



Your Child and **Hydrocephalus**

Section six

School and education



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School and education

Looking for pre schools, nurseries and schools

Going to school can be a big step for both you and your little one. It is often something that parents worry about and it's useful to do some research beforehand to understand your options.

You can gather information about pre schools, nurseries and schools in many ways. You may wish to send your child to your nearest local education setting. Talk with other parents you know and find out what the support is like for children who may need extra support. When you are looking at Early Years Provision it will be difficult to know for sure if your child will require extra support or what this may be.

For children who do require extra help in school this is delivered as additional needs provision. You may want to research other schools and education providers in the area that could meet your child's needs. You can do this by reading the Local Offer, which will be part of your Local Authority website, containing information about additional needs provision.

Hydrocephalus affects children in different ways and it is important that, whatever school you choose, the staff there are open to learning more about the condition and to using strategies to minimise the possible effects of hydrocephalus on your child.

Shine can support both you and staff at the school with strategies and information.

IMPORTANT TO KNOW...

Good communication between whatever educational setting you choose and your family will be essential throughout your child's schooling so it's worth taking some time over this.

Sometimes when children have hydrocephalus or other neurological conditions there is a predominant focus on additional needs, but it is just as important to look at general facilities that your child enjoys, such as the school library, sports facilities, clubs and activities, outside space, music, ICT or academic achievement.



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Specific areas for consideration could include

- Classroom management strategies to help your child stay focused and facilitate learning
- Medical support and staff training, for example if your child has epilepsy, or being alert to the effects of a shunt malfunction
- If mobility is a concern then you will want to check the school's accessibility with regards to the physical environment, room sizes, corridor width, uneven or sloping surfaces, door thresholds and ramps, etc. You may wish to invite your child's physiotherapist or occupational therapist to visit the school with you in order to get their opinion and advice
- If continence management is an issue then ask questions about staff training, respectful privacy and personal care

Tips for visiting an Early Years setting

- Visit during normal school hours, maybe with your partner, a relative or a trusted professional who knows your child well
- Have questions ready beforehand
- Ask to meet with the school's Special Educational Needs or Additional Learning Needs Co-ordinator, and find out what their areas of expertise are. If the co-ordinator has little knowledge of hydrocephalus let staff know that Shine can provide information, advice and training for school staff
- You may wish to use Shine's 'Visiting an Early Years Setting' checklist and add any further questions specific to your child's needs

There is probably no such thing as the perfect school, but you should find one you feel comfortable sending your little one to. As mentioned, the most important thing is that the school is open to good communication and has the best interests of your child in mind.

Getting ready for 'big' school

Starting school is an exciting time for children and their families. The transition from an Early Years setting, like a

pre school nursery, to full-time school is often daunting for many children so here are some top tips for getting ready to start school:

TOP TIPS for Starting School

Good Communication

- Build up good relationships with your child's class teacher, teaching assistants, SENDCo and head teacher
- Let them know that they can talk to you about hydrocephalus and how it affects your child. Let them know about Shine and our resources for schools
- Speak regularly to teachers and the SENDCo. If you have concerns, share them early.
- A communication book can be helpful for some children

Build your child's confidence about what to expect:

- **Read books together about starting school.** Picture books, such as the Shine publications *Benny Goes to School* and *Now I Am Four* about Bella Bear are recommended. Also *Starting School* by Janet and Allan Ahlberg and *Come to school too, Blue Kangaroo!* by Emma Chichester Clark, are good starting points for talking about going to school (see information about reading)
- Visit the school for fun events such as open days, plays, fundraising fetes and sports days
- Have play dates with friends who are starting in the same class
- Practise packing the school bag the night before
- Practise the morning routine for school to find out how long the process will take and where the hotspots of the morning will be. Time can be tricky. Use a phone with a countdown clock/timer so they can see how long different things take
- Practise the school run so your child experiences the journey and they are prepared for the route, sights and events along the way. Talk through the journey to reassure them about what to expect
- Wall charts may be helpful for your child to prepare for what to expect at school





“ Remember, everyone is different so these challenges may not apply to your child. ”

Independence

Hopefully by the time your little one starts school you will have developed strategies for your child to learn to help with everyday skills like getting dressed, toileting, feeding themselves and getting around independently. It is important to continue with these and to link with the school to make sure they are confident with how best to support your child in these areas.

If your child has spina bifida as well as hydrocephalus, this is particularly important, and if at this stage you still have concerns about any of these skills then do contact a professional for advice and support. Your child's OT and/or physiotherapist will be able to liaise with you and the school to make sure that your child is supported in the best way possible.

Remember, everyone is different so these challenges may not apply to your child. Some of the information that follows is written for, and to, your child. This may help you to explore and explain things to them as they are getting to the age where they can start to understand their hydrocephalus and start taking some responsibility for managing any challenges themselves.

IMPORTANT TO KNOW...

REWARD THE EFFORT rather than the achievement.

Tips for rewards and praise

You know what your child loves to do, so reward your child with the activities they love in readiness for school.

Reward the effort rather than the achievement. For example, instead of, "That's a lovely picture," you could say, "I can see you tried really hard," or, "I love the colours you used, can you tell me about your picture?" (acknowledging effort plus

opening up conversation. Also, you are less likely to put your foot in it by guessing what they drew and getting it wrong!).

Praise the small successes your child makes every day.

Some families use a reward system, such as sticker charts, for their children to maintain good behaviour both in and outside the home, leading to a chosen reward. Often very young children need the reward to follow the behaviour immediately, so that they can relate the two before they forget. This can be particularly true for children with hydrocephalus and may be something that needs to be continued as they grow older. However, for some other children, they work less well, as the child finds it hard to imagine the reward, and care whether they get it or not.

Avoid rewarding with food or sweets, or anything expensive. Reading a favourite book together can be a great reward.



IMPORTANT TO KNOW...

Often very young children need the reward to follow the behaviour immediately, so that they can relate the two before they forget.



Listen carefully

Sometimes a child's behaviour can change when they start school, so keep calm and maintain your routines and rewards to help your child settle in school.

- Listen to your child's concerns about starting school and find positive ways around their worries
- Make school aware of any hidden effects of hydrocephalus and give written information if possible
- When you pick up your child from school, listen when they talk about school, ask questions and offer positive feedback. Your child is trying to process the information and experiences they've had during the school day so they may want to talk about their day
- Some children with hydrocephalus have issues with episodic memory, and might not be able to remember details of the day. A communication book might help prompt
- Encouragement and motivation are vital to a child, who may have some anxiety about being separated from you, so positive reassurance will help your child settle in. Put aside some special time to chat about the day together

Organised activities out of school

Sitting all day in school can be difficult for children. You can support your child's physical development, like gross motor skills, balance and coordination by involving her in sports and activities out of school, with supportive and understanding leaders.

Learning at school and home

Some children will need some extra support in the classroom; many of the effects of hydrocephalus can be hidden. At the beginning of school life, children are taught basic skills (counting and arithmetic, word recognition and how to write).

As school progresses, children begin to use these skills to learn (reading to learn, writing to record information) These extra demands can be hard for children with hydrocephalus, who may have coped fine at the start. Encourage your child's teacher, support worker, (where they have one) and SENDCo to be aware of these difficulties and to have a written plan for how best to support your child in school, with clear achievable goals.

Continuing to practise the skills at home can be a big help.

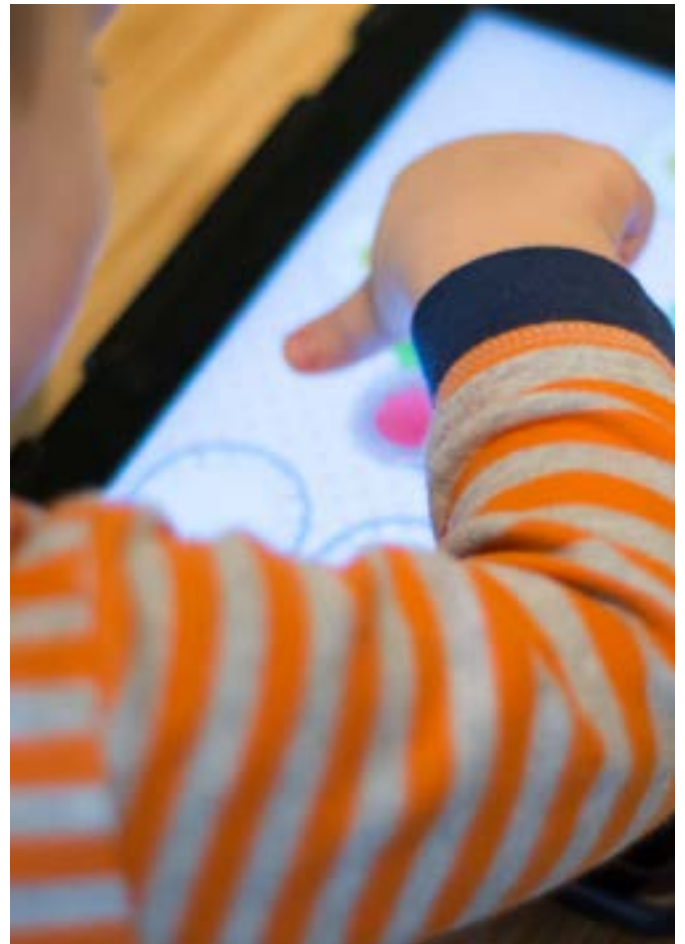
Reading together every day, construction toys, puzzles, baking and memory games are fun ways to support your child's learning.

Technology can help. Schools should follow the SEND Code of Practice to make 'reasonable adjustments' by providing 'an equivalent method for learning' so your child can effectively learn in the classroom.

IMPORTANT TO KNOW...

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Helpful technology in schools

- Dictaphone or other voice-recording device
- Apps to help with organisation and reminders
- Social stories on apps to embed routines
- Visual timetables to aid memory
- Talking photo albums with drop-in photos and paint tools to create order
- Talking mats as prompts
- Pen readers to speed up the reading process
- Apps to help with inaccurate touch on keyboards or screens
- Keyboards with word and phrase prediction to ease communication
- Change from QWERTY to ABC keyboard

At Annual Reviews in schools, parents and carers may wish to share details of technology that they have found to be helpful at home.

Young children learn best by doing and through experiential learning, but where a child is struggling to make the same 'expected progress' as their classmates then helpful technology may be used to prevent a child from becoming fatigued in the classroom.



School and education

Medical information for schools

It is always useful to give your school as much information as possible about your child's medical condition including what to look out for, in particular with regards to shunt malfunctions. You and your school should have a written health plan with details of what to do in an emergency.

Some symptoms of a shunt malfunction to be aware of include

- Headaches
- Vomiting
- Drowsiness
- Sensitivity to light
- Dizziness

Shunt malfunctions can occur and if this is the case then urgent medical treatment should be sought at your local neurosurgical unit.

Please see the additional information at the back of this book for more details of symptoms.

Shine has a range of shunt alert cards. Please contact us for your free card.

Taking part in school activities, including sports

Unless your neurosurgeon has said otherwise, your child should be able to participate fully in all aspects of school life, including PE.

Shunts themselves are not fragile: they are made from silicone, which is strong and flexible. As they are usually



positioned at the side of the head, they are difficult to break accidentally through a fall, as the shoulder would break the fall before the shunt hit the ground.

Some activities may need to be adapted if your child has balance or mobility issues.

Some contact sports that involve being grabbed around the neck, such as Judo, are best avoided, but there are non-contact versions of many sports and martial arts.

