Acute Training Solutions

Introduction to Learning Disabilities - Type Details

Down's syndrome

Down's syndrome is caused by an extra chromosome. Chromosomes are structures that contain genes - these contain the instructions for life and are inherited from parents. Normally, our cells contain 46 chromosomes: 23 inherited from each parent. In Down's syndrome a mistake is made during cell division, this is most likely to occur when the sperm or egg is being formed causing 24 chromosomes to be present rather than the usual 23. After the egg is fertilised by the sperm the cells have 47 chromosomes rather than the normal 46 chromosomes.

Types of Down's syndrome

- Trisomy 21 - this is when all the cells have an extra chromosome 21. This happens in most people with Down's syndrome.
- Translocation - this is when an extra fragment of chromosome 21 attaches to another chromosome. This happens in about one in 25 people with Down's syndrome.
- Mosaicism - this is when only some cells have an extra chromosome 21 while others don't. This happens in about one in 50 people with Down's syndrome.

Symptoms of Down's syndrome

The extra chromosome 21 causes characteristic physical features in people with Down's syndrome. These usually include some, but not always all, of the following:

- Low-set eyes that slope upwards, with vertical skin folds (epicanthic folds) between the upper eyelids and the inner corner of the eye.
- A small mouth, which means the tongue may seem big and may stick out.
- A flattening at the back of the head.
- A flattened nose bridge.
- Broad hands with a single crease.
- Floppiness due to loose muscle tone.
- Small, low-set ears.
- A low birth weight and short stature.

Many of these physical features can be found in the general population; having some of these characteristics doesn't necessarily mean that a person has Down's syndrome.

Complications of Down's syndrome

People with Down's syndrome are more likely to have the following:

- Heart problems.
- Eye problems, such as short- or long-sightedness or cataracts (cloudy patches in the lens of the eye).
- Hearing problems, ranging from mild to complete deafness.
- Thyroid problems, including low or more rarely, high levels of the thyroid hormones.
- Poor immunity and so are prone to chest infections, coughs and colds.
- Problems with the digestive system, such as persistent diarrhoea or constipation; babies may have feeding problems and may not gain weight normally.
- Dementia at an earlier age (it occurs 20 to 30 years earlier than in the rest of the population).

It's important for people with Down's syndrome to have regular health checks so that these conditions can be diagnosed and treated at an early stage.

Development

All people with Down's syndrome have some level of learning disability but the severity can differ between individuals. Children usually learn to walk, talk, read and write, but more slowly than other children of their age. People with Down's syndrome learn to do things throughout their lives at different rates.

Causes of Down's syndrome

Down's syndrome is caused by an extra chromosome. This happens as a result of a problem in cell division but it's not known what causes that to happen. However, the chance of having a baby with Down's syndrome increases with the mother's age. For women, the chance of having a baby with Down's syndrome at:

- age 20 - is one in 1500
- age 30 - is one in 900
- age 40 - is one in 100

However, most babies with Down's syndrome are born to women under 35, since these women account for the majority of the childbearing population.

The chance of you having a baby with Down's syndrome has nothing to do with where you live, your social class or your race. You can't do anything before or during pregnancy to change the chance of your baby having Down's syndrome.

Diagnosis of Down's syndrome

Babies with Down's syndrome are usually diagnosed in the first few days after birth. Doctors and midwives are trained to identify the physical characteristics associated with the condition. Some babies have almost no physical signs while others have all of them. A chromosome test is then used to confirm the diagnosis. The doctor will take a blood sample from the baby. This is sent to a laboratory for tests.

There are also screening tests for Down's syndrome that you can have while you're pregnant. Screening takes place during either the first trimester (three months) or second trimester (six months) by either ultrasound or through a blood test, or a combination of both. Screening tests don't give a definite answer, but can tell you if your baby has an increased risk of having Down's syndrome.

If the screening tests show that your baby has an increased risk of having Down's syndrome; you will be offered further diagnostic tests, such as chorionic villus sampling (following a first-trimester screening test) or amniocentesis (following a second-trimester screening test). These tests involve some risk to mother and baby so are usually only offered to women if earlier screening tests suggest the baby is likely to have Down's syndrome. For more information about these tests, see related topics.

Living with Down's syndrome

People with Down's syndrome have special medical and social needs, but they can live full lives, take part in further education, have jobs and relationships, and live independently.

Medical and social support

A team of professionals will help support people with Down's syndrome, and their families. This team may include your GP, a paediatrician, midwife, health visitor, occupational and speech therapists and a physiotherapist for example.

Specialist doctors monitor all babies with Down's syndrome for health problems, and children with the condition have regular growth, hearing and sight, and thyroid checks. It's also important for adults with Down's syndrome to have regular sight, hearing and thyroid function tests.

Occupational therapists and dieticians can help with issues such as nutrition and educational support. Most children with Down's syndrome go to mainstream schools, but there are schools for children with special needs.

www.bupa.co.uk

acute
TRAINING SOLUTIONS LTD

Autistic spectrum disorders

According to the National Autistic Society, over 500,000 people in the UK have an ASD. A study published in 2006 shows that as many as one in 100 children may have an ASD.

Children with an autistic spectrum disorder (ASD) don't develop the social and language skills that other children do. As a result, they find relating to other people difficult. They may also have unusual behaviours and learning difficulties.

The word 'spectrum' is used because ASDs vary widely from person to person and affect people to different extents. Autistic spectrum disorders include autism and Asperger syndrome.

Autism

Children with autism have difficulty communicating and interacting with others. This is often first noticed by the time they are two. Some children with autism may have learning difficulties. Autism is four times more common in boys than girls.

Asperger syndrome

Asperger syndrome is similar to autism, but is usually less severe. Children with Asperger syndrome generally communicate better than those with autism and have average or above average intelligence. They don't usually have the learning difficulties seen in children with autism.

Symptoms of autistic spectrum disorders

Children with an ASD have three main types of problems. These are to do with their:

- communication
- social development
- interests and behaviour (social imagination)

Communication

Children with ASDs don't develop the usual speech or non-verbal (eg pointing) skills of other children the same age. They may also have trouble with understanding meaning in spoken or written language.

Your child may have a very literal sense of language, and be unable to understand jokes or sarcasm. He or she may also find it difficult to read body language and facial expressions.

Your child may also:

- not babble or point by the age of one
- not respond to his or her name
- not learn two words by the age of two
- repeat words he or she has heard over and over again

Older children may have an unusual use of language, and difficulty starting or keeping up conversations.

Children with severe autism may never speak at all but can be helped to communicate in other ways, such as through signing or using picture symbols.

Social development

Children with an ASD have difficulty making friends and getting on well with their peers. They also find it difficult to understand how other people feel and may be unable to cope with new situations. Your child may:

- seem very independent as a toddler and aloof when older
- have poor eye contact

- not seek affection and resist being cuddled or kissed
- seem to be 'in a world of their own'
- not understand other people's thoughts and emotions
- find it difficult to accept simple social rules, causing problems at school
- find it difficult to manage emotions, which may be expressed as outbursts of anger or aggression.

Children with an ASD can be affectionate, but may may find it difficult to interpret another person's need for affection.

Behaviour and interests

Children with an ASD may show very little or no interest in play that involves pretending. Instead, they may be overly interested in repetitive activities.

Your child may take up a special interest at a young age, such as collecting, or music and art.

Older children and adolescents may develop obsessions such as an excessive interest in timetables or lists, and in storing up trivial facts.

Other symptoms

Your child may also:

- sit up or walk later than most children
- be oversensitive to noise or touch
- have odd mannerisms such as rocking back and forth, hand flapping, walking on tip- toes or head banging
- be clumsy and struggle with physical activity
- like sticking to the same routines, and may get very upset if these are disturbed
- be over or undersensitive to sight, sound, smell, touch and taste

Around three out of four children with an ASD have a learning disability. Many children with an ASD also have other conditions such as attention deficit hyperactivity disorder (ADHD), dyspraxia or epilepsy.

Causes of autistic spectrum disorders

The exact causes of ASDs aren't fully understood at present. Some research indicates that the genes we inherit from our parents play an important role. Many different genes have been implicated in ASDs, suggesting that ASDs have a variety of causes.

Autism and the MMR vaccine

There is no scientific evidence to support media reports about a possible link between autism and the MMR (measles, mumps and rubella) vaccine. However, there is plenty of evidence to support the safety of the MMR vaccine. The similar incidence of ASDs in adults who didn't receive the vaccine and children who did, strongly suggests no link.

Diagnosis of autistic spectrum disorders

If you notice signs of an ASD in your child, contact your GP or health visitor.

Children can usually be diagnosed between the ages of two and three. However, some ASDs, such as Asperger syndrome, only become apparent at school, when a child's poor social skills and challenging behaviour become more noticeable.

You will need to describe your child's behaviour to your GP. He or she will also observe your child's behaviour and development. Your GP may carry out a screening interview called CHAT (Checklist for Autism in Toddlers) if your child hasn't started school yet.

Your child may have some other tests such as a hearing test to exclude other conditions.

If your GP thinks your child may have an ASD, he or she may be assessed at a child development centre to identify any specific needs. You and your child may need to see a range of professionals including a paediatrician, a child psychiatrist, a speech therapist, an occupational therapist, a psychologist and an educational expert such as a specialist teacher or educational psychologist.

A tool commonly used by specialists is the Autism Diagnostic Observation Schedule - a complex group of structured tests that can be tailored to different age groups.

Your child should have an appointed key worker, such as a developmental paediatrician (a doctor who specialises in child development), health visitor or school nurse, who knows about the assessment process and acts as a single point of contact for you.

Treatment of autistic spectrum disorders

There is no cure for ASDs, but children can be helped in many ways. Therapies can be used to help your child to function independently, socialise and provide the best possible quality of life for him or her.

Many parents find the following therapies helpful for their child, although there is limited evidence that they are effective. These therapies may not always be available where you live.

Behavioural therapies

Therapies such as applied behaviour analysis (ABA) may help to improve your child's social functioning and communication. This type of therapy involves your child seeing a clinical psychologist or trained therapist, who will reward good behaviour with praise. The psychologist or therapist will also set out a consistent and structured way of dealing with challenging or harmful behaviour.

Other therapies

Other therapies aim to help your child with communication and learning. These include the following.

- Intensive pre-school training, where your child is taught a range of skills by therapists.
- Picture Exchange Communication System (PECS), where your child is taught to exchange a picture card for something he or she wants, helping your child to express him or herself.
- EarlyBird, a three-month programme to help you to manage your child at a pre-school age and pre-empt inappropriate behaviours. Speech therapy to help your child to communicate better.
- Occupational therapy to help your child adapt to living environments.
- Cognitive behavioural therapy (CBT), which can help your child to challenge negative thoughts and behaviour.

Remember that one therapy may work for one child but not for another, as all children have different levels of needs and abilities.

Medicines

Sometimes your doctor may prescribe medication for your child to take in the short-term to reduce symptoms such as agitation or obsessional or hyperactive behaviour. However, these medicines can have side-effects. For example, drugs to reduce hyperactivity can increase repetitive and obsessional behaviour.

Help and support

Health professionals involved in your child's care can provide help and support for you and your child's carers. Further advice is available from charities such as the National Autistic Society.

Respite breaks give you a chance to rest while somebody else looks after your child. They may be provided by social services. Some families are also entitled to benefits such as disability living allowance to help cover the extra expenses involved in caring for a child with an ASD.

School

Children with an ASD often need an educational assessment and some special educational support. Your child may go to a special school or attend a mainstream school with extra individual help, if required.

In general, autistic children do better if classroom activities are very structured. Most schools use the TEACCH approach, (Treatment and Education of Autistic and Communication-Handicapped Children) which provides a very structured learning environment, with mostly visual instructions. Parents work closely with teachers, using the same techniques at home.

www.bupa.co.uk

ADHD

ADHD is also known as hyperkinetic disorder (the official UK term) and attention deficit disorder (ADD). These different names can be confusing but are all used to describe the problems of children who are unable to concentrate and are overactive.

It's estimated that ADHD may affect up to one in 20 school-age children. ADHD is at least four times more common in boys than girls. Children are usually diagnosed around the age of 7, but symptoms continue into adolescence and adulthood.

If you think your child may have ADHD, it's important that you get a diagnosis and start treatment as soon as possible so that his/her symptoms don't get worse and his/her development isn't too badly affected.

Symptoms of ADHD

There are a range of symptoms or behaviours that are associated with ADHD. Many of these behaviours are also seen in children who don't have ADHD. These are only a problem if they affect your child's social and school life.

The following table lists a number of common ADHD symptoms.

Inattention symptoms	Hyperactive symptoms	Impulsive symptoms
Making careless mistakes in schoolwork	Fidgeting	Interrupting others
Not listening to or following instructions properly	Running or climbing when and where they shouldn't	Unable to wait for their turn or in queues
Not finishing things – being distracted easily	Unable to stay sitting down or to play quietly	Answering questions before they have been fully asked
Losing and forgetting things	Talking constantly	-

Children with ADHD may have mostly hyperactive or impulsive symptoms, mostly inattention symptoms or a combination of these.

Other symptoms common in children with ADHD include:

- aggressiveness and poor discipline - disruptive behaviour
- clumsiness
- fearlessness and reckless behaviour

- irritability
- emotional immaturity

ADHD won't make your child less intelligent but it may interfere with his/her ability to learn.

If your child has ADHD, it may become more noticeable or get worse when he/she starts school. Your child's learning may be slowed down by a lack of attention and concentration. If your child is hyperactive and aggressive he/she may have difficulty getting on with other children. If your child is dreamy and inattentive but not disruptive, his/her condition may go unnoticed.

Complications of ADHD

If your child has ADHD, he/she may find it more difficult to communicate and interact with other children and adults. Problems with speech development are also common.

As your child gets older, he/she may become involved in antisocial conduct (such as rowdy or threatening behaviour) and may be unaware of how his/her actions affect others.

Causes of ADHD

The exact cause of ADHD isn't known, but there are likely to be a number of factors involved.

Research suggests that people with ADHD may have differences in the parts of their brains that deal with controlling impulses and focusing attention.

Your child may be more likely to have ADHD if he/she:

- has a family history of ADHD
- had a low birthweight
- was exposed to cigarettes, alcohol or drugs (such as cocaine) in the womb

Your child's behavioural and emotional symptoms may be made worse if he/she also has other problems (such as an anxiety disorder). A stressful home environment, for example because of a divorce or separation, may also contribute. There is also evidence to suggest that there may be a link between television viewing in preschool children and development of ADHD behaviours.

Diagnosis of ADHD

If you're concerned that your child may have ADHD, visit your GP. Your GP will ask you about your child's symptoms and examine him/her. Your GP may also ask you about your child's medical history.

If your GP thinks that your child may have ADHD, he/she may refer your child to one of the following specialists for diagnosis and treatment.

- A child psychiatrist (a doctor who specialises in children's mental health).
- A child psychologist (a health professional who specialises in children's behaviour).
- A specialist paediatrician (a doctor who specialises in children's illnesses).

There are no specific tests for ADHD. Your child will be observed and reports of his/her behaviour will be studied. You and other people who spend time with your child (such as carers or teachers) may be asked to fill in a questionnaire about your child's behaviour.

ADHD is usually diagnosed if many symptoms are present and occur in more than one setting (such as home and school) and other mental or physical conditions (such as obsessive compulsive disorder or deafness) have been ruled out.

Treatment of ADHD

It's thought that the most effective way to treat ADHD is to use a combination of different approaches. The exact types of treatment used will depend on the specific requirements of your child - the symptoms he/she has and how he/she responds to each type of treatment. It's important to remember that your child may have to try a number of different treatments before a successful combination is found.

Self-help

Diet

In some children, ADHD symptoms can be improved by cutting down on certain ingredients (such as sugar, caffeine and food additives), or giving extra vitamins, minerals or omega-3 fatty acids. It's been found that children with ADHD often have lower levels of these essential nutrients than children who don't have ADHD. You should always speak to your child's doctor or a dietitian before making any changes to your child's diet.

Managing behaviour at home

You can help your child by providing a structured environment with clear rules of acceptable behaviour. Your child's specialist can help you learn how to manage his/her specific behaviours. You could also attend classes and support groups where parents can share their knowledge and experience.

School

Talk to your child's teacher about his/her condition. A structured and orderly classroom without too many distractions and small group or individual teaching may help your child to focus better in school.

If your child is diagnosed with ADHD, his/her school may offer extra help with reading, spelling, maths, organisational skills, speech therapy, physical education therapy and counselling. An educational psychologist will usually assess your child's needs and check on his/her progress.

Medicines

Your child's specialist doctor may prescribe medicines when diagnosing the disorder. He/she will identify a suitable medicine and dosage, and following this your child's care will usually be transferred to his/her GP.

The type of medicine prescribed for your child will depend on:

- his/her symptoms
- whether he/she has any other medical conditions
- how he/she responds to the medicine
- whether he/she gets any side-effects

Medicines that are often prescribed for children with ADHD include methylphenidate (eg Concerta XL), atomexetine and dexamfetamine. These medicines work by changing the levels of certain chemicals in the brain that have been found to be unbalanced in children with ADHD. They can help to reduce hyperactivity and impulsiveness, and can increase the attention span of children with ADHD, helping them to concentrate better at school.

Like all drugs, these medicines can sometimes have side-effects, including insomnia, headaches, irritability and weight loss.

Always ask your child's doctor for advice and read the patient information leaflet that comes with your child's medicine.

Talking therapy

Talking therapies such as psychological and behavioural therapy can also help children with ADHD. The therapy is designed to help your child learn to cope with his/her condition and reduce impulsive behaviour. Therapy may be offered to your child or your whole family. Talk to your GP or child's psychiatrist about what is best for you and your child.

Living with ADHD

Caring for a child with ADHD can be difficult and the effects on family life can be dramatic. National support groups are available for the families of children with ADHD, and your GP may be able to put you in touch with a local group. Through one of these, you can meet other families in the same situation and get support and advice on behaviour management for your child.

www.bupa.co.uk

Cerebral Palsy

Cerebral palsy isn't a specific illness; it's a term that describes motor (movement) disorders caused by damage to your child's brain. It isn't a progressive condition, so the damage doesn't gradually get worse. However, the manifestations may change throughout your child's life as his or her nervous system matures. This means the symptoms may change over time.

Cerebral palsy affects about one in 400 children, but each child is affected differently.

With support from nurses, carers and other specialists from an early age, your child can learn to manage his or her symptoms so as to be as independent as possible.

Types of cerebral palsy

There are four types of cerebral palsy which cause different problems with movement.

- Spastic cerebral palsy
- Dyskinetic (dystonic or athetoid) cerebral palsy
- Ataxic cerebral palsy
- Hypotonic cerebral palsy

Sometimes, one type is seen initially and then, as your child grows, another type becomes dominant. For example, your child may be hypotonic (floppy) soon after birth but may later develop more spasticity (stiffness).

In some children, it can be difficult to be sure whether the condition is cerebral palsy or a progressive neurological disorder. This means it may be some years before the diagnosis can be made with confidence.

It's important to remember that the condition varies between individuals and your child may show a mixture of different types of motor disability.

Spastic cerebral palsy

This is the most common type of cerebral palsy. Spasticity is the medical term for a certain type of increased muscle tone which makes muscles stiff and affects movement. Difficulties moving limbs may make walking harder for your child but if his or her cerebral palsy is mild, this may only affect certain activities such as running. He or she may also have difficulties forming words when speaking.

Spastic cerebral palsy can affect different areas of your child's body.

- Hemiplegia means one side of your child's body is affected.
- Diplegia means your child's legs are affected.
- Triplegia means three of your child's limbs are affected.
- Quadriplegia means all four your child's limbs are affected.

Dyskinetic (dystonic or athetoid) cerebral palsy

This causes slow, involuntary muscle movements and abrupt twitches that may be repetitive. Athetoid cerebral palsy can make speaking difficult because your child may find it hard to control his or her tongue, breathing and vocal cords. Your child may also have hearing problems.

Ataxic cerebral palsy

This can affect your child's co-ordination and balance, making it difficult for him or her to judge body position in relation to surrounding objects. It also weakens muscles and causes tremors. Your child may have difficulty walking steadily.

Hypotonic cerebral palsy

Hypotonia is the medical term for low muscle tone and causes floppiness. A hypotonic child therefore doesn't sit unaided until much later in his or her development and will have difficulty learning to walk.

Symptoms of cerebral palsy

The severity of symptoms varies greatly between children, from barely noticeable clumsiness to such severe problems with movement that your child may need a wheelchair.

Common symptoms include difficulty and delay with movement, balance and coordination, muscle stiffness, involuntary and uncontrolled movements, and shakiness. These symptoms are often noticed in the first months and years of life. In addition to motor problems, your child may have other neurological impairments including learning difficulties and epilepsy.

These symptoms aren't always a result of cerebral palsy but if your child has them, see your GP.

Complications of cerebral palsy

If your child has severe cerebral palsy, he or she may have another condition such as epilepsy, learning difficulties or sensory disturbances such as sight or hearing changes. Your child may need special assistance with daily activities and education.

Problems with movement can limit how your child learns about his or her surroundings and environment, which can limit learning opportunities and may affect development.

Causes of cerebral palsy

Damage to your child's brain during pregnancy, birth, or just after birth, causes cerebral palsy. It's often not clear why this happens. However, there are a number of possible factors that may cause such brain damage, including:

- getting an infection early in pregnancy
- getting an infection such as meningitis when your child is born
- premature birth or complications during birth
- cerebral (brain) bleeding - this is more common if your child is premature or one of a multiple birth (eg twins, triplets)
- changes in your child's brain as it's developing
- an inherited (genetic) cause - this is rare
- maternal iodine deficiency - this is rare in the UK but common in less developed countries

Researchers are currently trying to find the exact causes of cerebral palsy so that it may be preventable in the future.

Diagnosis of cerebral palsy

If you think your child is having problems with movement, see your GP who will ask about your child's symptoms and examine him or her. Your GP may also ask you about your child's medical history.

Your GP may refer your child to a paediatrician (a doctor who specialises in child health). Most children who have cerebral palsy are diagnosed around the age of two, but the condition can be diagnosed at any age. The paediatrician will monitor your child as he or she develops and grows to rule out similar conditions before making

a diagnosis. Tests, such as blood tests, a CT (computerised tomography) scan or an MRI (magnetic resonance imaging) scan, may be done to rule out other conditions. This may, however, depend on your child's age. Speak to your GP for more information.

Treatment of cerebral palsy

There is no cure for cerebral palsy, but with the right support your child can become as independent as possible.

Non-medical treatment

Often a multidisciplinary team of professionals working in different areas of health and social care are involved in the assessment and care of your child. This varies according to your local services. During the assessment stage, a detailed evaluation of your child's abilities is made. This includes an assessment of his or her movement, capabilities, vision, hearing and daily activities.

A detailed management plan can then be developed specific to your child's needs and capabilities. Some of the people who may be involved in your child's assessment and care are listed below.

- Your GP can give general advice and may help put you in contact with support services.
- A physiotherapist (a health professional who specialises in movement and mobility) will have a key role in helping your child. The physiotherapist will monitor and record your child's progress, teaching them how to control head movements, roll over, crawl and walk as much as possible. The physiotherapist will also help to reduce abnormal movements and give advice on equipment that may help your child's mobility. As your child grows older, physiotherapy will focus on helping him or her to be independent and adapt to his or her changing circumstances to take on increasing challenges. When your child is transferred to adult services, the physiotherapist will continue to help reduce symptoms, such as mobility challenges, as they arise.
- An occupational therapist will assess how much cerebral palsy affects your child's life and recommend specific activities or equipment that will help him or her adapt to difficulties and maximise his or her independence.
- A speech and language therapist (a health professional who specialises in identifying and managing speech and swallowing problems) will help to identify and manage any problems your child has with communication. This may include teaching languages using sign or symbols or other communication aids.
- A social worker from your local authority can help provide advice on practical and financial matters.
- A paediatric neurologist (a health professional who specialises in disorders of the central nervous system in children) may be involved in the initial diagnosis of cerebral palsy and ongoing monitoring if your child has epilepsy.
- An educational psychologist can help to manage any learning difficulties your child may have. This could involve visits to his or her school to assess progress.

Setting specific goals in the management of cerebral palsy, which are agreed by you and the team of healthcare professionals can help your child get the best care and support.

Medicines

An injection of botulinum toxin A is sometimes used to relieve muscle stiffness in children with spastic cerebral palsy. This is often given to older children who walk on tip-toes and have very tight calf muscles and tendons. It can also be used in arms and hands if your child's fist is permanently clenched.

Surgery

If your child has spastic cerebral palsy, a back operation called dorsal rhizotomy may help. Nerves in the lower back can be cut to help relieve spastic muscles, but this is a complicated procedure and is only carried out in specific circumstances, usually after other treatments (including physiotherapy and botulinum toxin) have not worked. The operation may not improve mobility in some children and once it's done, it can't be reversed. It may also have serious complications.

Another surgical treatment is tendonotomy, where tendons are cut to relieve stiffness.

Your paediatrician can advise you about surgery and if it's a suitable treatment for your child.

Living with cerebral palsy

Caring and supporting a child with cerebral palsy can be challenging. Ask your doctor for advice about managing your child's condition. Charity and patient groups can also provide advice and support.

www.bupa.co.uk

Fragile-X

Fragile-X syndrome is the most common inherited form of mental retardation. It results from a mutation on a single gene. Problems are caused when the mutated gene is unable to produce the needed amount of a protein used by the body's cells. It is especially damaging to brain cells. The severity of the condition is directly related to the amount of the protein that is produced. The syndrome is also known as Martin-Bell syndrome, named after the researchers who first described the disability (although its cause was not then known).

Genetics

Since the genetic mutation that causes Fragile-X syndrome occurs on the X chromosome, fathers cannot pass the condition on to their sons. Keep in mind that males are XY while females are XX. The father contributes the Y chromosome. Therefore if a son has Fragile-X syndrome, the malfunctioning X was obtained from the mother. Mothers with Fragile-X have a 50 percent chance of passing it to their children.

Males with the syndrome have a high probability of severe intellectual disability. Females are usually less affected, as they have an additional "backup" copy of the X chromosome. However, females can be affected in the range from fully normal to severe intellectual disability. Since males and females are affected differently, this may explain the apparent "under diagnosis" of females with Fragile-X syndrome.

Diagnosis

There is no cure for Fragile X. Physical, education and behavioural therapy can reduce the severity of some symptoms, while other expressions of the condition can be treated with medications. If treatment is started early, it can be more effective than waiting until later.

DNA testing for Fragile-X syndrome was introduced in 1992. Because symptoms can be subtle and prevalence is relatively high (1 in 4000 males, 1 in 6000 to 8000 females), it is important to test for Fragile-X when unexplained developmental delays or mental retardation are observed.

Characteristics

It has been observed that children with Fragile X are often quite good at imitation and tend to be highly social. This combination bodes well for the success of early intervention programmes. The more time a Fragile X child spends with children who are developing at a normal pace, the more benefit they can derive from the interaction.

Although females with Fragile-X syndrome often face difficulties in maths, they perform well with spelling and reading. They tend to prefer social isolation and may exhibit disabilities similar to schizophrenia. Males with

Fragile-X have the potential to achieve higher levels than might be predicted from IQ. However, they tend to have difficulty with skills that require sequential processing of information (reading is an example). Fragile-X males often need to see the whole before they are able to understand the parts.

Teachers and parents should understand that children with Fragile-X syndrome are capable of achieving a level higher than expected based on measured IQ. Best results are usually obtained when these children are included in mainstream schools, provided that the classroom is an organized environment. Individualized assistance provided by trained inclusion teachers is also critical for success. Other effective strategies include cooperative learning situations and assistance from peers.

www.aboutlearningdisabilities.co.uk

Rett Syndrome

Rett Syndrome is named after Andreas Rett, the paediatric doctor who first described this neurological disorder in 1966. However, the syndrome was not generally recognised until later, when a second article by the Swedish researcher Dr. Bengt Hagberg was published.

The syndrome is caused by a genetic mutation within the X chromosome, and in the vast majority of cases, is not inherited from either parent. Is it thought that in some rarer instances, the syndrome can be inherited from the mother.

The Basics

Rett Syndrome tends to only affect girls, and manifests itself after a period of normal early development. It is very rare for male foetuses with the disorder to survive a full term.

Typically, between three months and three years, the child's growth and development will begin to slow down, with the head and brain (grey matter) growth also slowing. In the very early stages, as development may appear relatively normal, the disorder can be overlooked until developmental progress becomes noticeably delayed or regressed.

Subtle signs of the disorder might begin to present after three months – hypotonia (loss of muscle tone) and erratic or juddering limb movement and difficulty feeding could prove early indicators. Apnoea (breath holding) and hyperventilation may begin to emerge during the early stages of the syndrome, and as the child ages, emotional and intellectual developmental problems such as anxiety, social behavioural problems and learning difficulties will become more apparent.

Apraxia and Other Problems

Other characteristics of Rett Syndrome during the early developmental period may begin to become more evident. Apraxia, or the inability to perform motor functions – can become the most limiting symptom of the disorder. Hand wringing and spasmodic hand movements, avoidance of eye contact or an inability to retain a gaze may also be noted.

The mental and physical disorders arising as a result of this syndrome might include almost a regression in walking or crawling, a gradual or sudden loss of purposeful use of the hands, such as an ability to grasp objects, reach or touch and even a regression in any speech developments. Children with Rett Syndrome may also show certain behaviours that have lead to the syndrome being described as one of the autism spectrum disorders, although this classification remains controversial.

Other problems common to those with Rett Syndrome, but not exclusively related to the syndrome, are seizures, scoliosis, gastrointestinal problems such as constipation, cardiac disorders, difficulty with chewing, swallowing and feeding, and problems with sleep patterns.

The Four Stages

The different stages of Rett Syndrome have been described in four stages. During the first early onset stage,

development begins to slow or stop. In the second stage of the syndrome, developmental skills begin to regress; this can include loss of speech and purposeful hand movements. The third stage is known as the plateau phase, where regression begins to slow and in some cases, problems may improve or lessen to some degree. The majority of people with Rett Syndrome spend their adult life in this phase. However, there are those that may lose mobility, become stuff or experience muscle deterioration during a fourth phase, known as the late motor deterioration phase.

There is currently no cure for Rett Syndrome, and treatment for the disorder is symptomatic as the syndrome may present differently from person to person. Many symptoms and manifestations of Rett Syndrome mean that those with the disorder may require a moderate to high level of day-to-day support from carers and families. Specialists and occupational therapists can provide additional support which will have been shown to improve the general health and wellbeing to those with the syndrome.

www.aboutlearningdisabilities.co.uk

Angelman Syndrome

Angelman syndrome is a rare genetic condition, the symptoms of which include severe learning difficulties, jerky movements and a happy disposition. Around 48 years ago, English physician Harry Angelman first described the condition that would later bear his name. However, the prevalence of Angelman syndrome was low and debate over its existence continued for many years.

Angelman syndrome is generally considered to be a chromosomal disorder. Most cases can be traced to the partial deletion of a gene on chromosome 15. Chromosomes perform different functions throughout our body, but it is the way in which chromosome 15 functions in the brain that leads to the behaviours associated with Angelman syndrome.

Genetics

Everyone inherits chromosomes and genetic material from their mother and father. In the case of chromosome 15, the parts contributed by each parent function in different ways. For instance, only the maternal copy is active in the brain. If the mother's contribution to this particular chromosome has been deleted or, in some cases, replaced by a copy of the father's contribution, then this can result in Angelman syndrome.

There is no known cause for this genetic abnormality. It is thought to happen when an unknown factor randomly goes awry in the normal reproductive process. The condition is not passed on from parent to child, nor does it run in families. Diagnosis of the syndrome usually occurs between the ages of three and seven. Development is delayed even at the youngest ages, but usually becomes apparent by the age of six months. The characteristic features of Angelman syndrome often take a few years to become noticeable. It is worth knowing that once the syndrome is diagnosed, genetic tests are commonly used to confirm the diagnosis.

Angelman Syndrome History

Dr. Angelman first described the syndrome in an article entitled "Puppet Children" – a description that had been inspired by a painting. Children with the syndrome came to be called "happy puppets". As you may expect, this term describes two of the more noticeable manifestations of the disorder. Children that have Angelman syndrome are subject to a variety of jerky, involuntary movements as if they are being controlled by a puppeteer. In addition, the children also possess an almost unfaltering happy disposition. They smile almost constantly and often break into laughter for no apparent reason. Today, however, it is worth noting that the phrases "happy puppets" and "puppet children" are considered derogatory--the appropriate term for the condition is Angelman syndrome.

Sleep Problems

Children with Angelman syndrome may experience altered sleep patterns. The syndrome also often leads to difficulty going to sleep and staying asleep. Children are easily awakened by noise and are very disoriented when awakened. Young children with this disorder rarely sleep longer than five hours at a time, and Melatonin is often prescribed in small doses to help children fall asleep. Sleep problems almost always diminish with age, so by late adolescence and adulthood, sleep patterns are relatively normal.

A Rare Syndrome

Angelman syndrome is actually quite rare. In fact, it is so rare that precise prevalence numbers have not been established. A few studies have suggested that about 1 in 25,000 have this disorder.

Since Angelman syndrome is a genetic condition and not a disease, there is no cure. Most of the physical manifestations of the condition lessen with age, and it is believed that individualised instruction is the best way to deal with educational development delays. One program in particular, PORTAGE, has been highlighted as an excellent choice for helping parents encourage communication skills in affected children

www.aboutlearningdisabilities.co.uk

PMLD

When acquiring knowledge about disabilities and learning disabilities, the term 'profound and multiple learning disability' may be mentioned. But what does it mean exactly, and what are the implications of having profound and multiple learning disabilities?

Firstly, it's important that the term 'learning disability' is recognised as a label that is convenient for some purposes, such as planning services and in discussion – however, the person, and not the disability, should always come first. A learning disability forms only one aspects of the person's character.

A learning disability is usually identified by the presence of three conditions – one or more intellectual impairments, social and intellectual dysfunction, and an early onset of the above. All learning disabilities are present (and usually identified) in childhood, the most progressive developmental period of life. Learning disabilities are not sustained in adult life, due to a disease, illness, injury or degenerative disease such as dementia.

Different Degrees of Learning Disabilities

One way that learning disability is classified is via the person's IQ. A person with an IQ of 50-70 is thought to have a mild learning disability. A person with an IQ of 35-50 is said to have a moderate learning disability, and an IQ of 20-35 may indicate a severe learning disability. An IQ score below 20 is classified as a profound learning disability.

There is, however, some debate surrounding the use of IQ scores to determine levels of learning disability. This is because whilst some people may score poorly in certain areas, they may attain average or above average results in other areas, yet their score remains low. This is why IQ scores alone should not form the absolute basis of the degree of learning disability - social adaption and social functioning are also important aspects to consider.

The kind of disabilities and their impact that the person has, and environment that the person lives in, will all affect the kind of support that they require.

Profound Learning Disabilities

The term 'profound' literally means deep or extreme, so a person with one or multiple profound learning disabilities usually requires support with day-to-day activities, such as feeding, washing, dressing and communication. The specific support that is required will always depend on the way in which the different learning disabilities impact the individual, and the environment they live in. But people with profound and multiple learning disabilities often have additional physical, sensory, mental or mobility problems that mean that they may need a minimum of around 7 hours of support each day.

For a person with profound and multiple learning disabilities, the amount of support that is required may stay at this level throughout their lives, whereas those with mild or moderate learning disabilities may require different levels of support as they experience new situations and circumstances.

Communication

One of the major challenges facing a person with profound and multiple learning disabilities, is the ability to effectively communicate their thoughts, opinions, needs and requirements. This can sometimes lead to community and social exclusion.

But in recent years there have been moves in the spheres of social care, education and health services to help ensure advocacy and promote independent living for people with learning disabilities. However, it is still thought that the needs of people with profound and multiple learning disabilities may not always be met in a satisfactory way, in part due to communication issues.

A person with profound and multiple learning disabilities may find it difficult to understand and use formal or verbal communication, and so rely on body language, facial expression, vocal sounds and behaviour to communicate. This means that they may also rely on another person to help interpret and communicate to other people on their behalf.

Sometimes what is first seen as 'challenging behaviour' could actually be an attempt to communicate an opinion or a need. A simple behaviour, such as tapping the face or body, may indicate a health issue. It is important that the person with profound and multiple learning disabilities has a solid and consistent network of support around them. This helps to ensure that their unique and individual needs, behaviours and methods of communication are met, which in turn helps them to live as valued citizens with equal rights.

www.aboutlearningdisabilities.co.uk