We do hope that you find the information in this section of the book helpful, whether you're a parent or a professional working alongside them.

We couldn't have produced this resource without the support from all the parents and professionals who have contributed, either directly or indirectly.

If you would like to know more about the work of Shine and how we can support you, either as a parent or an individual with the condition, then please do contact us: www.shinecharity.org.uk/

Additional **Information**

This section provides further in-depth information from our Health Team on hydrocephalus including:

The causes

Treatments

Shunts and shunt malfunction

Hydrocephalus and epilepsy

Additional therapeutic interventions

Hydrocephalus and learning

A glossary of useful terminology.

More about hydrocephalus

Hydrocephalus comes from the Greek words 'hydro' meaning water, and 'kefale', meaning brain.

A watery fluid, known as cerebrospinal fluid or CSF, is constantly produced inside each of four spaces (ventricles) inside the brain by a tissue called choroid plexus. The amount of CSF increases until, in adulthood, between 400 and 600mls is produced every day.

CSF normally flows through narrow pathways from one ventricle to the next, out over the outside of the brain and down the outside of the spinal cord. The CSF is absorbed into the bloodstream through cells on the coverings of the brain (meninges). The amount of CSF and pressure inside the head are kept within a fairly narrow range when all is working as it should.

If the drainage of CSF is prevented at any point, the fluid accumulates in the ventricles inside the brain, causing them to swell. This results in compression of the brain tissue and blood vessels. This is hydrocephalus. In babies, the bones of the skull are not firmly joined, so as the ventricles swell the head enlarges. In older children and adults, the bones which form the skull are completely joined together so the head cannot get bigger and the pressure in the head increases.

What causes hydrocephalus?

There are many reasons why hydrocephalus develops. These can be congenital or acquired.

Congenital hydrocephalus means that hydrocephalus is present at birth.

It does not mean that it is hereditary. Often the exact cause of congenital hydrocephalus is never discovered but, these are the most common causes:

- Aqueduct stenosis describes a condition in which one of the channels (aqueduct) linking the ventricles in the brain is narrowed (stenosis), preventing the flow of CSF. Although the condition is always congenital, symptoms may not occur until many years later
- Some babies with spina bifida have hydrocephalus from birth. Spina bifida leads to changes in the way the brain develops and this can prevent the flow of CSF. The increase in pressure can then compress the lower parts of the brain even further. **For further information about spina bifida, see Shine's Information Sheet: 'What is spina bifida?'**
- Other babies with spina bifida may be born with small ventricles but develop hydrocephalus after their operation to close the spina bifida lesion. This happens as the CSF flows down the spine rather than creating the two channels that allow CSF to flow on to the surface of the brain. Once the lesion is closed, the CSF becomes trapped in the ventricles
- There is group of disorders where fluid-filled cysts develop in the CSF system, e.g. Dandy Walker cysts. In these cases, hydrocephalus is often due to pressure on the surrounding tissues by the enlarging cyst, which then blocks the CSF channels

- In very rare circumstances, hydrocephalus is due to genetic factors, which might affect future generations. X-linked hydrocephalus is the best known of these; girls in affected families may be carriers, but boys with the gene can develop hydrocephalus
- Some maternal infections can be passed from a pregnant woman to her baby in the womb, and some of these can lead to hydrocephalus. Cytomegalovirus (CMV) and toxoplasmosis (a parasite caught from cat faeces and undercooked meat) can both cause hydrocephalus in this way. Group B streptococcus can be passed to the baby during birth and cause neonatal meningitis

Acquired hydrocephalus means hydrocephalus that develops after birth:

- All forms of brain haemorrhage, such as from head injury, can result in post-haemorrhagic hydrocephalus. Any blood in the CSF can damage the cells which absorb the CSF, allowing it to build up within the head
- Tumours of the brain cause compression and swelling of surrounding tissues, resulting in poor drainage of CSF. In the treatment of brain tumours, it is often necessary to control hydrocephalus, which might only be temporary
- Meningitis is an infection of the membranes covering the brain (the meninges). The inflammation and debris from this infection damages the cells which absorb the CSF, resulting in hydrocephalus. Meningitis can occur at any age, but it is more common in children and teenagers
- Babies born prematurely are at risk of developing hydrocephalus. The brain of a baby born early is far more vulnerable than one which goes to full term, as it is still developing. The area which lies just under the lining of the ventricles in the brain is particularly important as it has a rich blood supply. Blood vessels are very fragile and can easily burst if the baby suffers a large swing in blood pressure or becomes severely ill from other causes. Bleeding can lead to a blood clot developing, which in some cases is big enough to break through the wall of the ventricle. If the clot blocks the flow of CSF, the baby will develop hydrocephalus. The blockage may be temporary or permanent. Even if a blood clot does not develop, the blood cells from the haemorrhage can cause a blockage by damaging the cells which absorb the CSF. The more premature and the lighter the baby is at birth, the more likely they are to have a serious bleed in the first few days of life. Improvement in the care of very premature babies means babies are much less likely to develop hydrocephalus than previously, with around 5% of premature babies needing shunts

Treatment of hydrocephalus

- Hydrocephalus is usually treated by diverting the CSF to a place in the body where it can be absorbed, by inserting a shunt, or creating a hole for the CSF to drain through, which is known as an endoscopic third ventriculostomy (ETV). An ETV involves using a flexible tube (endoscope) to create a hole in the ventricle, to divert CSF from the third ventricle to the space between the brain and the skull (subarachnoid space). There it can be absorbed in the usual way. The advantage of this procedure is there in no foreign body to present a risk of blockages, the ETV can't drain too much, and the pressure inside the head doesn't fluctuate as it can with a shunt
- Very occasionally, an ETV is combined with removal of some choroid plexus to reduce the amount of CSF produced. ETV is more successful in older children than in small babies. Occasionally, the hole closes and the procedure needs to be repeated. Very occasionally, CSF doesn't flow through the hole, and a shunt is needed overall, but, for older children with obstructive hydrocephalus, it can be a very good option

Shunts

- A shunt is the most commonly used way of controlling the increased pressure inside the head caused by hydrocephalus. All shunts are thin tubes which drain CSF from a space where it is collecting to another part of the body to be absorbed
- Nearly all ventricular shunts have a valve in the 'neck' area of the tubing which opens when the pressure in the head reaches a certain level. These can be fixed pressure, adjustable pressure (programmable), or dual pressure (gravitational). Gravitational shunts can also be programmable
- The shunt itself is made from silicone – a strong, long-lasting and inert substance that very few people are allergic to. Some shunts – such as Bactiseal – are antimicrobial and can help reduce infection after surgery

Common sites for shunts

Ventriculoperitoneal (VP)

Ventriculoperitoneal shunts have the proximal (head) end catheter placed in the ventricles (usually lateral ventricles) and the other (distal) end in the space surrounding the intestines (the peritoneum). This space has a fluid similar to CSF, so the CSF mixes with this fluid and is absorbed. If the shunt is infected, the membrane covering the intestines, (the omentum) can block the distal end of the shunt. Occasionally, the fluid is not properly absorbed and collects in the abdomen. This is often fixed by changing the position of the distal shunt to another area of the abdomen.

VP shunts can become infected following bladder surgery. Your urology team would need to be aware of this possibility, and be vigilant after your operation. VP shunts do not need to be changed (revised) routinely in children because of growth. They are changed only if and when they stop working effectively, for example if they block or begin to over drain. VP shunts won't be suitable if peritoneal dialysis is needed.

Ventriculoatrial (VA)

Ventriculoatrial shunts drain from the ventricles into the heart. These are less commonly used than VP shunts. If placed in babies or children, the shunt often has to be changed (revised) when the child grows, to ensure the distal end remains in the heart.

Unlike VP shunts, they don't block if the shunt is infected, but bacteria can flow into the bloodstream. This can lead to symptoms such as feeling generally unwell, low-grade fever, night sweats, blood in the urine or a persistent cough. If your child has a VA shunt and experiences these symptoms, shunt infection can be ruled out through a blood test.

Contact Shine's Health Team for details.

Lumbo-peritoneal (LP)

Lumbo-peritoneal shunts drain from the CSF space around the lumbar spine to the abdomen. This type of shunt is used for draining CSF where there is no blockage through the ventricles but not enough CSF is being absorbed, such as in communicating hydrocephalus.

They can be combined with gravitational valves to reduce over-drainage. Sometimes LP shunts become dislodged from the spine and sometimes, because the shunt is placed below the brain, it can create a downward pressure on the base of the brain, leading to a condition called Chiari Malformation.

Ventriculo-pleural (VPL)

This shunt drains from the ventricles to a thin, fluid-filled layer between the coverings of the lungs. The CSF mixes with this fluid and is absorbed into the bloodstream. It would only be placed here if other sites weren't suitable. If fluid is not absorbed effectively, it can collect and prevent the lung from expanding. If your child has a VPL shunt and is getting short of breath, especially during exercise, tell your neurosurgeon as the shunt may have to be moved to a different site.

External shunts

These shunts have the proximal end in the space between the brain and the skull (subarachnoid space); the distal end is usually placed in the peritoneum. These are used when fluid is collecting around the outside of the brain but is not trapped within the ventricles.

Ventriculosubgaleal

This shunt is often used for new or premature babies who are too small for a shunt, or who may not need a permanent shunt. One end is placed in the ventricle, the other into a 'pocket' the surgeon forms between the skin on the baby's scalp and the underlying tissue. Because the scalp has many small blood vessels, the fluid is easily absorbed directly into the bloodstream.

Types of shunts

Programmable

Some shunts have valves that can be adjusted to open at varying pressures by using a special device placed on the skin. This way, the neurosurgeon can alter the way the shunt works without having to replace it. This is particularly helpful in children as the drainage pattern changes as the child grows.

Currently the most commonly used programmable shunts are adjusted with a magnetic device. This can mean that occasionally some types can be accidentally reset by magnetic fields coming close to the valve area or by powerful magnets such as those in MRI scanners.

Some types of programmable valves, such as proGAV, need physical pressure to be applied to 'unlock' the mechanism before the magnet resets it, so it can't be changed unintentionally by magnetic fields of 3 tesla or less. Others, such as Codman CERTAS, can only be changed by magnetic fields in a certain direction, meaning MRI should not change the setting.

Children with other programmable shunts should be supervised when playing with magnetic toys or around children using Vagal Nerve Stimulators (VNS) to control seizures.

Gravitational

Shunts drain at different rates depending on whether we are standing or lying, due to the effects of gravity. Shunts tend to drain more when we are upright, owing to a 'siphon' effect, and the greater the height between the head and the bottom end of the shunt, the more drainage tends to occur. This only happens with shunts, not ETVs. To counteract this effect some shunts, such as GAV, and paediGAV, operate with two settings - one for standing and another for lying down, to help reduce over-drainage.

Antimicrobial

Bactiseal shunts are impregnated with two antibiotics to kill bacteria that are introduced at the time of the shunt surgery. The antibiotics are embedded throughout the shunt's material rather than being coated on to the inside of the shunt. This means the antibiotics aren't washed off the shunt by the flow of the CSF, so continue to kill bacteria for several weeks after the shunt is inserted.

Shunt accessories

Antisiphon devices

Some shunts have devices included or added to reduce or prevent over-drainage owing to gravity when standing up (siphoning).

Ommaya reservoirs

Although not strictly a shunt, these are often used alongside shunts or ETVs. They are formed of silicone, with one end in the ventricle. The other is a closed end placed just under the surface of the scalp. No CSF flows through the device, but it provides direct access to the ventricle and can be useful for measuring intracranial pressure, or for doctors to draw off CSF to relieve pressure in the case of suspected shunt or ETV blockage.

Shunt complications

Shunt infections

Occasionally, bacteria from the skin can infect the shunt at the time of surgery. Bacteria live within layers of the skin, no matter how clean it is or how thoroughly the skin is prepared for surgery. These bacteria are harmless when on unbroken skin but can cause infections in other parts of the body. The bacteria are released into the surgical cut and the underlying tissue.

Signs of shunt blockage usually develop very quickly in infected VP shunts, but infected VA shunts do not block and may not result in any symptoms for several years after insertion. It is not possible for a shunt to become infected through day-to-day illnesses such as colds, flu or dental problems. You will not need antibiotic cover for dental work.

It is important to note that VP shunts can become infected following abdominal infections like a burst appendix, or bladder or bowel surgery; do ensure surgeons know your child has a VP shunt if these situations arise.

If it is suspected that a VP shunt is infected, it will usually block and you will need to seek medical attention straight away. The shunt will be removed and sent for testing, and an External Ventricular Drain (EVD) system will usually be inserted. This will allow the infected CSF to be drained into a bag outside the body, whilst antibiotics are used to clear the infection. It is important that blood or protein present in the CSF clears before the new shunt is fitted as these could block the new valve.

Shunt blockages

Shunts can block for a number of reasons.

Proximal (near the top)

- The tiny drainage holes in the proximal catheter may become clogged with healthy brain cells as the catheter is passed through the brain on its way to the ventricle. This may be a repeated problem for some people, leading to shunts blocking within a few days of being inserted, even with no infection present. Some people are more prone to this and at the moment we don't know why that is
- The drainage holes can become blocked with choroid plexus, a tissue in the ventricles that produces CSF
- The shunt can move slightly so the tip is no longer in the ventricle but in the brain tissue itself
- The valve can become blocked with protein or blood from haemorrhage, although this is rare

Distal (near the bottom):

- The bottom end of a VP shunt can become blocked by the tissue covering the bowel, if there is a lot of scar tissue (adhesions) in the abdominal cavity, or from infections or blood in the abdomen

Shunt revisions

If it is necessary to change part or all of your child's shunt, the neurosurgeon will aim to achieve this with the smallest risk of complications as possible. Shunts may, over time, become attached to surrounding tissues and it can be difficult to remove them without causing complications. However, if the shunt is infected, it will usually be necessary to remove the whole shunt so that the infection can be treated effectively.

If the shunt needs changing for another reason, it may be possible to leave a non-functioning shunt in place and just add another shunt system in another part of the head. If the proximal catheter is blocked but the distal catheter is working, it may be possible just to change the blocked component. Shunts which are draining too much or too little may be 'tied off' when another shunt is inserted to stop them working.

When shunts go wrong

Shunts can malfunction and medical attention should be sought. The pressure in the head may rise quickly – this is acute malfunction and you should take action immediately, getting your child seen in your **neurosurgical centre within 4 hours of symptoms starting.**

Acute shunt malfunction

If there is an acute shunt malfunction before the bones in your baby's head have fused together (around 18–24 months), an increase in head circumference may be noticed before you see signs of intracranial pressure.

Other signs include

- **bulging or tense soft spot** (fontanelle)
- **separation of the bones of the head** – looking like ridges or furrows across the top of the head, or down the centre of the forehead
- **lethargy** – not wanting to play or do anything when awake
- **sleepiness** – babies and small children should be fully alert when awake
- **needing to be woken for feeds, slow and reluctant to feed, falling asleep during feeds**
- **irritability, high-pitched crying**
- **sunsetting eyes** - eyes look downwards, showing white above the coloured part instead of below
- **vomiting**

In older children and adults, the signs and symptoms may vary from person to person, and in the same person from one shunt malfunction to the next. The signs and symptoms below should be for guidance only. Not everyone will present with all the symptoms.

Possible signs and symptoms of shunt malfunction include

- **headaches**
- **neck pain**
- **dizziness**
- **vomiting**
- **drowsiness**
- **photophobia (light sensitivity) or other visual disturbances**
- **seizures**
- **loss of consciousness**

In cases of **unusual drowsiness, becoming unresponsive, reducing level of consciousness or unconsciousness: THINK SHUNT**

What to do if you suspect an acute shunt malfunction

- **Call 999 to arrange transport to a local Accident & Emergency Unit.** Ensure paramedics and A&E staff are aware of shunt/hydrocephalus – SHINE Shunt Alert Cards may be helpful
- **Call the neurosurgical unit if the person is under a neurosurgical team.** If delayed in A&E triage, call the neurosurgical unit again
- **Encourage contact between emergency services and neurosurgical unit**

Some families may have their own agreements with their neurosurgical units in the event of emergencies, such as 'open access' arrangements. These should be clearly recorded in healthcare plans, etc.

Unless you have arrangements in place to go straight to your neurosurgical centre, you should go to your local A&E. Trying to get yourself to another town or city could result in delays.

Chronic shunt malfunction

Shunts can also malfunction over a prolonged period, and symptoms may be less clear, possibly including:

- fatigue
- general feelings of being unwell, lethargy
- new or worsening visual or perceptual problems
- changes in behaviour
- decline in schoolwork

A review by a neurosurgeon should be arranged if you think the shunt may not be working as well as it should.

Epilepsy and hydrocephalus

Some children with hydrocephalus may also have epilepsy. Epilepsy means recurrent seizures and often occurs in people with differences in the way their brain has developed, or those who have had an injury to their brain at some point.

Brain cells communicate with each other using electrical activity. Epileptic seizures come about when a sudden burst of electrical activity spreads over the whole or part of the brain and stops the brain functioning in the usual way, until the typical electrical activity is restored.

There are various types of seizure. Absences are common in childhood and can be easy to miss. Other types of seizures can involve involuntary movements in part of, or all of, the body.

Most seizures will stop within a few minutes but sometimes, or in some people, they may not stop without medication. As the muscles for breathing might be affected, it's vital that treatment is given quickly.

More information on seizures and first aid is available: www.epilepsy.org.uk

What you can do

If you suspect your child may be having seizures of any type, always seek medical help. In the case of less noticeable episodes, as with absences, trying to get it on video can be helpful.

You can also start to keep a written record of episodes including how often, when, how long for and any other information that might be helpful for your doctor to know.

Therapy activities

Your child may benefit from several types of therapy. Some will be available on the NHS, some you may need to arrange privately.

Physiotherapy

Paediatric physiotherapists work with people of varying ages from premature babies to adolescents to ensure optimal physical function and development. Like all physiotherapists, they are concerned with movement, coordination, posture and the cardiorespiratory system.

Occupational therapy

Occupational therapists help children and young people improve their ability to participate in everyday activities ('occupations'). These may include self-care tasks (e.g. getting dressed, eating), play and leisure activities (e.g. riding a bicycle, playing with building blocks) and participating in school life (e.g. using a pencil and scissors).

Speech and language therapy (SALT)

Speech and language therapy can help if there are difficulties producing speech or using language appropriately. It can also be useful for feeding difficulties associated with chewing or swallowing, or over sensitivity to certain textures of food.

Aquatic therapy/hydrotherapy

Aquatic therapy refers to water-based treatments or exercises of therapeutic intent. Treatments and exercises are performed while floating, partially submerged or fully submerged in water.

Water is helpful for children to develop strength and coordination. The water helps to eliminate the effects of gravity, which makes it easier for your child to move in a coordinated manner. It is also beneficial for circulation, respiratory and digestive functions.

Swimming is very beneficial for all children and, if appropriate, lessons can be useful for developing core strength, coordination and breath control.

Hippotherapy

Through horse riding, specially trained physiotherapists, occupational therapists or speech/language therapists apply the movement, rhythm and repetition of the horse as a treatment strategy to help children achieve therapeutic goals.

Rebound therapy

This is exercise therapy using a trampoline to provide opportunities for movement, therapeutic exercise and recreation for people across the whole spectrum of additional needs.

Hydrocephalus and **learning**

As your child with hydrocephalus grows and develops, you might notice the way they think, learn and behave has similarities to other conditions, such as autistic spectrum condition (ASC) or attention deficit hyperactivity disorder (ADHD). School staff might mention that they have noticed similar traits and may suggest testing for these conditions.

There may be features of self-regulation disorder, sensory processing disorder or non-verbal learning disorder that teachers and educational psychologists may notice when working with a child, which can sound distressing to parents and carers, but these short-hand descriptions can sometimes be useful when putting forward helpful ways to teach your child.

Sometimes, it can be useful to have a 'diagnosis', as it opens up the possibility of gaining extra support in school. A 'diagnosis' can effectively describe the way your child learns and behaves that education staff will easily recognise, and points them towards resources and strategies which will help your child to thrive. It isn't that there is an 'extra' condition on top of hydrocephalus, but a description of how your child's brain development is affecting them.

Trying to get a diagnosis can be time-consuming and frustrating; the important thing is that your child gets the right support at the right time and a professional assessment can help to identify what support and strategies will be most helpful. If your child is getting the support he needs, you might decide having a formal diagnosis isn't necessary.

About 25% of pupils with additional needs in schools have an ASC, so teaching professionals are usually trained to use strategies to support the learning of this large group of children. When your child has a less well-known neurological condition, like hydrocephalus, then it is useful to know that teachers have classroom strategies to teach pupils who learn in a similar way.

As well as features of ASC, a child with hydrocephalus may also have difficulties with processing information quickly, executive functioning and their working memory. Your child may gather together a collection of diagnoses.

If you notice 10 or more of the features on this list, then your child may need extra support in school to learn.

If you notice your child

- Finds it difficult to start concentrating or maintain their focus
- Finds it hard to control their impulse to do something
- Finds it hard to manage changes to their routine or adapt to different situations
- Doesn't start activities themselves or doesn't finish things
- Talks a lot, with repetitive speech
- Has literal understanding and comprehension differences
- Responds to questions and commands differently from what's expected
- Finds it difficult to complete abstract reasoning and executive functioning tasks
- Struggles to retrieve and recall information
- Struggles with visual memory and recognising visual patterns
- Has a reduced processing speed
- Finds it hard to maintain attention on a task by organising and planning for learning
- Lacks understanding of the concept of time, prospective memory and anticipation
- Needs help with place value, symbols, instructions and processes
- Takes a long time to understand money values and budgeting
- Has little awareness of the passage of time
- Finds it hard to transfer skills to new situations
- Struggles to build relationships
- Has feelings of frustration
- Does not know the appropriate behaviour for a situation
- Has habitual or obsessive behaviours and compromise issues
- Shows an eagerness to please or high compliance
- Has low confidence and self-esteem
- Finds it difficult to cope with change, leading to panic attacks
- Struggles to function effectively under time or social pressure

Teachers can use free resources and training opportunities on My World Teaching Hub to support your child in class: www.autism.org.uk/professionals/teachers/myworldhub/myworld-signup.aspx

Other conditions...

If you notice your child…	Then try this…
Features of Autistic Spectrum Condition (ASC)	
Finds it hard to manage changes to their routine or adapt to different situations	**Routines** throughout the day help to create security and consistency. Practise what to do when changes occur so your child has a range of language and actions to use in different situations. Let your child know well in advance, if possible, of any changes and show these changes on a visual timetable at home to remind your child and to calm them
Has literal understanding, understands different meanings from what is intended	Talk about alternative meanings of words, using cards or their own experiences, so that your child is aware that the same word can have several meanings, e.g.. like 'orange'
Responds to questions and commands differently in social situations	Allow **time** for rehearsal of speech and the behaviour required for different social situations so your child is aware of the expected response
Struggles to build relationships	Maintain a 'buddy' or 'chaperone' system to help with **social anxiety** and to **reduce social isolation**
Struggles to show expected emotions, especially when under pressure	Encourage your child to **talk about their feelings** and how other people feel with the use of pictures and other visual representations of how your child feels
Does not know the appropriate behaviour for a situation	Play alongside your child in unstructured situations to establish play skills and to try out new situations in a safe way
Features of Attention Deficit Hyperactive Disorder (ADHD)	
Doesn't start activities themselves or doesn't finish things	Help them 'own' a task and be responsible for something, rather than blaming for not finishing, by talking through what needs to be done to complete the task. This leads to a sense of pride when a goal is reached. That sense of success can be built on and used as evidence to give your child a 'can do' attitude
Talks too much and uses repetitive speech	Use simple mindfulness techniques such as breathing, stretching or tapping to calm down their thought processes Make a 'calm down corner' at home or at school for your child to practise these exercises
Has low self-esteem	**Positive behaviour reinforcement strategies** are very helpful for a child with hydrocephalus in order to develop their social skills. Use positive language, explain what good behaviour you want and keep it short and simple (KISS)

If you notice your child…	Then try this…
Features of Self-Regulation Disorder (SRD)	
Has difficulty keeping still and listening attentively	Play games which require **turn-taking** or **start-and-stop skills**
Struggles to control their emotions	Keep track of inappropriate or unexplained behaviour. Look for what triggers a particular behaviour and **look for patterns**
Lives 'in the moment' and finds it hard to control impulses, beyond an age when they could be expected to able to regulate themselves	Use **descriptive praise** and talk about the qualities you admire about your child, such as, "Look at the nice thing you did there for your friend when you let them borrow your toy". Practise impulse control with games like 'Simon Says', and 'Ready, Steady, Go'
Has problems going to sleep and waking up at expected times	Establish a soothing bedtime routine like bath-book-bed. Some children find 'white noise' easier to sleep in than silence if they can't block out their own thoughts. White noise can be found on various apps
Features of Sensory Processing Disorder (SPD)	
Seeks particular sensations	Playing with a stress ball or fidget spinner
Avoids certain textures, sounds, tastes, smells, and coming into contact with them leads to a 'meltdown' which is sensory overload distress	Your child is fatigued by sensory overload. They may need a calm space away from the sensations they find 'too much', and reassurance
Hums, rocks or moves their head rhythmically	Try a hug vest or a sensory weighted blanket to provide feedback to their body
Features of Non-Verbal Learning Disorder (NVLD)	
Has a limited visual memory and finds it hard to recognise visual patterns	Try playing with Lego together. Build a simple shape with your child watching. Then ask them to make the shape the same way, using identical shapes and colours
Has problems working out a step-by-step process unaided	Follow a recipe or a fun science formula together, doing each part of the task side by side and taking time over it. Then repeat the task regularly to reinforce the vital parts of the process
Features of Dyslexia	
Difficulty with processing and remembering information, particularly with regard to reading and spelling, associated with verbal memory and processing speed.	Ask your child to repeat the instructions they have been given and 'scaffold' their learning using working memory aids Learn through doing activities together, e.g. like 'paired reading'
Features of Dyspraxia	
Struggles with fine and gross motor coordination and that may also affect articulation and speech	Try repetition of movements and tasks involving the whole body, or just hands and fingers, with no time limits or pressure to 'do it right'. Threading games, painting a wall with a big brush and just water, are examples
Becomes anxious and holds things too tightly	Anxiety can have a physical effect on a child, so self-talk can help. Ask your child to state their anxious thought, to talk about why that thought comes back, and create a response. E.g. such as, "Most dogs are friendly," when they have a fear of dogs

If you notice your child…	Then try this…
Features of Dyscalculia	
Finds the recognising of numbers, place value, number sequences and telling the time difficult	Practise number vocabulary like ‘more than’ and ‘smaller’ when playing. Use lots of ‘hands-on’ ways of showing how everyday things have numerical value (three cars, five apples), and practical ways of learning concepts like ‘equal to’. Weighing games, measuring cups and maths blocks can help show what numbers mean
	Link numbers to familiar contexts and to real situations like playing at shopping using real coins to show two times, five times and ten times amounts
Features of Dysgraphia	
Impaired writing, associated with difficulty ‘holding’ words and shapes in your mind (the working memory) in order to reproduce them on paper	Develop working memory by playing copying games, completing half-finished pictures and dot-to-dot puzzles Practise sequential movements of fingers by playing with clay and crafting materials

Glossary

Here are some useful words or terms you might find in this book, or hear from health or education professionals.

Aqueduct stenosis – blockage of the connecting pathways between the ventricles

Auditory – to do with hearing

Autism – a condition affecting a person's social interaction, communication, behaviour, attention and interests

Cerebrospinal fluid (CSF) – fluid which surrounds the brain and the spine

Cognitive – thinking, learning or behaviour

Cognitive functions – memory, attention, language, processing speed and spatial processing

Congenital – born with (not to be confused with 'genetic', which is something inherited)

Developmental milestones/stages – important events in a child's development (e.g. what a child should be able to do and at what stage they are usually able to do it)

Dysarthria – difficulty in pronouncing or saying words clearly, due to muscle difficulties

Endoscope – tube with a light at the end for looking inside the body

Epilepsy – a disorder of the brain characterised by recurrent seizures

Executive functions – abilities such as regulating behaviour, working memory, planning and organisation

Fine motor skills – hand and finger movements

Functional language – language which is appropriate to the situation

Genetic – something that is inherited

Gross motor skills – general movements of the arms, legs and body

Haemorrhage – bleeding

Hydrocephalus – when the brain is put under pressure by a build up of CSF

Hypothalamus – region of the brain, which controls temperature, thirst and hunger

Intracranial – within the skull

Intracranial Pressure (ICP) Monitoring – technique for measuring the pressure inside the head

Lexical/semantic skills – knowledge and use of words

Menarche – start of periods (in girls)

Non-ambulant – not walking

Papilloedema – swelling of the optic nerve caused by raised intracranial pressure

Perception – understanding messages received by the senses

Pervasive developmental disorders – autistic spectrum disorders

Phonological development – development of the sounds of language

Pragmatic language skills – recognise and use appropriate and functional language

Precocious puberty – puberty which occurs unusually early

Proto-words – sounds that describe the object, e.g. "Brrm, brrm," for car, or "Baa," for sheep

Psychological development – development of the mind and how this influences behaviour and feelings

Psychosocial – involving both mental and social aspects

Receptive language development – development of comprehension or understanding of language

Rote learning – learning something 'off by heart' in order to repeat it from memory

Semantic – the meaning of words

Sensory – to do with the senses of touch, smell, taste, hearing, sight, proprioception and vestibular

Sexual maturation – the process of becoming fully sexually developed

Shunt – a tube that drains excess fluid from the head or spine

Siblings – brothers and sisters

Spatial awareness – understanding where things are in relation to other things

Syntactic skills – knowledge and use of grammar

Third ventriculostomy (ETV) – an alternative treatment to a shunt, whereby a small hole is made in the floor of the third ventricle to divert the flow of CSF

Ultrasound scanning – examination of parts of the body using high-frequency sound waves

Ventricles – spaces in the brain that contain the cerebrospinal fluid

Working memory (short-term memory) – temporary recall of information currently being thought about

References and resources

Shine thanks Twinkl for kindly allowing the use of their resources in this book

Twinkl
Educational resources including SEND sections
www.twinkl.co.uk/resources

Fledglings
Providing disability aids and products 0–19
www.fledglings.org.uk

Newlife Charity
Provides equipment, charitable funding, free play pods and much more
www.newlifecharity.co.uk

Turn2us
Charitable funding resource
www.turn2us.org.uk/Get-Support

Children's Therapy & Family Resource Centre
www.kamloopschildrenstherapy.org/social-emotional-infant-milestones

Who are Shine?

With around 12,000 members across England, Wales and Northern Ireland, Shine is Europe's leading charity for people affected by spina bifida and hydrocephalus.

For over 50 years, we've been at the centre of developments which have improved the lives of thousands of people, enabling and empowering our members to lead the lives they want to live.

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Shine
Spina bifida • Hydrocephalus
Information • Networking • Equality

Little Stars

Shine offer specialist support for parents of children aged 0–10

For more information, visit:
www.shinecharity.org.uk/littlestars

or call 01733 555988 or email us at firstcontact@shinecharity.org.uk for support

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