NHS
East of England
Community Health and Care
NHS Trust

Development and learning of children who were born preterm or had medical difficulties around the time of birth

Information for parents, carers and educational professionals

Cambridgeshire and Peterborough
Children and Young People's Services

Table of Contents

This booklet is a collaboration between NHS and Education with key contributors:

Erin Bannister, Paediatric Trainee, Portsmouth University Hospital NHS Trust
Francesca Seregni, Paediatric Neurodisability Consultant, East of England Community Health and Care NHS Trust
Brigitte Vollmer, Professor of Perinatal and Developmental Neurology, University of Southampton, and Honorary Consultant Paediatric Neurologist, Southampton Children's Hospital
Gabriel Whitlingum, Paediatric Neurodisability Consultant – Hampshire Hospitals NHS Trust and Evelina London Children's Hospital – Guys and St Thomas's NHS trust

As a team of professionals and parents who have experience of the challenges and triumphs that come with nurturing infants who had a challenging start in life, we believe it is essential to share awareness of the research to families and professionals to support the long term needs of this group of children. This is why we updated this information booklet in 2025 by using the most recent research evidence and contributions of a multidisciplinary team including nurses, teachers, educational psychologists, paediatricians and parents.

We would particularly like to thank:

Jackie Taylor, Community Paediatric Consultant East of England Community Health and Care NHS Trust.
Rebecca Ferris, Consultant Paediatrician, and **Jo Birbeck**, Senior Educational Psychologist, for their contribution on a previous version of this booklet.
Maria Ionides, Senior Educational Psychologist, Cambridgeshire County Council Educational Psychology Service. And a mother of 14 years old born at 29 weeks and a 9 year old born at 26 weeks.
Rachel Edwards, Specialist Practitioner, SEND Service, Cambridgeshire County Council.
Claudia Chetcuti Ganado, Neonatal Consultant & Executive Coach, Bedfordshire Hospitals, who inspired and supervised a collateral piece of work between Cambridgeshire schools, NHS neonatal units and community paediatrics.
Leigh Drury, Inclusion Team Leader (Basingstoke and North Test Valley) Services for Young Children, Children's Services, Hampshire County Council

University of Southampton

NHS Hampshire Hospitals NHS Foundation Trust

NHS Guy's and St Thomas' NHS Foundation Trust

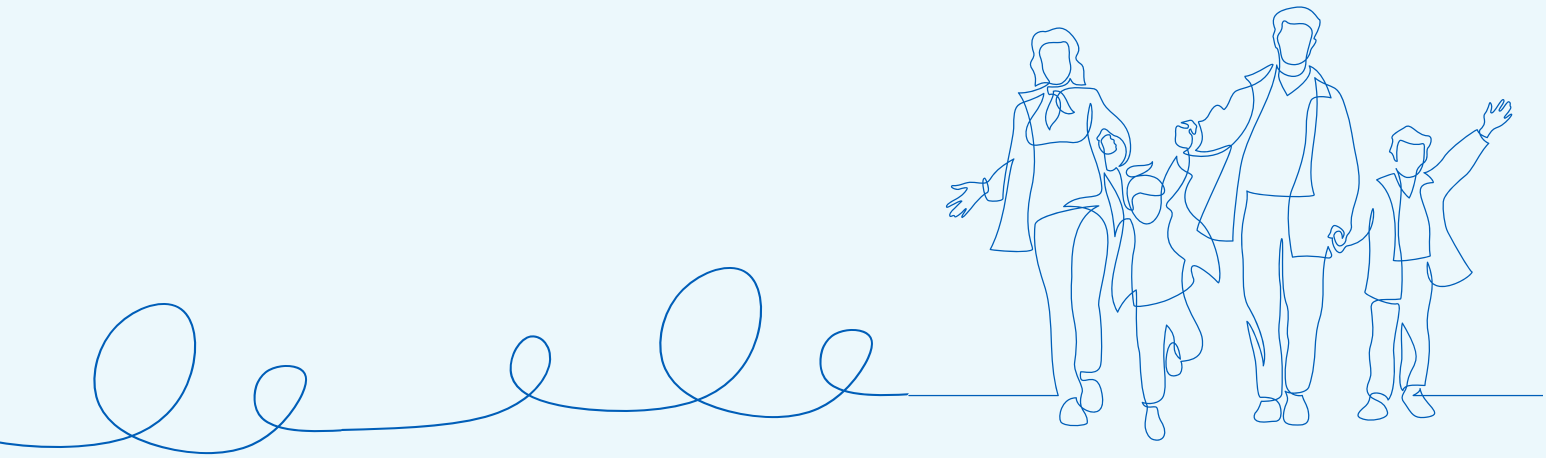
Evelina London Children's Healthcare

Introduction

This booklet has been provided for parents, carers and education professionals who want to know more about how children develop and learn. This booklet is intended to support children who had problems in the neonatal period, who are now attending school and need help with learning. It is not for children with severe cerebral palsy or epilepsy. It will cover common neonatal health conditions that may affect development, such as prematurity, hypoxic-ischaemic encephalopathy (HIE), perinatal stroke, neonatal hypoglycaemia, and meningitis.

Although these health conditions are very different from one another, presentation in school of children who had such a condition when they were newborns, can be similar due to the similarities in baby's brain development in the last parts of pregnancy and in the first 2 years.

During pregnancy and in the first couple of years the brain is very sensitive: the general health of babies and medical complications can have an impact on the way the brain cells mature, wire and connect between each other. There is an association between health conditions in the neonatal period and development in childhood. The complex wiring of the brain is essential for planning complex tasks, organising activities and social and emotional development. At the same time, at this stage of development the brain is also highly adaptable and can compensate for many early health difficulties when the child is provided with supportive, low stress environment, and a wide range of learning experiences.



After the first few years, most parents' initial concerns about their baby's health settle and the child's schooling becomes more of a focus. Even if the early development in the first few years of life can be as we would imagine it, and milestones like walking and talking happen at the expected time, sometimes children can show difficulties when they grow older and their brain is required to do more complex tasks like reading, writing, keeping concentration for long periods of time, understanding social cues and developing friendships.

The child may have extra learning needs, which may not be immediately obvious or visible. These may be hard to identify, especially if a child has a variety of subtle difficulties. Sometimes, periods of transition (moving from nursery school to primary school, or from primary school to secondary education) will highlight difficulties.

Parents may feel frustrated that these differences are not acknowledged or recognised by friends, family or professionals. Parents may find that their child's behaviour can differ in different settings such as at school and nursery compared to at home. Some children will have been discharged by health services, whilst other children might still be under follow up. Education staff sometimes might be best placed to recognise differences in development and might be able to offer support more quickly and effectively, especially if health services are no longer involved.

Every child is an individual and all children have their personal set of learning strengths and needs, regardless of their early journey in life. At the same time, research has found that there are similarities in the difficulties children experience if they were born prematurely or had difficulties around the time of birth.

We hope that this booklet can give you a greater understanding of why developmental differences can happen and what can be done to support children who experienced health complication around the time of birth in the weeks after birth.

Common Concerns

At home, parents might notice that their child has some differences or delays with:

- Hand-eye coordination - this can affect taking part in some sports, but also self-help skills like dressing and undressing and fine motor skills coordination like using small objects or handwriting.

- Being efficient in processing information and problem-solving - where it takes longer to process tasks and take appropriate actions to resolve a situation or answer a difficult question. These challenges are often linked to executive functioning skills such as planning, organising, flexible thinking, working memory (a form of short-term memory), and processing speed.

- Emotional and social development – social communication difficulties like understanding social dynamics, emotional difficulties such as shyness, anxiety, or sadness or it may be hard to make and maintain friendships

- Hearing or vision – e.g. not answering when asked questions in noisy environments or not seeing obstacles causing frequent trips and falls

- Sensory processing - children might struggle with sensory experiences and might find touch, sounds or lights overwhelming; children may also seek out sensations with certain behaviours like touching particular objects or textures.

- Daily living skills - children may find certain things challenging and will try to avoid them or might have trouble controlling their emotions around them. Those can include everyday tasks like showering, wearing clothes, eating or teeth-brushing.

Many times, it is school or nursery that notice difficulties first. Recognising those difficulties early allows teachers to plan prepare for further support and help the child learn how to use their strengths to compensate for their needs. They might notice some delays or differences in:

- Learning and progressing through the curriculum. The teacher might notice that a child takes longer to learn new things, needs more time to practise new skills or might perform below average on tests and assessments. There might be certain areas of learning which appear to be more difficult than others.

- Attention and hyperactivity. School might report that a child struggles to stay focused in class and easily loses attention. They might find it hard to stay sitting on their spot/chair, raise their hands, and stay still during lessons.

- Following the classroom routines, social dynamics and friendships.

Matthew's Story

"Matthew was born at 25 weeks and 6 days of gestation. He required neonatal intensive care for three months. His medical health has always been fine, and he did not have any physical problems identified subsequently. He is now 10 years. On the surface he looks the picture of health. His expected date of delivery was in November, but his birthday is in August. This means that he has always been the youngest in the class. He is currently in year six at primary school.

IIn preschool, it was noticed that he was a little behind the others of his age group but there was nothing specific that could be identified to get him any extra help. When he started school, it became more noticeable. He was the smallest in the class, and he started to suffer from terrible shyness and anxiety. He was not able to retain information, and everything needed to be repeated several times before he could understand it or remember it. His fine motor skills were slower, affecting his pencil skills and self-help skills. Everyone put it down to him being 'smaller' and that he would catch up.

School has always been a struggle for both Matthew and us as a family. I really wish that the needs of children who were born prematurely were recognised by professionals. We hope that this booklet will help parents and educational professionals recognise these problems and address them as early as possible."

Why do children who were born preterm have a higher risk of learning difficulties?

Babies who have been born prematurely are at a higher risk of physical disabilities and chronic lung problems. This is because the lungs have to mature outside of the protective environment usually provided by the womb. For the same reason, brain development may also be affected.

A baby born early has a much smaller and less complex brain when they are born. This is because most of the growth and development has not yet occurred. This complex process then has to occur outside of the womb in babies who have been born prematurely.

What specific areas may cause difficulties for children born prematurely?

Many children born preterm develop and grow up just like their peers (children of the same age) who were born at full term. However, other preterm children, despite having general cognitive abilities ("intelligence") within the normal range, have specific learning, motor (movement) and/or behavioural differences. These issues may lead to the child struggling at school.

These specific areas are:

- Co-ordination skills.
- Sensory differences (for example, being oversensitive to sound or touch; not being responsive to pain, heat or cold).
- Difficulties understanding complex language, where memory and processing are needed.
- Relationship, social interaction and social behaviour skills.
- Attention and concentration.
- Executive functions. This includes the ability to plan, organise or be flexible in thinking. It also includes functions known as working memory (a type of short-term memory) and processing speed.
- Specific learning difficulties (for example, finding reading, spelling or maths difficult).
- Children born preterm frequently have difficulties with movement - how well they can move and how fast - and co-ordination in tasks such as holding a pencil. These areas may be referred to by professionals as sensorimotor functions, visuo-motor and visuo-perceptual skills.

The risk of developmental problems is highest in children born extremely preterm (before 28 weeks of gestation).
Although severe impairments such as cerebral palsy can be detected early, it is difficult to predict more subtle problems during infancy or pre-school age. Often issues only become obvious when the child reaches school age.

The ability to use language is less often affected though. Most preterm born children develop their vocabulary and learn how to make sentences at a level appropriate for their age. However, some preterm children may have difficulties with more complex language linked with memory and processing. This means that they may take more time to follow and understand instructions, but they can use sentences and vocabulary correctly. It can sometimes be difficult for parents and professionals to grasp how a child can speak fluently but may not always understand when spoken to.

Bella's Story

"Bella was born at 26 weeks, a sole surviving triplet, weighing 780 grams. She was discharged from hospital after five months and despite being warned of potential health problems, Bella was generally fit and well and was signed off by the paediatrician at the age of two. In school she made progress, but it soon became clear that she was different to other children in her ability to learn. It was difficult to put your finger on exactly what the problem was, but she particularly struggled with retaining information and understanding the more abstract concepts of learning, particularly in maths.

She was never deemed as needing a Statement (now known as an Education and Health Care Plan), but she struggled in most areas of school life, both physically and mentally. As she progressed through school, her difficulties became more obvious. Despite being given some additional support with reading and maths, she made little progress in the latter years of primary school. Now aged 13 and at secondary school, although she is a happy and sociable child, it is clear she finds school life a struggle. She has little desire to engage with schoolwork, describing it as 'boring', but we believe this is because she finds it hard, and struggles to maintain concentration. She has difficulty understanding the context of what is being taught, as well as processing and retaining information. Language can also pose difficulties, and she sometimes gets her words muddled up when speaking.

She is prone to minor accidents such as falls or injuries which although not serious, collectively make life harder. She is often exhausted at the end of the day. Bella is part of a large family and is a happy and content child who engages in family life but sometimes struggles to understand the context of conversations and events. She finds it hard to read situations and be aware and sensitive to her surroundings. This can lead to her appearing insensitive to other people's circumstances. She benefits from support with her organisation skills, such as making lists or clearly discussing and reiterating instructions and tasks. We have often spoken about how we wished both her primary and now secondary school had a better understanding of Bella's needs, and a greater awareness of the needs of children with extreme prematurity. It would be good to see schools recognising the issues prematurity brings educationally and having strategies in place to deal with them. "

Hypoxic-Ischaemic Encephalopathy (HIE)

Lilly's Story

Lilly was born after a normal pregnancy shortly before her due date. She was very poorly when she was born and had to be admitted to the NICU because she needed brain cooling. She was a little slow with her development initially but did meet her developmental milestones. Lilly started nursery when she was one year old and this went very well; she enjoyed the company of the other children.

Pre-school and school start went very well, but we noticed that at times she was easily overwhelmed and needed her routines. Her gross motor skills and her fine motor skills lagged a little behind those of the other children and sometimes she found it hard to focus on a task. In the beginning her progress academically was not different from her classmates and she did very well at school. Over time, however, it became more obvious that she was often very emotional, much more so than other children in her year, most times for no reason. She is now 8 years old, and she is a happy child, but she struggles with remembering new information and completing more complex tasks and this makes schoolwork hard for her. Lilly is very "sensory", which can make it difficult for her to be in busy environments, for example, at school during break times, when we go shopping, or when the family comes together.

Why do babies with HIE have a higher risk of learning difficulties?

Neonatal Hypoxic-Ischaemic Encephalopathy (HIE) develops when the baby's brain does not receive enough oxygen around the time of birth. The brain is very sensitive in babies, and the lack of oxygen can cause injury to the cells which are developing and wiring together. Depending on the extent of the injury to the brain, some babies with HIE may recover with little to no lasting difficulties but others may go on to develop cerebral palsy and learning difficulties as they get older.

Despite advances in the interpretation of brain scans and baby's movements, it remains very hard to predict the degree of difficulties in the period around birth and only time will tell whether difficulties emerge.

What specific area may cause difficulties for children who had HIE?

Children who had HIE may have difficulties that affect their general cognitive abilities ("IQ"). A large proportion of children though have general cognitive abilities that are in the normal range and at the same time they can have difficulties in specific areas such as attention, executive functioning, memory and social-emotional regulation. These difficulties may be more pronounced in children with severe HIE compared to children with mild or moderate HIE. Difficulties might become apparent at school age and manifest as need for extra support and special educational needs and they may struggle in areas such as reading and spelling. Most children will still attend mainstream school, but some may require education at specialist schools.

Children with HIE are more at risk of challenging behaviours, for example, inattention and hyperactivity, and some are a little more anxious and withdrawn than other children. Other challenges children with HIE may face include difficult peer relationships, or sleep difficulties.

Eddie's Story

Eddie's start in life was difficult to say the least. We had a very normal pregnancy without any concerns up until 38 weeks when I couldn't feel him moving. We went to hospital and very quickly it was decided for us to have an emergency c-section. When he was born Eddie didn't cry at first. They whisked him away straight to NICU with his father whilst I was still in theatre.

After recovery I met my beautiful boy the first time. Things were a blur from this point, but we spent the next few days by his side in NICU. He was hooked up to all sorts. Electrodes on his head, drips and many beeping machines. To begin with the staff were really concerned and we were told he would likely be very unwell. But after a week they discharged him from NICU, and we were onto a more general maternity ward. This felt like we might have a 'normal' boy (whatever that is!)

One night I was trying to feed him, and he was making jerking movements. I didn't think much of it as it was very subtle, but I asked the nurse to come and check. Straight away she rushed him back down the lift to NICU. We were taken to another room, and we were told that he was having a seizure and they were struggling to control it. He had an MRI which showed '30 plus multi-foci bleeds' across his brain, we didn't really know what that meant beyond that he was likely to have some sort of disability. His seizures came under control and after another week or so on NICU we finally took him home.

We had no idea what his prognosis or future would be, and we kept trying to ask doctors, physio's and therapists at the numerous appointments we had. I now know that they didn't know either, and we had to wait and see what his future held. I remember all I wanted to know was would he talk, then would he walk, would he have friends, all questions that no one knew the answers to. We clung onto everything that every medical person said and over analysed it.

At the time we found a lot of information about children born prematurely but little about what to look out for in our circumstances.

Fast forward now 8 years and we are so lucky. It's not been easy and I know we will have more hard times ahead, but he has done all these things and more. He has a diagnosis of Cerebral Palsy which effects his right side, but he can walk and when playing football (his absolute favourite thing in the world) can run. He gets physically exhausted but loves to play football. He struggles to write but can read brilliantly. We managed to get him an EHCP (Education Health and Care Plan) when he was still at nursery, so he has always had appropriate support for his needs at school for example, he uses a laptop at school, and this really helps him access his learning. We are awaiting an autism assessment, and he struggles with some sensory environments and social communication, but he is smiley, loveable and happy.

Why do babies with perinatal stroke have higher risks of learning difficulties?

Perinatal stroke is a stroke that occurs just before, during birth or shortly after. This occurs where the blood vessels in the brain become blocked or burst resulting in injury to the brain. Some babies with perinatal stroke may recover with little to no lasting difficulties but some babies may go on to develop learning difficulties or disabilities as they get older. The impact of the stroke can depend on factors such as location and size of stroke.

What specific areas may cause difficulties for children who had a perinatal stroke?

Children with perinatal stroke are at risk of poorer executive functioning. The specific executive functioning skills most affected can be difficult to identify, but some research has shown that one of the most vulnerable skills is inhibition. These children may have behavioural difficulties with symptoms of inattention and hyperactivity and may be more likely to go onto develop ADHD traits or to have a diagnosis of ADHD.

Children with perinatal stroke are more at risk of having difficulties with their cognitive abilities including language problems, poorer performance in school, memory, and learning. Research studies on cognitive skills in children with perinatal stroke have found conflicting results with some studies finding that children born with perinatal stroke have lower IQ scores whilst others have found IQ within the normal ranges.

Regardless of the general cognitive abilities, research shows that most of the children with perinatal stroke have a good quality of life, attend mainstream school and participate in physical activities. Education support may be required for help with reading, spelling, and mathematics. Factors that can influence outcome in children who have had perinatal stroke include age at stroke onset, location and size of the stroke.

Neonatal hypoglycaemia

Why do babies with neonatal hypoglycaemia have higher risks of learning difficulties?

Hypoglycaemia refers to a state of low blood sugar. This is a relatively common problem in babies shortly after they are born. This happens because in the womb babies receive glucose from their mother and after they are born, they adapt to receiving glucose from milk. The adaptation process can be complicated for various reasons including gestational diabetes and insulin production, use of medications or health conditions related to the production of insulin in babies. Hypoglycaemia in babies is usually a transient problem and babies in most cases then learn to regulate their glucose appropriately. However, after birth, if blood sugar levels drop too low or for too long, this can lead to brain injury as the brain uses glucose as main fuel. If this happens the baby might be at risk of visual, neurodevelopmental and learning difficulties.

What specific area may cause difficulties for babies with neonatal hypoglycaemia?

Children exposed to neonatal hypoglycaemia shortly after birth have a higher risk of visual-motor impairment in early childhood. Visual-motor skills refer to the way we process visual information and use it to complete tasks. Therefore, these skills are very important in hand eye coordination and spatial awareness. Problems in this area may manifest as problems with catching items and playing sports or writing and drawing.

In later childhood, some studies have found that exposure to neonatal hypoglycaemia increases the risk of developing difficulties with literacy and numeracy skills and executive functioning. Therefore, these children may require more support in school. However, the quality of evidence in these areas is low and other studies have found that educational achievement was similar in older children regardless of hypoglycaemia exposure, therefore it can be difficult to predict what kind of difficulties these children may have in school.

Meningitis

Kye's Story

Kye was diagnosed with meningitis two weeks following birth. He then went on to have seizures. We were made aware of various complications which may happen with him. Kye made very little noise as child and was around half his age as he developed. He only started to talk at four and half years old. Despite this, he always showed determination and a positive attitude to trying tasks. He would obsess until he achieved the goal, if he didn't manage the task, he would become very disgruntled.

Kye went to nursery at the local primary school at the age of two, and this played a great part in his development and ensured he was challenged and pushed. He thrived very well with the support of the nursery team all the way through even though he was pre-verbal. When Kye went to mainstream education this was where we noticed he struggled. He was clearly behind his peers, the teaching staff due to limited resources struggled to cope with his learning needs. Kye greatly benefitted from the social side of mainstream school but sadly the lack of resources put him further behind. We struggled for a few years to get an accurate EHCP set up as the mainstream school kept saying they could meet his needs. It was only through challenging and the support of his paediatrician that we were able to get him a placement at a SEN school. Since Kye has been there, he has come on greatly. The support he now receives means he can communicate a lot better by both speaking and writing. Kye learns very well through being shown tasks and then following.

Kye's early years at nursery were great building blocks for his education but later let down by the two years in mainstream. Being at mainstream school did support greatly with his social skills. Now he is in a SEN school his educational needs are met. It would be good to see SEN schools and mainstream schools holding joint interactions to further support the needs of his social skill development.

Why do babies with neonatal meningitis have higher risks of learning difficulties?

Neonatal meningitis refers to inflammation of the layers surrounding the brain occurring shortly after birth. This can be caused by bacteria or viruses. With the right treatment most babies will recover with few lasting effects. However, in some cases, the infection may damage the brain which may cause babies to have longer term problems. Outcomes vary a lot in children who suffered from neonatal meningitis and it can be very difficult to predict the level of difficulties.

What specific area may cause difficulties for babies with neonatal meningitis?

Children exposed to neonatal meningitis have been found to be more at risk of hearing impairments. This impairment can range in severity with some children having mild hearing loss or requiring hearing aids and some children having more severe hearing loss.
Children exposed to neonatal meningitis may also be more at risk of cognitive impairments including lower than average IQ. Therefore, these children may need educational support during school.
Children exposed to neonatal meningitis have also been found to be more at risk of motor impairments including cerebral palsy. The severity of this can vary.

These findings were found in children with Group B Streptococcus (GBS) meningitis (the most common cause), but also in children exposed to meningitis caused by other pathogens (such as E.coli and Listeria, or Parechovirus) meaning that the bacteria causing the infection has not been necessarily found to be related to later outcomes in children exposed to neonatal meningitis.

Useful learning strategies

All children have temperaments and ways of learning that are individual to them. Learning strategies used in schools can work well for all children with learning difficulties, regardless of whether they were born premature, had other neonatal problems or didn't have difficulties in their neonatal period.

Many strategies listed in this booklet can be used with children of any age, although some of them are more appropriate for younger children. We suggest you use them selectively taking the child's views into account.

Fine motor co-ordination

These are activities to build up strength, dexterity and control. For example:

- Playing with sand, water or making and playdoh. This can be very good for squeezing, pushing, pinching, rolling, and being creative.
- Using a pincer grip – games with clothes pegs, peg boards and patterns, sorting small objects, using the child's imagination to make games out of these activities.
- Large and small mark making (using big arm movements and finer detail) with various materials and tools (paints, chalk, pens, large paper) creating scribbles, random or planned patterns, colouring and developing into the child's drawings.
- Helping your child to bake cakes or cook a simple meal will help develop their fine motor coordination skills.

You can make manipulative play and activities fun: doing them together with an adult or socially with other children, using shared humour, and following the child's interests and lead. Make sure the child's efforts are valued and praised to further enhance the positive experience around these activities to help them to persevere. It is important to notice even small achievements.

Visual perception, motor co-ordination and planning skills

- Introduce and provide step by step pictures of how to do a task. For example, pictures in the correct order for a regular routine, such as getting ready for school.
- Develop cue cards or other visual aids with the child for tasks that they find difficult. For example, place dots on the left of a page to indicate where to start on a new line, and directional prompts (such as up/down or left/right arrows) for specific letters and numbers that they may struggle with.
- Help the child to think how to visually organise their toys, tasks, belongings or materials in a way that helps them with the task.
- Give time and visual prompts if needed for the child to process spatial language (for example, top, bottom, in front, behind and so on).

It is important to recognise the unpredictability and uncertainty that the child may feel when experiencing these difficulties, and the impact on their emotions and reactions. Providing positive feedback, reassurance and prompts might help when the child becomes stuck.

Responding to sensory differences

- Children process sensory information via hearing, smell, taste, vision, movement, body position and touch. Difficulties can occur within one or more of these senses and can be related to being under-sensitive (where more stimulation is needed) or oversensitive (where less stimulation is needed). Some children can be under-sensitive in one sense and over-sensitive in another. Sensory processing skills can also change day to day – depending on the environment, tiredness, distractions and presence of other stressors.

- Observing and making a note of how the child reacts – their likes/ preferences, dislikes/ things they avoid, any distress they show – to each of these senses will help you to understand the child. You may have access to a sensory checklist to help you do this. Share information with key people involved with the child, at home or at school.

- In general, if the child is under-sensitive to a particular sense and seeks more stimulation, the focus should be on recognising that need and organising suitable activities to provide it. The focus will be different for each of the senses.

Example 1

If the child is under-sensitive to movement, they may seek a lot of physical activity by running, spinning, crashing, hitting and bumping into things or people. Regular and planned activities could include rough and tumble play; jumping; using swings, trampoline, space hopper, ball pools and soft play areas; playing with weighted balls; pushing and carrying heavy objects; digging; using a weighted jacket or backpack; crawling through tight spaces/tunnels; firm rolling in a mat, blanket or sleeping bag; using a 'move and sit' cushion when doing table-top activities.

Example 2

If the child is over-sensitive to sounds, they may react with distress or cover their ears to noises and particular environments which would not cause problems to other children. A planned approach could include: reducing the noise level and/or length of time they are exposed to it; providing a quiet area in school for certain times; giving the child a job/activity so that they are out of the classroom at a particularly noisy time; preparing and warning the child of predictable loud noises, such as the vacuum cleaner, washing machine, fire alarm practice; allowing the child to wear earplugs or headphones; allowing the child to have control over the source of a loud sound, for example to blow the whistle or press the play button on a music device such as a music player can help to gradually reduce their sensitivities.

Always work with the child and their feelings about different activities or approaches and note how they cope. Use what helps and adapt to new strategies as the child develops.

Auditory and receptive language skills

(listening to and understanding language)

- Reduce background noise whenever possible.
- Simplify verbal and written instructions.
- Give verbal information in short chunks.
- Allow 'processing time' (e.g. count to 10 after you've asked the child to do something) and look for signs of understanding before giving the next piece of information.
- Don't change the instruction if you need to repeat it.

- Accompany verbal instructions or information with visual clues like pictures, symbols or simple written words.
- Visual cues can be used to support all aspects of daily life, such as understanding objects, verbs, books and daily routines.
- Provide information when and how activities will be done.
- Encourage the child to tell you what they are going to be doing. Use prompts as above if needed.
- Keep your voice friendly and warm.

- Actively encourage the child to have the confidence to say when they do not understand or are unsure, and to ask what a word means (this is known as self-monitoring).
- Check every so often that the child is 'on track', giving guidance and support if needed.
- Encourage understanding and vocabulary through fun activities. For example, play, practical activities and language games, with lots of repetition and use in daily/ school life.

Expressive language skills

(use of words)

- Name what the child is doing, seeing and feeling in the moment. Commenting tends to be much more helpful than asking them questions. This gives language linked to where their attention is focused and encourages the child to start using this language themselves.

- Value the child's expressions of feelings, words and ideas, respond to and follow these and the child's interests, and build from them.

- Give the child time to express him/herself at their own pace – not rushing them or losing interest in what they are saying.

- Repeat back or summarise key information to show that you have listened, and to check that you have understood the child's meaning and model good use of words.

- Encourage retelling of events, experiences and stories. Support this by offering verbal and visual prompts, such as photos and who, what, where, what happened, the end.

- This technique can also be used for problem solving and can help with written work when a child needs to note events in a particular order.

- Continue to value and develop spoken expression for the organisation of thoughts, ideas and information, using visual prompts if needed. Substitute spoken language for written recording tasks and use alternative recording such as scribing (where the child dictates their ideas to someone else to write down) or tape.

Relationships, social interaction and social behavioural skills

- Show interest and pay attention to things or activities that are important to the child.
- Be attentive and responsive to any interaction (non-verbal and verbal) that they initiate.
- Provide a commentary on what they are doing and what you are doing. Have times of connecting and being together without a lot of instructions or questions.
- Name emotions, feelings or situations– particularly positive feelings such as enjoyment, fun, pleasure, happy or relaxed, and feelings that often come before anger and more challenging behaviour such as disappointment, frustration, hurt, bounciness, uncertainty or confusion.
- Show you understand their feelings or situation. For example, say aloud "Oh this is a bit tricky, I'm wondering what might help. Perhaps we could…."
- Adapt the pace of conversation so that the child can follow and take part. Support and encourage the child's brothers, sisters, friends and classmates to adapt their pace.
- Provide social and emotional commentary to help the child understand what is happening, as well as learn and practice social skills.
- Give the child clear, positively reinforced boundaries, routines and predictability.
- Prepare for and support any changes.
- Support and manage social situations and expectations, based on an understanding of your child's underlying needs and demands on him/her in that situation – to help them have a positive social experience.

Working memory

Find games and fun ways to practise and rehearse (try out and then practise). For example:

- Post and name objects/pictures into a box, then see how many the child can remember. Start with a small number and increase as the child progresses.
- Memory games such as 'I went to market and bought a cake; a cake and a carton of juice…' (You can vary this with different objects and categories, such as fruit, vegetables, farm animals, transport etc).
- Sing and establish familiar songs and rhymes.
- Encourage fun with rhymes – make up or learn short poems; play with words, actions and rhymes.
- Repeat and rehearse auditory information. Encourage the child to talk through what they are going to do.
- Support auditory memory with visual cues/sequences (pictures, symbols, words) in key learning and daily tasks.

Processing speed

- Allow extra time – adapt your style to enable their thinking and contribution to be successful.
- Support and encourage the child's peers (friends, classmates and siblings) to give additional time, so that the child can be part of a conversation or an activity, for example.
- Avoid emphasis on timed completion and comparison with others.
- Help the child know their strengths and interests and give them plenty of opportunities to build on those and experience success.
- Support the child to name things which are 'hard' or 'a bit tricky' or 'frustrating' for them and notice what helps them to get better or work around their difficulties.
- Demonstrate and name whatever helps the child listen and respond.Value effort, individual achievement and the progress they make.

Organisation and planning

- Introduce, build up and develop the child's acceptance of using tools or aids. For example, prompts/reminder cards, stepped or sequenced schemas with linear and visual prompts (e.g. written, symbols, colour coding).
- Prepare for new events and learning – introduce them by giving the child small chunks of information to process.
- Develop new processes and learning through doing things together – make it a 'we task'. The adult repeatedly does the task and the child gradually gains the confidence to join in, doing part of the task and building up to doing it all.
- Name the steps (known as self-talk) as you are doing them.
- Encourage the child to check what they need to be doing, by watching what others are doing.
- Encourage the child to work with a partner, such as a friend or classmate.
- Let the child know it is okay to ask a trusted person for help when stuck.
- Help the child to learn and use some key phrases such as 'I'm not sure what to do next' or 'I need to think'.
- An adult can demonstrate the technique of self-asking questions (such as 'what do I need to do next?') or statements ('now I need to stand up') to support thinking

1) Some parents of children born extremely premature might want to consider delaying school entry.

Overall, there is no conclusive evidence that delaying school entry is beneficial for children that were born premature as school might be the best place for them to receive the specialist support they need from the earliest opportunity. Things like an individual child's overall development, their access to support in other settings like early years nurseries, their gestational age and the time of birth in the year (e.g. summer babies) should all be taken into consideration. Talking to the school SENCo in the prospective school, nursery staff and health visitors can help your decision-making process.

You can find more information about delaying school entry in prematurity here: https://www.bliss.org.uk/parents/growing-up/starting-primary-school/deferring-and-delaying-a-primary-school-place

2) Inform teachers and SENCo that your child was born premature or had medical complications after birth which might affect their learning and social and emotional development.

Teachers might not be aware of the neonatal history and the medical follow up unless you explain it to them. Sometimes even if the nursery was aware, this information might have not been passed onto school staff. If you have any concerns about your child's health or development, it is important to make school aware during the admission process or talk to the class teacher or SENCo.

3) Encourage your school to become Prem Aware

Ask the schools if they are aware of the **Prem Aware** award and encourage them to sign-up if they are not. The Prem Aware award was created by **The Smallest Things** charity. It is a campaign with the aim of training teachers in how prematurity can affect development and help schools to recognise the needs of the children born prematurely. https://www.thesmallestthings.org/prem-aware-award

The Prem Aware scheme promotes a training package for teachers called 'Preterm Birth Information for Education Professionals'. This is an online training programme available for free on the website www.pretermbirth.info. It was developed by the PRISM Study, a group of doctors, professors and psychologists from various UK universities in partnership with parents, to improve the knowledge and confidence of teachers and other educational professionals for supporting premature children in the classroom. While this training programme is aimed at teachers, it is also a useful resource for parents if you want to know more about how premature birth can affect educational development.

On average, each primary school class across the UK has two children who were born premature. It is important that teachers understand the child's potential challenges and know the best ways to support them. Although teachers are trained to deal with special needs and disabilities, studies have shown that only a small number of teachers feel they have received enough training to support children who were born premature.

Even if your child was not born prematurely, a lot of the knowledge and strategies used for premature children can be applied to other neonatal conditions, so it is still helpful for your school to know more about this.

Recognising each child is unique

It is extremely important to recognise that each child, regardless of their birth history, is different. Each child has their specific strengths and difficulties, like every one of us. While statistics provide valuable insights, they should not be seen as rigid expectations. Just like all children, children who spent time in NICU do not adhere to specific timetables when it comes to development and academic achievements. What truly matters is their progress and the support they receive to reach their full potential.

While recognising a child's additional needs and supporting them is very important, it is equally important to remain confident in their resourcefulness and resilience, focus on their strengths and progress, and help them feel that they are – just like everyone else – a unique and capable individual with their own set of strengths and challenges.

Whether you are a parent, a teacher, or a professional, your ongoing involvement, understanding, and advocacy are crucial in ensuring the success and well-being of children at school and at home.

Finn's story

"Finn was born at 32 weeks and 5 days gestation with a congenital heart problem. He had a difficult neonatal period complicated by an episode of severe Group B Streptococcus infection at six weeks of age. After being discharged home, he required numerous admissions to hospital during the early days. There was a degree of recognised developmental delay due to his poor health, and he remained unsteady on his feet after he learnt to walk. When he was two years of age, there was a noticeable delay in his speech and language. He was referred for speech and language therapy which also led to him attending a special needs class at pre-school. His motor skills were also slow to develop, with poor balance and fatigue preventing him from accessing full pre-school hours.

During this time, he started to become very anxious about going to pre-school and had difficulties with transitions (moving from one situation or activity to another). He displayed more and more quirky behaviour around sensory input such as loud noises, and the feel of wind, sand and messy play, which he avoided. He experienced frequent meltdowns, which were extreme and would last for up to an hour. These meltdowns were put down to normal toddler behaviour, although I couldn't help but feel that these were at the more extreme end of what I saw other parents experiencing with their toddlers.

After a tricky start in Reception at school, it was agreed that he should be held back a year and we also applied for a statutory assessment of his special educational needs. Finn now has a Statement (a joint Education and Health Care Plan) which has supported him through the repeat of his Reception year. It has also ensured that he has received occupational therapy for his sensory processing difficulties, as well as speech and language therapy, and physiotherapy.

Through the statutory assessment process, we discovered that Finn had developmental coordination disorder, difficulties with sensory processing, executive functioning, and emotional regulation. A speech impairment and difficulties with attention also made it hard for him to process language in busy environments. Difficulties with word finding and working memory impact on his expressive language. However, he is very bright and the frustration caused by this and his degree of specific learning difficulties made it very difficult for him to access formal learning in a classroom environment without support.

It has been a long journey, but we now feel that Finn is at a stage where he is ready to start more academic learning. Through his access to intensive therapy at this early stage, he will hopefully gather the skills necessary to support himself through education and life, despite his difficulties. It took us a long time and much angst to reach a point where we understood what was going on for Finn, but we now feel that we are unlocking his amazing potential. We would really love for more educational and health professionals to understand the difficulties that children with difficult neonatal journeys have, so that more children like Finn can be appropriately supported. "

Other useful resources

1. Information and resources to support coordination and motor skills difficulties: https://www.cambspborochildrenshealth.nhs.uk/services/cambridgeshire-childrens-occupational-therapy-service/online-learning-and-training/co-ordination-and-motor-skills

2. Sensory difference training for families: https://www.cambspborochildrenshealth.nhs.uk/services/cambridgeshire-childrens-occupational-therapy-service/online-learning-and-training/sensory-differences-training-for-families/

3. BEAM programme to support the development of motor skills including balance, coordination and body awareness for children who find this challenging: https://www.kentcht.nhs.uk/childrens-therapies-the-pod/physiotherapy/beam-and-jump-ahead/

4. Strategies for children with attention difficulties: https://www.arcslambeth.co.uk/attention-difficulties-resource-pack/

5. Stroke Association Perinatal Stroke information and resources: https://www.stroke.org.uk/stroke/childhood/stroke-unborn-newborn-babies-perinatal-stroke

6. Information and resources regarding HIE: https://www.bliss.org.uk/parents/about-your-baby/medical-conditions/hypoxic-ischaemic-encephalopathy-hie

7. Information and resources regarding neonatal meningitis: https://www.bliss.org.uk/parents/about-your-baby/medical-conditions/meningitis#:~:text=Meningitis%20Research%20Foundation%20%E2%80%93%20for%20information,at%20any%20age%2C%20including%20babies

References

Aarnoudse-Moens CS, Weisglas-Kuperus N, van Goudoever JB, Oosterlaan J. Pediatrics. 2009;124:717-28.

Abusaleem MY, Ebrahim MEE, Hamed NF, Eladwy MFM. Cureus. 2024;16:e68227.

Allen KA, Brandon DH. Newborn Infant Nurs Rev. 2011;11:125-33.

Allotey J, Zamora J, Cheong-See F, et al. BJOG. 2017;125:16-25.

Bhutta AT, Cleves MA, Casey PH, et al. JAMA. 2002;288:728-37.

Bröring T, Oostrom KJ, Lafeber HN, Jansma EP, Oosterlaan J. PLoS One. 2017;12:e0170828.

Brydges CR, Landes JK, Reid CL, et al. Dev Med Child Neurol. 2018;60:452-68.

Cassiano RGM, Provenzi L, Linhares MBM, Gaspardo CM, Montirosso R. Infant Behav Dev. 2020;58:101417.

Conway JM, Walsh BH, Boylan GB, Murray DM. Early Hum Dev. 2018;120:80-7.

Dean B, Ginnell L, Boardman JP, Fletcher-Watson S. Neurosci Biobehav Rev. 2021;124:151-67.

Delobel-Ayoub M, Arnaud C, White-Koning M, et al. Pediatrics. 2009;123:1485-92.

Edwards T, Alsweiler JM, Gamble GD, et al. JAMA Netw Open. 2022;5:e2235989.

FitzGerald TL, Kwong AKL, Cheong JLY, et al. Phys Ther. 2018;98:691-704.

Fuentefria RN, Silveira RC, Procianoy RS. J Pediatr. 2017;93:328-42.

Geldof CJA, van Wassenaer AG, de Kieviet JF, Kok JH, Oosterlaan J. Res Dev Disabil. 2012;33:726-36.

Giraud A, Stephens CM, Fluss J, et al. Arch Pediatr. 2023;30:600-6.

Harding JE, Alsweiler JM, Edwards TE, McKinlay CJD. BMJ Med. 2024;3:e000544.

Horváth-Puhó E, van Kassel MN, Gonçalves BP, et al. Lancet Child Adolesc Health. 2021;5:398-407.

Johnson S, Hennessey E, Smith R, et al. Arch Dis Child Fetal Neonatal Ed. 2009;94:F283-9.

Johnson S, Hollis C, Kochhar P, et al. J Am Acad Child Adolesc Psychiatry. 2010;49:453-63.

Kelly MM, Griffith PB. J Pediatr Health Care. 2020;34:e59-76.

Kerr-Wilson CO, Mackay DF, Smith GC, Pell JP. J Public Health. 2012;34:209-16.

Kirton A, Deveber G. Stroke. 2013;44:3265-71.

Kohli-Lynch M, Russell NJ, Seale AC, et al. Clin Infect Dis. 2017;65:S190-9.

References continued...

Kovachy VN, Adams JN, Tamaresis JS, Feldman HM. Dev Med Child Neurol. 2014;57:410-9.

Marlow N, Wolke D, Bracewell MA, Samara M. N Engl J Med. 2005;352:9-19.

Martínez-Nadal S, Bosch L. Int J Environ Res Public Health. 2021;18:74.

McBryde M, Fitzallen GC, Liley HG, et al. JAMA Netw Open. 2020;3:e202027.

Moore GP, Lemyre B, Barrowman N, Daboval T. JAMA Pediatr. 2013;167:967.

Moreira RS, Magalhães LC, Alves CRL. J Pediatr. 2014;90:119-34.

Mukerji A, Shah V, Shah PS. Pediatrics. 2015;136:1132-43.

Pabst L, Hoyt CR, Felling RJ, et al. Pediatr Neurol. 2024;157:19-28.

Puzone S, Diplomatico M, Caredda E, et al. Arch Dis Child Fetal Neonatal Ed. 2023;109:18-25.

Rees P, Callan C, Chadda K, et al. BMJ Paediatr Open. 2023;7:e001810.

Ritchie K, Bora S, Woodward LJ. Dev Med Child Neurol. 2015;57:899-918.

Rivella C, Viterbori P. Child Neuropsychol. 2020;1-23.

Saigal S, Doyle LW. Lancet. 2008;371:261-9.

Sandoval CC, Gaspardo CM, Linhares MBM. Appl Neuropsychol Child. 2021;1-18.

Schreglmann M, Ground A, Vollmer B, Johnson MJ. Acta Paediatr. 2019;109:20-30.

Shah R, Harding J, Brown J, McKinlay C. Neonatology. 2019;115:116-26.

Shah R, Dai DWT, Alsweiler JM, et al. JAMA. 2022;327:1158-70.

Stevens JP, Eames M, Kent A, et al. Arch Dis Child Fetal Neonatal Ed. 2003;88:F179-84.

van Noort-van der Spek IL, Franken MC, Weisglas-Kuperus N. Pediatrics. 2012;129:745-64.

Wang C, Jiang H, Wu J, Yu Z, Li Q, Jiang CM. BMC Pediatr. 2024;24:699.

Wickström R, Skiöld B, Petersson G, et al. Eur J Epidemiol. 2018;33:1011-20.

Zimmerman E. J Speech Lang Hear Res. 2018;61:53-65.