org.uk)  
Tel: 01278 684060

### Brain and Spine Foundation

Information and resources for people with neurological conditions.

Web: [www.brainandspine.org.uk](http://www.brainandspine.org.uk)  
Tel: 0808 808 1000

### Brain Injury Rehabilitation Trust (BIRT)

Helps people regain skills following a brain injury.

Web: [www.birt.co.uk](http://www.birt.co.uk)  
Tel: 01924 896100

### Brainwave

A charity offering individualised therapy for children with a range of neurodevelopmental disorders.

Web: [www.brainwave.org.uk](http://www.brainwave.org.uk)  
Tel : 01278 429 089

### Carers UK

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

Web: [www.carersuk.org](http://www.carersuk.org)  
Adviceline: 0808 808 7777  
Tel: 0207 378 9781

### Care Co-ordination Network UK (CCNUK)

Promoting and supporting care co-ordination or key working for disabled children.

Web: [www.ccnuuk.org.uk](http://www.ccnuuk.org.uk)

Tel: 01904 567 303

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

Parent support line: 0800 328 1159

Stress helpline: 0800 439 385

### Challenging Behaviour Foundation

Provides information and support to parents and carers of individuals with severe learning disabilities who are described as having challenging behaviour.

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

Support from Family Support worker : 0845 602 7885

Tel: 01634 838 739

### Charge

Charge is a syndrome with multiple conditions. The group has a network of families who aim to promote and support all activities leading to an improved quality of life for their children.

Web: [www.chargesyndrome.org.uk](http://www.chargesyndrome.org.uk)

Tel: 020 8265 3604

### Child Brain Injury Trust UK (CBIT)

Offers support and information on childhood acquired brain injury.

Web: [www.cbit.co.uk](http://www.cbit.co.uk)

Helpline: 0845 601 4939

### Children's Legal Centre

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

Web: [www.frg.org.uk](http://www.frg.org.uk)

Helpline: 08088 020 008

Family Rights Group: 0808 801 0366



### 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](http://www.cafamily.org.uk)  
[www.cafamily.org.uk/medicalinformation/conditions/azlistings/a.html](http://www.cafamily.org.uk/medicalinformation/conditions/azlistings/a.html)  
[www.makingcontact.org](http://www.makingcontact.org)

Helpline: 0808 808 3555  
Tel: 020 7608 8700  
Textphone: 0808 808 3556

### Crossroads

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 disabilities and health conditions..

Web: [www.crossroads.org.uk](http://www.crossroads.org.uk)  
Tel: 0845 450 0350

### Cry-sis

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

Web: [www.cry-sis.org.uk](http://www.cry-sis.org.uk)  
Helpline: 08451 228 669

### Dial UK

Provide a range of location- specific disability information .

Web:[www.dialuk.info](http://www.dialuk.info)

### Directgov

A range of information for parents – from finances to education. A general source of information.

Web:[www.direct.gov.uk](http://www.direct.gov.uk)

### Face to Face

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

Web: [www.face2facenetwork.org.uk](http://www.face2facenetwork.org.uk)

Tel: 0844 800 9189

### Family Rights Group

Provides advice and support for families whose children are involved with social services.

Web: [www.frg.org.uk](http://www.frg.org.uk)

Helpline: 0808 801 0366

Tel: 020 7923 2628

### Headway

Provides support following a brain injury.

Web: [www.headway.org.uk](http://www.headway.org.uk)

Helpline: 0808 800 2244

Tel: 0115 924 0800

### Henry Spink Foundation

A charity that helps families to learn more about varying diagnoses and to find alternative methods of treatment.

Web: [www.henryspink.org](http://www.henryspink.org)

### Home Start

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

Web: [www.home-start.org.uk](http://www.home-start.org.uk)

Tel: 0800 068 6368

Tel: 0166 2587900

### Incentive Plus

Resources to promote social, emotional and behavioral skills.

Web: [www.incentiveplus.co.uk](http://www.incentiveplus.co.uk)

Tel: 0845 180 0140



### Mencap

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

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

Helpline: 0808 808 1111

Tel: 0121 707 7877

### Mumsnet

Provides the opportunity to talk to other parents about their experiences.

Web: [www.mumsnet.com](http://www.mumsnet.com)

### National Institute of Clinical Excellence (NICE)

Independent organization responsible for creating guidelines on good health and prevention and treatment of ill health.

Web: [www.nice.org.uk](http://www.nice.org.uk)

Tel: 0845 003 7780

### National Institute of Neurological Disorders and Stroke (NINDS)

Provides information on a variety of neurological disorders, and stroke.

Web: [www.ninds.nih.gov](http://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](http://www.neural.org.uk)

Tel: 020 7584 6457

## NHS Choices

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

Web: [www.nhs.uk/Conditions/Pages/bodymap.aspx](http://www.nhs.uk/Conditions/Pages/bodymap.aspx)

## NHS Choices Carers Direct

A range of information and support for carers.

Web: [www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx](http://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](http://www.nhsdirect.nhs.uk)

Tel: 0845 4647

Textphone: 0845 606 4647

## Parent Partnership Network.

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

Web: [www.parentpartnership.org.uk](http://www.parentpartnership.org.uk)

Tel: 0207 843 6058

## Parentline Plus

Provides help and support for anyone in a parenting role.

Web: [www.parentlineplus.org.uk](http://www.parentlineplus.org.uk)

Helpline: 0808 800 2222

Tel: 020 7284 5500

Textphone: 0800 783 6783

## National Portage Association

Offers support and information to parents and professionals involved in Portage, a home visiting educational service for pre- school children with additional support needs and their families.

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

Tel: 0121 244 1807



### The Princess Royal Trust for Carers

Provides information, support and practical help for carers through 144 Carers' Centres in the UK.

Web: [www.carers.org](http://www.carers.org)  
Tel: 0844 800 4361

### Royal College of Psychiatry

Professional and educational body for psychiatrists.

Web: [www.rcpsych.ac.uk](http://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](http://www.scope.org.uk)  
Tel: 0808 800 3333  
Text: SCOPE plus message to 80039

### SNIP

Information and advice on services available to children with additional support needs.

Web: [www.snipinfo.org](http://www.snipinfo.org)  
Helpline: 0131 536 0583  
Tel: 0131 536 0360

### UK Self-help

A database of over 1000 self-help organisations, patient support groups and charities.

Web: [www.ukselfhelp.info](http://www.ukselfhelp.info)

## 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](http://www.youngminds.org.uk)  
Parents helpline: 0808 802 5544  
Tel: 020 7336 8446

## Information on therapies

### Action Against Allergy

Provides information about diagnosis and treatment of allergies in the National Health Service (NHS).

Web: [www.actionagainstallergy.co.uk](http://www.actionagainstallergy.co.uk)  
Tel: 020 8892 2711

### Afasic

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

Web: [www.afasic.org.uk](http://www.afasic.org.uk)  
Helpline: 0845 355 5577  
Tel: 020 7490 9410

### Aromatherapy Council

Offers information on aromatherapy and member associations.

Web: [www.aromatherapycouncil.co.uk](http://www.aromatherapycouncil.co.uk)  
Tel: 0870 7743 477

### Association of Reflexologists

A non-profit making membership organisation providing support to professionally qualified practitioners.

Web: [www.aor.org.uk](http://www.aor.org.uk)  
Tel: 01823 351010





### 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](http://www.helpwithtalking.com)  
Tel: 01494 488 306

### Bibic

Developmental therapy provider.

Web: [www.bibic.org.uk](http://www.bibic.org.uk)  
Tel: 01278 684 060

### Brainwave

Parent training of exercise techniques tailored to their individual child.

Web: [www.brainwave.org.uk](http://www.brainwave.org.uk)  
Tel: 01278 429 089

### 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](http://www.cot.co.uk)  
Tel: 020 7357 6480

### British Association for Applied Nutrition and Nutritional Therapy

Professional body which gives details of how to contact a therapist and also how to train as one.

Web: [www.bant.org.uk](http://www.bant.org.uk)  
Tel: 0870 6061284

### British Homeopathic Association

Charity which promotes homeopathy and raises money for research and the training of doctors, vets and other health care professionals in homeopathy.

Web: [www.britishhomeopathic.org](http://www.britishhomeopathic.org)  
Tel: 01582 408675

### British Medical Acupuncture Society

A group of medical doctors promoting the use and scientific knowledge of acupuncture. Web: [www.medical-acupuncture.co.uk](http://www.medical-acupuncture.co.uk)

Tel: 01606 786782

### British Reflexology Association

Acts as a representative body for persons practising the method of Reflexology as a profession and for students training in the method. The Association also aims to help promote the practice of Reflexology in Great Britain and abroad.

Web: [www.britreflex.co.uk](http://www.britreflex.co.uk)  
Tel: 01886 821 207

### British School of Osteopathy

Largest and the oldest school of osteopathy in the United Kingdom.

Web: [www.bso.ac.uk](http://www.bso.ac.uk)  
Tel: 020 7407 0222 (Teaching centre); 020 7089 5330 ( Research)

### Chartered Society of Physiotherapy

A member-led organisation governed by an elected Council. They provide a wide range of member services and campaign on behalf of physiotherapists and the physiotherapy profession.

Web: [www.csp.org.uk](http://www.csp.org.uk)  
Tel: 020 7306 6666

### Dietitians Unlimited

Provides contact details of freelance dietitians that work independently in the broad areas of food, nutrition and dietetics.

Web: [www.dietitiansunlimited.co.uk](http://www.dietitiansunlimited.co.uk)



### EEG Neurofeedback

The UK's only comprehensive provider of full-time professional EEG Neurofeedback training services to individuals and organisations.

Web: [www.eegneurofeedback.com](http://www.eegneurofeedback.com)  
Tel: 01727 874 292

### Electronic Medicines Compendium

Provides information about a vast range of medicines.

Web: [www.emc.medicines.org.uk](http://www.emc.medicines.org.uk)  
Tel: 01372 388381

### Incredible Years Cymru

Its aim is to develop and promote evidence based interventions for children with conduct disorders and their families.

Web: [www.incredibleyears.wales.co.uk](http://www.incredibleyears.wales.co.uk)  
Tel: 01248 383 758

### Hyperactive Children's Support Group (HACSG)

A charity that provides information on the dietary approach to ADHD.

Web: [www.hacsg.org.uk](http://www.hacsg.org.uk)  
Tel: 01243 539 966

### International Association of Infant Massage (IAIM)

Provides information and training in the use of baby massage.

Web: [www.iaim.org.uk](http://www.iaim.org.uk)  
Tel: 020 8989 9597

### General Council for Massage Therapy

Provides information on massage and offers signposting to registered masseurs.

Web: [www.gcmt.org.uk](http://www.gcmt.org.uk)  
Tel: 0870 850 4452

### National Institute of Conductive Education

A charity providing direct services to children and adults with motor disorders.

Web: [www.conductive-education.org.uk](http://www.conductive-education.org.uk)

Tel: 0121 449 1569

### 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](http://www.nhsdirectory.org)

### OT Direct

An independent site for Occupational Therapists, OT Assistants and OT students.

Web: [www.otdirect.co.uk](http://www.otdirect.co.uk)

### Parents for the Early Intervention of Autism in Children (Peach)

A parent-led charity that is committed to promoting early interventions (particularly ABA)

Web: [www.peach.org.uk](http://www.peach.org.uk)

Tel: 01344 882248

### Peakmind

A reputable neurofeedback centre based in Swansea, South Wales, but can offer services in England also.

Web: [www.peakmind.co.uk](http://www.peakmind.co.uk)

Tel: 01792 828 242

### Pyramid Educational Consultants

Are the UK providers of PECS.

Web: [www.pecs.org.uk](http://www.pecs.org.uk)

Tel: 01273 609 555

### 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](http://www.rcslt.org)

Tel: 020 7378 1200



### Sensory Integration UK

Information on sensory integration therapy, and a list of therapists who are members.  
Web: [www.sensoryintegration.co.uk](http://www.sensoryintegration.co.uk)

Tel: 01751 432298

### Sign Along Group

A charity helping children and adults with communication problems via a sign supporting system based on British Sign Language.

Web: [www.signalong.org.uk](http://www.signalong.org.uk)

Tel: 0845 450 8422

### Society of Applied Neuroscience.

The organisation to which most neurofeedback practitioners belong.

Web: [www.applied-neuroscience.org](http://www.applied-neuroscience.org)

Tel: 01792 295 908

### Society of Homeopaths

Online searchable register of qualified practitioners, articles, online leaflets and list of accredited schools.

Web: [www.homeopathy-soh.org](http://www.homeopathy-soh.org)

Tel: 0845 450 6611

### The Bobath Centre

The Bobath Centre specialises in: the treatment of cerebral palsy in children and adults; Bobath training courses; and cerebral palsy research in the UK.

Web: [www.bobath.org.uk](http://www.bobath.org.uk)

Tel: 0208 444 3355

### The British Acupuncture Council

The main regulatory body for acupuncture in the UK.

Web: [www.acupuncture.org.uk](http://www.acupuncture.org.uk)

Tel: 020 8735 0400

### The British Complementary Medicine Association

Offers a variety of resources on many complementary and alternative medicines, accredited therapists and training.

Web: [www.bcma.co.uk](http://www.bcma.co.uk)

Tel: 0845 345 5977

### The General Chiropractic Association

Sets standards for chiropractors and information for customers on available registered chiropractors.

Web: [www.gcc-uk.org](http://www.gcc-uk.org)

Tel: 020 7713 5155

### The General Osteopathic Council

Provides details of registered UK osteopaths.

Web: [www.osteopathy.org.uk](http://www.osteopathy.org.uk)

Tel: 020 7357 6655

### The Gray Centre for Social Learning and Understanding (USA)

This is the founder of Social Stories™, offering information and guidance about writing social stories, with some sample stories and allied merchandise for sale.

Web: [www.thegraycenter.org](http://www.thegraycenter.org)

Tel: - +1 (616) 748 6030

### 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](http://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](http://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](http://www.nas.org.uk/earlybird)  
Tel: 01226 779218

### The National Institute of Medical Herbalists

Offers information on herbalism and a service to locate a registered herbal practitioner.

Web: [www.nimh.org.uk](http://www.nimh.org.uk)  
Tel: 01392 426 022

### Transcendental Meditation

Offers information and advice.

Web: [www.t-m.org.uk](http://www.t-m.org.uk)  
Tel: 01695 51213

### UK Young Autism Project (UK YAP)

Provides centre-based services in London, Birmingham and Bristol and can offer consultancy-based services elsewhere in the UK.

Web: [www.ukyap.org](http://www.ukyap.org)  
Tel: 020 8947 8373

## Daily living

### 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](http://www.eric.org.uk) and [www.ericshop.org.uk](http://www.ericshop.org.uk)

Helpline: 0845 370 8008

Tel: 0117 9603060

### PINNT

PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy) is a support group for patients receiving parenteral or enteral nutrition therapy.

Web: [www.pinnt.com](http://www.pinnt.com)

## 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](http://www.abilitynet.org.uk)

Tel: 0800 269545

Minicom: 01926 312847

### Action for Kids

Provides mobility aids.

Web: [www.actionforkids.org](http://www.actionforkids.org)

Helpline: 0845 300 0237

Tel: 020 8347 8111

Minicom: 020 8347 3486

### Assist

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

Web: [www.assist-uk.org](http://www.assist-uk.org)

Tel: 0161 238 8776 0870 770 2866





### Cerebra

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

Web: [www.cerebra.org.uk/grants](http://www.cerebra.org.uk/grants)  
Helpline: 0800 328 1159

### Disabled Living Foundation

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

Web: [www.dlf.org.uk](http://www.dlf.org.uk)  
Helpline: 0845 130 9177  
Textphone: 020 7432 8009  
Switchboard: 0207 289 6111

### 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](http://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](http://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](http://www.motability.co.uk)  
Tel: 0845 456 4566  
Textphone: 0845 675 0009

## The Disability Equipment Register (DER)

A database of specialist equipment for people with disabilities, listing items either for sale privately, or wanted.

Web: [www.disabilityequipment.org.uk](http://www.disabilityequipment.org.uk)  
Tel: 01454 318818

## 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](http://www.familyfund.org.uk)  
Tel: 0845 130 4542  
Minicom: 01904 658 085

## Whizz-kidz

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

Web: [www.whizz-kidz.org.uk](http://www.whizz-kidz.org.uk)  
Tel: 0207 233 6600 (national rate)  
0845 052 1231 (local rate)

# Sensory

## Sensory Developments

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

Web: [www.sensorydevelopments.co.uk](http://www.sensorydevelopments.co.uk)  
Tel: 01284 826012

## Sensory Plus

Provides sensory products and advice.

Web: [www.sensoryplus.co.uk](http://www.sensoryplus.co.uk)  
Tel: 0800 212709



### Sensory UK

Provides a range of sensory equipment.

Web: [www.sensoryuk.co.uk](http://www.sensoryuk.co.uk)

Tel: 0845 6385 111

### Spacekraft

Offers a range of sensory and interactive equipment.

Web: [www.spacekraft.co.uk](http://www.spacekraft.co.uk)

Tel: 01274 581 007

### Special Needs Toys

Offer a range of special needs toys.

Web: [www.uk.specialneedstoys.com](http://www.uk.specialneedstoys.com)

Tel: 01299 827820

### The Sensory Company

Offers a vast range of sensory equipment.

Web: [www.thesensorycompany.co.uk](http://www.thesensorycompany.co.uk)

Tel: 0845 838 22 33

## Education

### Advisory Centre for Education (ACE)

A charity that offers information and advice to parents and carers on a range of school based issues, including exclusion, special educational needs, admissions, and bullying.

Web: [www.ace-ed.org.uk](http://www.ace-ed.org.uk)  
Helpline: 0808 800 5793(general)  
0808 800 0327(exclusions)

### Bullying

Advice and support for anyone being bullied.

Web: [www.bullying.co.uk](http://www.bullying.co.uk)

### Family Information Service (FIS)

Provides 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.nafis.org.uk](http://www.nafis.org.uk)  
Tel: 0207 953 4085

### Independent Schools Council (ISC)

Information about SEN in private schools and offers a school search service.

Web: [www.isc.co.uk/ParentZone\\_Welcome.htm](http://www.isc.co.uk/ParentZone_Welcome.htm)

### IPSEA (Independent Panel for Special Education and Advice)

Advice and support on all aspects of special education, including help with second options on children's educational needs.

Web: [www.ipsea.org.uk](http://www.ipsea.org.uk)  
Helpline: 0800 018 4016  
Tel: 01394 446575  
Tribunal support: 0845 6029579



## National Association for Special Educational Needs (NASEN)

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

Web: [www.nasen.org.uk](http://www.nasen.org.uk)

Tel: 01827 311 500

## Parents for Inclusion

A network of parents of children with disabilities and children with 'special needs', working to promote inclusion.

Web: [www.parentsforinclusion.org](http://www.parentsforinclusion.org)

Freephone helpline: 0800 652 3145

## Recreation

### Action for Leisure

Information and advice on play and leisure activities for children and adolescents with disabilities.

Web: [www.inclusive.co.uk/support/actleisure.shtml](http://www.inclusive.co.uk/support/actleisure.shtml)

Tel: 01457 819790

### English Federation of Disabled Sports

Information and advice about sport for people with disabilities.

Web: [www.efds.co.uk](http://www.efds.co.uk)

Tel: 0161 247 5294

### Get Kids Going

Helping to get children with disabilities into sport.

Web: [www.getkidsgoing.com](http://www.getkidsgoing.com)

Tel: 020 7481 8110

### National Association of Toy and Leisure Libraries.

Supports all toy libraries across the UK that loan play equipment to all children. Can also advise on suitable play resources.

Web: [www.natll.org.uk](http://www.natll.org.uk)  
Tel: 020 7428 2280

### 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](http://www.phab.org.uk)  
Tel: 020 8667 9443

### Playwork Partnerships

Play activities for children with disabilities.

Web: [www.playwork.co.uk](http://www.playwork.co.uk)  
Tel: 01242 714601

### Riding for the Disabled Association

Information on horse riding for therapy, achievement and enjoyment.

Web: [www.riding-for-disabled.org.uk](http://www.riding-for-disabled.org.uk)  
Tel: 0845 658 1082

### School Sports and Disabled Children

Information regarding support for disability sports and finding out about local facilities.

Web: [www.direct.gov.uk/en/DisabledPeople/Everydaylifeandaccess/SportsAndHobbies/DG\\_4017665](http://www.direct.gov.uk/en/DisabledPeople/Everydaylifeandaccess/SportsAndHobbies/DG_4017665)

### Special Needs Kids

Provides a list of suggestions for days out suitable for children with special needs.

Web: [www.special-needs-kids.co.uk](http://www.special-needs-kids.co.uk)



## Childcare

### 4 Children

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

Web: [www.4children.org.uk](http://www.4children.org.uk)  
Tel: 020 7512 2112

### Childcare Alliance

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

Web: [www.pre-school.org.uk/what-we-do/childcare-services](http://www.pre-school.org.uk/what-we-do/childcare-services)  
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.nafis.org.uk](http://www.nafis.org.uk)

Tel: 0207 953 4085

## Holidays and short breaks

### 3H Fund (Help the Handicapped Holiday Fund)

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

Web: [www.3hfund.org.uk](http://www.3hfund.org.uk)  
Tel: 01892 860207

### Break

A charity that provides holidays and respite care for children and adults with disabilities, and their families.

Web: [www.break-charity.org](http://www.break-charity.org)  
Tel: 01263 822 161

## Directgov

Explains more about short breaks and can put you in contact with your local authority to make an application.

Web: [www.direct.gov.uk/en/CaringForSomeone/HealthAndTakingABreak/DG\\_4000163?CID=DWP&TYPE=Sponsoredsearch&CRE=TimeOut](http://www.direct.gov.uk/en/CaringForSomeone/HealthAndTakingABreak/DG_4000163?CID=DWP&TYPE=Sponsoredsearch&CRE=TimeOut)

## Scope (residential short breaks)

Provides opportunities for short breaks.

Tel: 0808 800 333

Web: [www.scope.org.uk/education/breaks.php](http://www.scope.org.uk/education/breaks.php)

## Shared Care 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.sharedcarenetwork.org.uk](http://www.sharedcarenetwork.org.uk)

Tel: 0117 941 5361

Textphone: 0117 941 5364

## The Children's Trust

Provides short breaks for children with multiple disabilities, complex health needs and acquired brain injury.

Web: [www.thechildrenstrust.org.uk](http://www.thechildrenstrust.org.uk)

Tel: 01737 365 000

## 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](http://www.direct.gov.uk/disability-money)

Tel: 0800 882 200  
Textphone: 0800 243 355

### Benefits Now

Benefits and health information service.

Web: [www.benefitsnow.co.uk](http://www.benefitsnow.co.uk)





### 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](http://www.citizensadvice.org.uk) or [www.adviceguide.org.uk](http://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/publications.html?scat=37](http://www.cafamily.org.uk/publications.html?scat=37)

Helpline: 0808 808 3555

Textphone: 0808 808 3556

Tel: 020 7608 8700

### Directgov

Provides information on financial support for carers.

Web: [www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG\\_10037637](http://www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG_10037637)

### SNIP Funder Finder

Can conduct funding searches on your behalf. Can also help you fill in any benefit related forms.

Web: [www.snipinfo.org/Fundfinder.pdf](http://www.snipinfo.org/Fundfinder.pdf)

Helpline: 0131 536 0583

Textphone: 0131 536 0360

## Family relationships

### Be Grand

The website for grandparents. If you search 'special educational needs' there is a range of useful information available.

Web: [www.begrand.net](http://www.begrand.net)

Tel: 0845 423 5565

### Contact a Family

Provides information and support for fathers.

Web: [www.cafamily.org.uk/families/familyissues/dads/index.html](http://www.cafamily.org.uk/families/familyissues/dads/index.html)

Tel: 0808 808 3555

Textphone: 0808 808 3556

### Relate

Provides relationship counselling.

Web: [www.relate.org.uk](http://www.relate.org.uk)

Tel: 0300 100 1234

### Relate for parents and 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/](http://www.relateforparents.org.uk/)

Helpline: 0300 100 1234

### SIBS

For brothers and sisters of children and people with special needs, disability or chronic illness. Their purpose is to make a positive difference to the lives of siblings- to make growing up with someone with special needs a bit easier.

Web: [www.sibs.org.uk](http://www.sibs.org.uk)

Tel: 01535 645 453

### The Couple Connection

Is a self-help website.

Web: [www.thecoupleconnection.net](http://www.thecoupleconnection.net)



## Single parents

### Child Maintenance Options Service

Impartial information and support to help both parents assess their child maintenance options.

Web: [www.cmoptions.org](http://www.cmoptions.org)  
Free phone: 0800 988 0988

### Dads UK

Provide information and support for single dads.

Web: [www.dads-uk.co.uk](http://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](http://www.gingerbread.org.uk)  
Helpline: 0808 802 0925  
Tel: 020 7428 5400

# Glossary

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

**Apgar score** - A simple and repeatable method to quickly and summarily assess the health of newborn children immediately after childbirth.

**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.

**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.

**Degeneration** - The state or process of deterioration.

**Development** - A specified state of growth or advancement.

**Disinhibition** - The process of becoming less inhibited or less self-aware.

**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.

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

**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.

**Electrode** - A conductor through which electricity enters or leaves an object.

**Endocrine** - Relating to, or denoting, glands which secrete hormones or other products directly into the blood.



**Enzymes** - A substance produced by a living organism, which acts as a catalyst to bring about a specific biochemical reaction.

**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.

**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.

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

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

**Interferons** - Naturally occurring substances that interfere with the ability of viruses to reproduce. They also boost the immune system. There are a number of different interferons. They fall into three main classes: alpha, beta, and gamma. All are proteins (lymphokines) normally produced by the body in response to infection.

**Intrauterine** - Within the uterus (womb).

**Malformation** - An abnormally formed part of the body.

**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.

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

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

**Nervous system** - The network of nerve cells and fibres, which transmits nerve impulses between parts of the body.

**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.

**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 goes beyond the bounds of usual childhood behaviour

**Orthoses** - Orthopaedic appliances used for support.

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

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

**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.

**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.

**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.

**Teratogen** - An agent or factor, which causes malformation of an embryo.

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

**Trauma** - A deeply distressing or disturbing experience.

**Vacuum extraction** - The application of reduced pressure to extract something, particularly to assist childbirth.

**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

**Early Support** is the Government's programme to improve the quality, consistency and coordination of services for young disabled children and their families across England. **Early Support** is funded and managed by the Department for Children Schools and Families (DCSF) and is an integral part of the wider Aiming High for Disabled Children (AHDC) programme, jointly delivered by DCSF and the Department of Health. The AHDC programme is seeking to transform the services that disabled children and their families receive.

**Early Support** is targeted at families with babies or children under five with additional support needs associated with disability or emerging special educational needs although the principles of partnership working with families can be applied across the age range. This partnership working between families and professionals means that families remain at the heart of any discussions or decisions about their child – their views are listened to and respected and their expertise is valued by the professionals working with them.

To find out more about the **Early Support** programme and associated training or to view or download other materials produced by the programme, visit [www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport)

This booklet is one in a series produced in response to requests from families, professional agencies and voluntary organisations for better standard information about particular conditions or disabilities. This is the first edition of the booklet. The other titles in the series are:

Cerebral palsy (ES10)

Autistic spectrum disorders (ASDs) and related conditions (ES12)

If your child has a rare condition (ES18)

Learning disabilities (ES15)

Down syndrome (ES13)

Deafness (ES11)

Speech and language difficulties (ES14)

Multi-sensory impairment (ES9)

Visual impairment (ES8)

When your child has no diagnosis (ES16)

Sleep (ES82)

Behaviour (ES81)



Other [Early Support](#) information about services is available separately, or as part of the Early Support [Family pack](#). The Family pack helps families who come into contact with many different professionals to co-ordinate activity and share information about their child through the first few years of life, using a [Family file](#).

These are resources that families say make a difference. If your family is receiving regular support from professionals, please feel free to ask them about the [Early Support family pack](#). It may help and is available free of charge.

[Early Support](#) would like to thank the many families and professionals that have been involved in the development of these resources, and to thank [Cerebra](#) and all the parents and families who were involved in producing this material for their help in writing this booklet.

### [Cerebra](#)

Cerebra 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.

Second Floor Offices,  
The Lyric Building, King Street  
Carmarthen  
SA31 1BD

Parent support helpline: 0800 328 1159  
Fax: 01267 244201

Web: [www.cerebra.org.uk](http://www.cerebra.org.uk)  
Email: [info@cerebra.org.uk](mailto:info@cerebra.org.uk)

Copies of this publication can be obtained from:

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PO Box 5050  
Sherwood Park  
Annesley  
Nottingham NG15 0DJ

Tel: 0845 602 2260  
Fax: 0845 603 3360  
Textphone: 0845 605 5560

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1st edition

[www.dcsf.gov.uk/everychildmatters/earllysupport](http://www.dcsf.gov.uk/everychildmatters/earllysupport)

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