



Your Child and **Hydrocephalus**

**Section seven**  
**5–11 years**

# 5–11 years

This is a very exciting time for your child and is often a time of mixed emotions for many parents. Going to school and coping with new experiences and expectations can be a challenge for many. Children with hydrocephalus may find some things difficult because of the way that their brain has been altered. The brain has all sorts of important jobs such as making sure we don't forget things. There are many reasons why it may not be able to do these jobs properly, but the good news is that if parts of the brain do not work well, other parts of the brain will try to help out (neuroplasticity). This means that if your child does find some things difficult, there are things that can be done to help and these are explained at the end of this section.

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.

## Cognition and learning

Learning can be difficult sometimes for everyone. Having hydrocephalus can make learning even more difficult. **Some people with hydrocephalus find it hard to remember things. Others find it hard to concentrate or control the impulse to do something they're not meant to.** This can be confusing and frustrating.

Shine's video, 'Get Inside My Head,' helps to explain some of the effects of hydrocephalus on learning information.

In all of the areas that follow in this section there are tips and strategies that your child could use to help them. It would



be really helpful for your child and for you if you encourage her to take a lead in following the tips. It is important for their confidence and independence that they are encouraged to take responsibility for their learning at this stage, as it will help them to become much more confident adults.

## Working things out (processing speed)

Your child's brain has to process information like a computer. Hydrocephalus can make the brain sort out information more slowly. This makes it hard to think and tricky to take in lots of information at once. **This is why your child can find long and complicated instructions difficult to understand.** They may understand each word on its own, but too many at once don't make sense. Their brain needs time to work out what it means, and it can be harder if your child feels worried or rushed.

If your child cannot think quickly they can take longer to do things, like finishing work or keeping up with other people in the class. It can be hard for their brain to cope with lots of things at once. Too much information at once can overload their brain, a bit like when a computer crashes! Keeping up can be especially difficult if they struggle to hold a pen or write neatly. Support your child to talk to their teachers about any difficulties and you could show them the tips below. They might have other ideas that could help too.



## Tips to help your child

- Tell their teacher and other important people that it takes longer to take things in. They should then plan to give your child more time
- Ask for written instructions or handouts so they don't have to worry about writing everything down and can focus on listening instead
- Some children will have visual difficulties as well. Having worksheets in larger print can help
- Your child may be able to get a spare copy of textbooks to take home. If they find it hard to keep up in a lesson, they can go over it again at home. If there is a computer at home, perhaps they could look things up on the internet to help them understand and learn
- A Dictaphone or voice memo could be used to record things so your child can play it over again. This gives more time to understand, and it might help their memory too!
- Don't be embarrassed to ask for instructions to be repeated if they need to write them down
- Try not to panic about keeping up. If your child feels stressed it will be harder to keep up



## Attention and concentrating

It can be hard to concentrate for a long time. Your child might get tired more easily from trying so hard. When someone is tired it makes it even harder to concentrate! They may be easily distracted by other people or sounds in the room and it can be really difficult to pay attention to two things at the same time. This can be a problem when trying to listen and take notes in class. It can also take longer for your child to settle to a task and for them to switch attention from one task to another.

## Tips for concentration

- Try to find a quiet place to work. It is harder to concentrate with the TV on or people talking. Your child may need to tell people that they find it hard to concentrate when it is noisy
- Do homework at a time of day when concentration is best. This might be as soon as they get home from school or after they've had some tea. Your child will concentrate better if they are not too tired
- Encourage your child to take a short break between one task and the next, to allow time to clear their mind and switch their focus
- Encourage your child to try working hard for 30 minutes and then having a short break before starting again. This gives their brain a rest before restarting
- If your child is worried, they will find it hard to concentrate. Encourage them to talk about their worries with a trusted adult. Help them to try not to worry about how well they are doing, as long as they are doing their best
- Make sure your child has water to drink and is reminded to drink frequently throughout the day if necessary. Dehydration can make concentrating much harder

## Planning and organising

People with hydrocephalus can find it difficult to be organised. Planning ahead can be confusing. Your child may get confused about what they need for each lesson, or even which lessons they need to be at! This may be to do with memory problems, but also the part of the brain that works out what order things go in may not be working as well. Organising a piece of work may be difficult because it can be hard to know where to start, or what to do next, or how to finish a piece of work, especially if they have to write a conclusion. It can also be hard for them to judge whether what they've done is what was required.



### Tips for being a bit more organised

- Create a school timetable using pictures or colour-coding. This will make it easier to work out what they are going to be doing each day
- Keep things in their bag so they know where to look for them. They could use colour-coded plastic wallets to keep things together. Encourage them to check their notebook for things they may need to remember, to keep it tidy and to tick things off once they are done
- Set goals for things that they want to get done. Encourage them to decide on and to give themselves rewards when they do them, such as going out with friends or watching a favourite TV show



### Tips for planning work

- Don't rush into things. Support and encourage them to take their time to work out how they are going to do something. It can be hard to stop, but they can get into a muddle if they rush it
- Get instructions written down before starting a piece of work. They can then focus on thinking about how they are going to do it, without worrying about remembering what they are supposed to be doing!
- Break a new task down into small steps. This makes it look less scary and helps to get started. Do one step at a time and tick them off when they are done. Encourage them to ask someone to help with this to start with
- If your child is not sure what order to do things in, they could write them on post-it notes or small pieces of paper. These can then be moved around to find an order which makes sense for your child

### Understanding what we see (spatial problems)

This was addressed earlier in relation to a younger child. This section adds to what was discussed and how it may relate to your child as they get older.

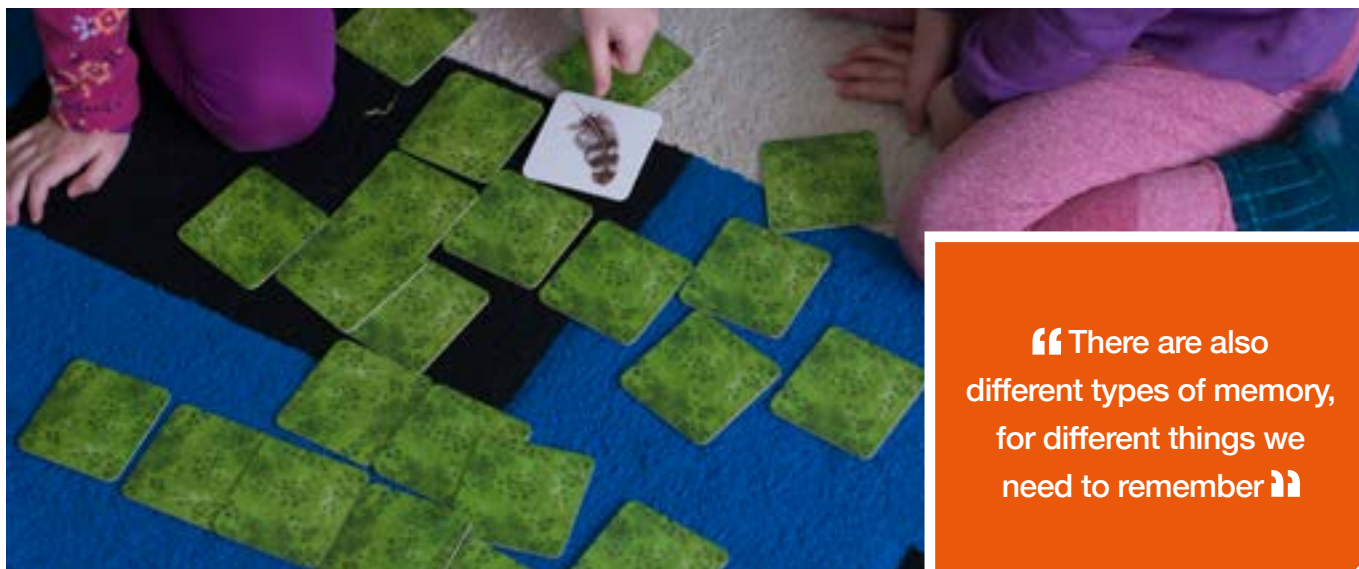
Spatial perception is the way in which our brain understands what our eyes see. It is not about how well our eyes work. It can be tricky going downstairs if you can't tell how far it is from one step to another. Some people find it hard to ride a bike, others have problems finding their way around new places. It can be scary for your child if they can't find their way around a new school.

Spatial difficulties can make lots of things hard such as: building towers with blocks, doing jigsaws, hitting a ball, setting up science experiments, doing maths puzzles with diagrams, or even writing neatly.

### Tips to help with spatial problems

- If your child finds it hard to write or read on a flat surface, tilt the book upwards. There are special desks or pads to help with this
- Practising helps. The more your child does something, like climbing stairs, or finding their way around school, the better at it their brain and body will become
- Play games that involve building or making things
- Encourage your child to try thinking about puzzles that have diagrams or pictures by describing them in words. Talk about them or they can ask someone else to talk about the puzzles with them
- If you feel your child is having difficulties in these areas, then a referral to a paediatric occupational therapist may help. They can assess areas of difficulty and provide practical support.





“ There are also different types of memory, for different things we need to remember ”

## Memory

Everyone forgets sometimes, but having hydrocephalus can make it much more likely. The old adage of, ‘If it was important to you, you wouldn’t have forgotten’, does not hold true if your brain is not ‘wired’ to remember. However, this can be improved.

### There are three processes of memory

- Encoding (putting information into store)
- Storing (keeping the information in mind over a period of time)
- Retrieval (getting the information out again and using it to guide actions)

There are also different types of memory, for different things we need to remember. For example, how to do things, what happened during our day and remembering facts. This is important, as some areas of memory might be affected, but others are not.

A memory is not simply a copy of what happened in the past. Recalling events is based on information that is stored in small bits, as well as the thoughts and emotions that people will have about what probably occurred. The brain is very good at spotting themes or patterns in events, but generally less good at the tiny details; think about your past birthdays for example. Most of them would have had a cake, gifts and cards. But unless something different happens, you’ll probably find it hard to distinguish between one birthday and another. Therefore, memory is not totally reliable and confusion can arise about what happened at one time, and what happened at another, especially if you have difficulties with time concepts. Several parts of a memory can become mixed together. **When memory is affected, the gaps are subconsciously filled by the brain with guesswork.**

### There are several types of memory

**Sensory memory:** receives sensory information coming in from all of the sensory systems including eyes, ears and

touch. This information is either ignored or paid attention to. Your child should be helped to pay attention to the task by cutting down distractions.

**Visual memory:** if your child is trying to concentrate on looking at objects, then a quiet room will help them to focus on the task and remember which ones have been seen. An increase in the number of objects seen and remembered will increase the visual memory. Noise levels need to be kept to a minimum, e.g. background chatter, TV, dogs barking.

**Auditory memory:** is the information you hear. Children with hydrocephalus can find filtering out unwanted noise very difficult, so keeping noise and distractions to a minimum is important if they are to learn.

**Memory of touch:** stroking his or her hand over toys with different textures will build up the information going to your child’s brain. Feeling toys with different weights and those that vibrate, buzz or hum will add to the sensory experience.

Many children with hydrocephalus have problems with recent memory as well as difficulty planning ahead. A limited sense of the future will make it difficult to know when events and tasks end. **Life seems to be lived ‘here and now,’** in a concrete state, without a sense of thinking backwards or forwards - so planning ahead is a problem. This can also make it harder for them to get excited about something, or engage in reward charts, if they can’t imagine the event or getting the reward.

There may be mistakes in memory when information is retrieved. Sometimes the information recalled is similar, but not the same as that which is needed.

Short instructions are easier to remember – this is why it is important to know the number of items a child can hold in their auditory memory. Knowledge of the language levels is also vital so that confusion and frustration do not occur – which will happen if the words are beyond the level that your child can understand.



**Information can be held in short-term memory** by rehearsing and repeating information **and saying the words out loud**. Children with hydrocephalus need plenty of practice and also time to process the information.

There may be a time delay for the words to ‘sink in’ and even though this may only be slight it can still be enough for your child to have difficulty following the conversation.

The reason for keeping information in the short-term memory is to allow for it to be encoded into long-term memory.



### Tips to help short-term memory

- Try games such as ‘I packed my bag and in it I put ...’ you need two or more players for this game, each ‘adding’ another item to the bag but first listing the items already added by other players. A player is ‘out’ if they forget any items
- Play card games like ‘Happy Families’ and ‘Concentration’
- Try ‘Kim’s Game’ – show a tray of objects and then take one item away. Can your child remember what’s missing?

### Long-term memory

Long-term memory stores a large amount of information over a long period of time. The information is normally either transferred from the working (short-term) memory after a few seconds or discarded if it isn’t needed. Children with hydrocephalus may have more difficulty putting information into long-term store. Long-term memory can keep information in two ways:

1. Memory of events or experiences that have taken place in life and the ability to reconstruct them
2. It holds a structured record of facts, skills (spatial/perceptual) and concepts (attitudes and beliefs)

Rehearsal and repetition are necessary to store information from short-term into long-term memory.

Memory is necessary for the construction of language. It’s also necessary for organising our behaviour, and learning from our mistakes. **Making plans and setting goals requires us to imagine ourselves in the future, which can be hard for people with hydrocephalus.** It is also possible for people with hydrocephalus to remember something needs doing, but not recognise that ‘now’ is the right time to do it. It looks like ‘forgetting’, but comes from an affected sense of time, rather than memory.



## Here are some tips to support your child with memory issues

- Get them to develop the habit of doing things as soon as possible, not 'in a minute'. The longer things are left, the more chance there is of forgetting
- Use alarms to remind them what to do, and when to do it
- Make a colourful wall chart, (but not too cluttered with information), to remind them what to take to school each day
- Help them get in the habit of writing important things in a notebook (or asking others to), and writing 'to do' lists (include things that have been completed and when, to help get things in time order). Remind them to check the book regularly
- Use a homework diary, with exactly what to do and when to hand it in, with any supporting information, worksheets, etc. to provide cues and prompts (in case they've forgotten the lesson by the time they get home)
- If they can't remember the exact name of something, get them to describe it. This will help them or the person they are talking to work out the answer
- Clues can help to remember things. Your child's brain may have stored the information but just can't find it. Give specific clues to prompt remembering ("Have you forgotten something?" won't help)
- Help them decide the most important things to focus on remembering
- A scrapbook with photos can help remember important events in the right time order
- Worrying makes it harder to remember, so reassure them it's ok to tell people that they find it difficult to remember things, especially if their concentration is interrupted

## What about things like maths?

Lots of people have trouble with maths, even if they don't have hydrocephalus! People with hydrocephalus might find it especially hard. Maths involves lots of the things above like memory, concentration, planning and spatial skills. Still, this doesn't mean you can't get better at it! If teachers, and you as parents, understand what your child finds hard, then you might be able to find ways to make it easier.

Children with hydrocephalus may take longer to learn maths concepts and may need concrete experience for longer, such as blocks for counting and visual reminders to understand different processes like multiplying numbers. It is really important that your child understands every stage thoroughly before going on to the next. They may need more practice to make sure that they've really got it securely.

If you do have concerns about how your child is managing at school, speak to their teacher and SENDCo. It may be that your child would benefit from an assessment by an

educational psychologist who can identify areas of difficulty and give practical advice.

Shine's Education Service can offer support.

## Social and emotional

### Controlling impulses

**During early childhood we usually get better at stopping ourselves from acting on impulse, as we become better at 'thinking through' what we're doing.** Some children with hydrocephalus act before thinking for longer than their peers. This can affect behaviour (for example not being able to stop themselves doing something they know they shouldn't do), learning (thinking they can't do something before they've had time to think it through) or safety (crossing roads without looking).

Relationships are super important. When they work well, they offer a source of support and protection against life's inevitable stresses and strains. Of course, all relationships go through periods of change and challenges and sometimes it can be helpful to have extra support to make sure that they are working well. This goes for family, friends and other relationships that you or your child has.





### Some practical tips for parents

- Express your feelings – tell your family, partner or friends how you feel and don't keep things bottled up
- Widen your support network as much as possible. Take time to build and develop connections with the people around you
- Allow yourself time to relax and do something that you enjoy – your health is as important as anyone else's. Just ten minutes every day or an hour or two every week can really help
- Talk to your GP or Shine support worker if you feel that you would like to have more professional support
- In some areas of the country there may be the opportunity for you to access respite support. If your child has complex needs, your Shine support worker will be able to advise you on provision in your area

### Self-image and self-esteem

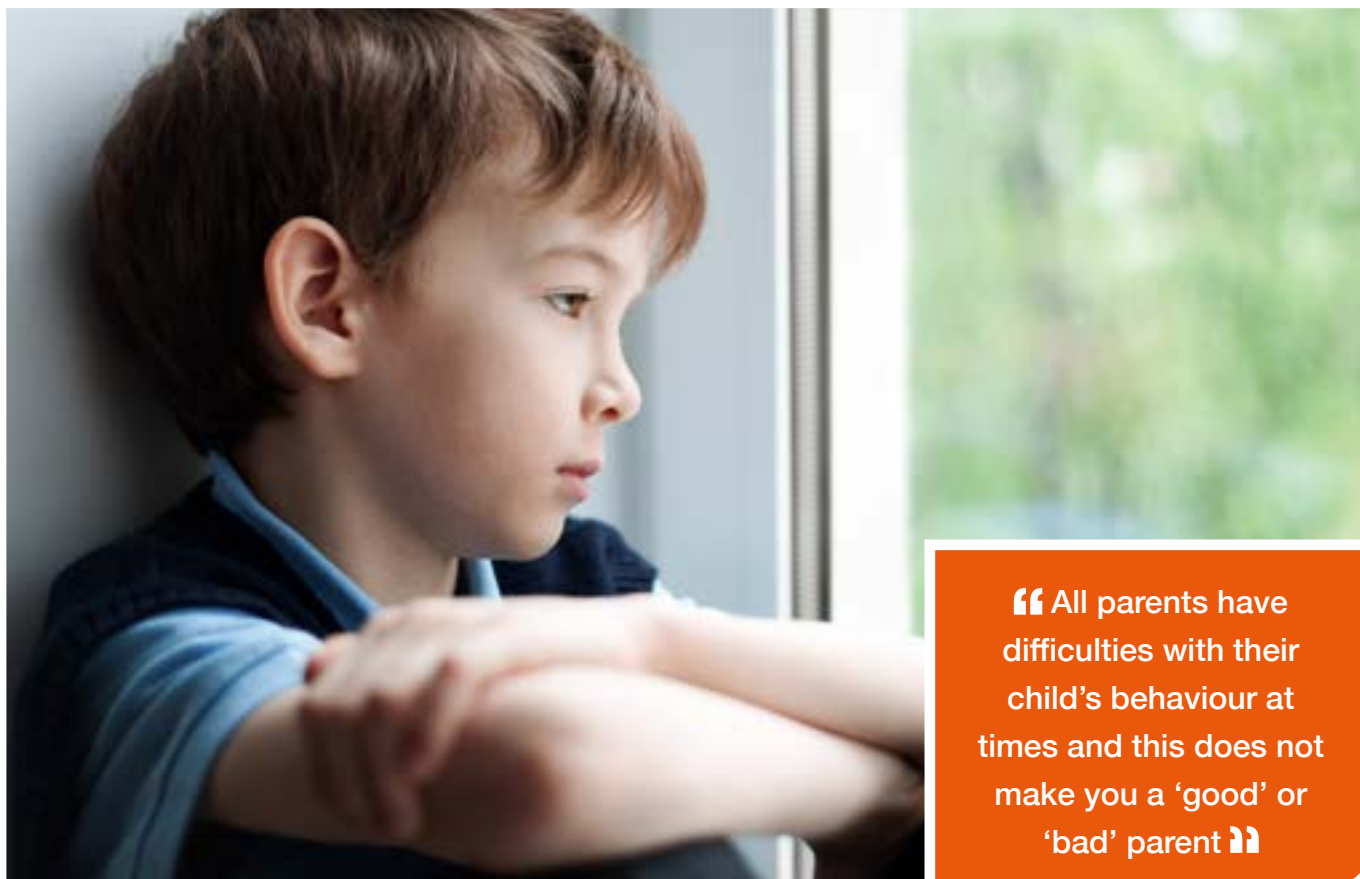
Some children with hydrocephalus struggle with low self-esteem. Factors could include concerns about their appearance, behavioural issues or precocious puberty.

It is important to guide your child through these experiences so that their self-esteem remains high.

### What you can do

- Some children have emotional difficulty adjusting to the diagnosis of hydrocephalus. Their concerns may be about their physical health and future. Give your child plenty of reassurance and simple explanations about their condition
- Other children may worry about how their school life will be affected. Wherever possible, children with hydrocephalus should be included in mainstream schooling
- Give your child positive feedback and praise when they succeed or improve
- Let them choose clothes they feel good in, and give opportunities to show off their skills
- Children with low self-esteem may like to meet other children who have hydrocephalus to hear about positive experiences. Shine often runs events to bring families together
- Use an 'errorless' learning approach to build self-esteem, focussing on successes so the child will not fail. When teaching and asking for an answer, work in very small steps and provide many cues and prompts. These cues can gradually be taken away until they are no longer needed. By doing this, your child will not fail and will feel confident rather than disheartened





“ All parents have difficulties with their child’s behaviour at times and this does not make you a ‘good’ or ‘bad’ parent ”

## Understanding how your child behaves and positive parenting

**Many parents of children with hydrocephalus have concerns about their behaviour. Human behaviour is complicated. Specialists have developed many, many theories about how behaviour can be managed, and there are numerous television programmes, which make it look very easy!**

All parents have difficulties with their child’s behaviour at times and this does not make you a ‘good’ or ‘bad’ parent. Although we can’t control children’s behaviour, we can help them (and ourselves!) learn to manage it.

### How hydrocephalus may affect learning and behaviour

As we’ve said before, hydrocephalus can affect children’s concentration, memory, understanding of language and their processing of information. Any of these can have an impact on behaviour.

#### If you

- Can’t remember instructions or don’t understand them, then you won’t be able to carry them out
- Have trouble transferring knowledge to new situations it may be that you can do something in one place but not another
- Don’t understand jokes you may think you don’t fit in

The impact that hydrocephalus can have on learning and behaviour varies with each child. Some children, young people and adults with hydrocephalus may have no, or very few difficulties, whereas for others the effects can be much more serious. Children and young people with hydrocephalus can have a number of specific learning difficulties, which may mean that they learn in a different way and need a range of strategies to help them.

For some children with hydrocephalus, it can be very hard to adjust their behaviour to different situations. For example, some teachers may allow more chatting than others, or for children to listen to music in class. Sometimes, when playing, children might adapt a game or change the rules to please themselves.

For children that struggle with this flexibility it can cause anxiety or upset, or refusal to cooperate, which can get them into trouble. Helping children understand from a young age that situations can change, and still be all right, can help develop this flexibility. Games with changing rules can help develop flexibility.

If children are struggling at school, either academically or with their friendships, this can lower self-esteem, which in itself can lead to behavioural difficulties. If you think this may be an issue it is important to talk to your child’s teachers at school.



Parents can feel de-skilled when faced with a child who does not behave appropriately. This can lead to a difficult situation as parents get more frustrated and children and young people feel more powerful but also less secure, making their behaviour even more extreme. When children have developmental difficulties, the situation becomes even more complicated as they may not react in the way you would expect.

### What you can do

Every situation is different and may require different strategies, but there are ways that we can begin to work out, by seeing what is going wrong, how to put it right.

- Firstly, try to detach yourself from the situation a little and approach it 'scientifically'. Try and see it as a challenge or 'problem' to be solved!
- Make a list of the behaviours which you are finding difficult, then prioritise them from the most to the least troubling
- Concentrate on the behaviour you find most troubling; list anything which might be relevant to it



**There are usually three parts to a behaviour event: Think ABC**

- A Antecedent** – what happened just before the behaviour?
- B Behaviour** – step-by-step description of the observed challenging behaviour
- C Consequences** – what happened after the behaviour? (e.g. event, activity?) This can sometimes be the motivator

### You may need to observe your child's behaviour for a few days...

- When does it happen?
- Where does it happen?
- Is any other particular person involved?
- How often does it happen?
- What happens before?
- What happens after?
- How do you react?
- How do other people react?
- How does it stop?

### Then try to work out what the child is getting from this behaviour...

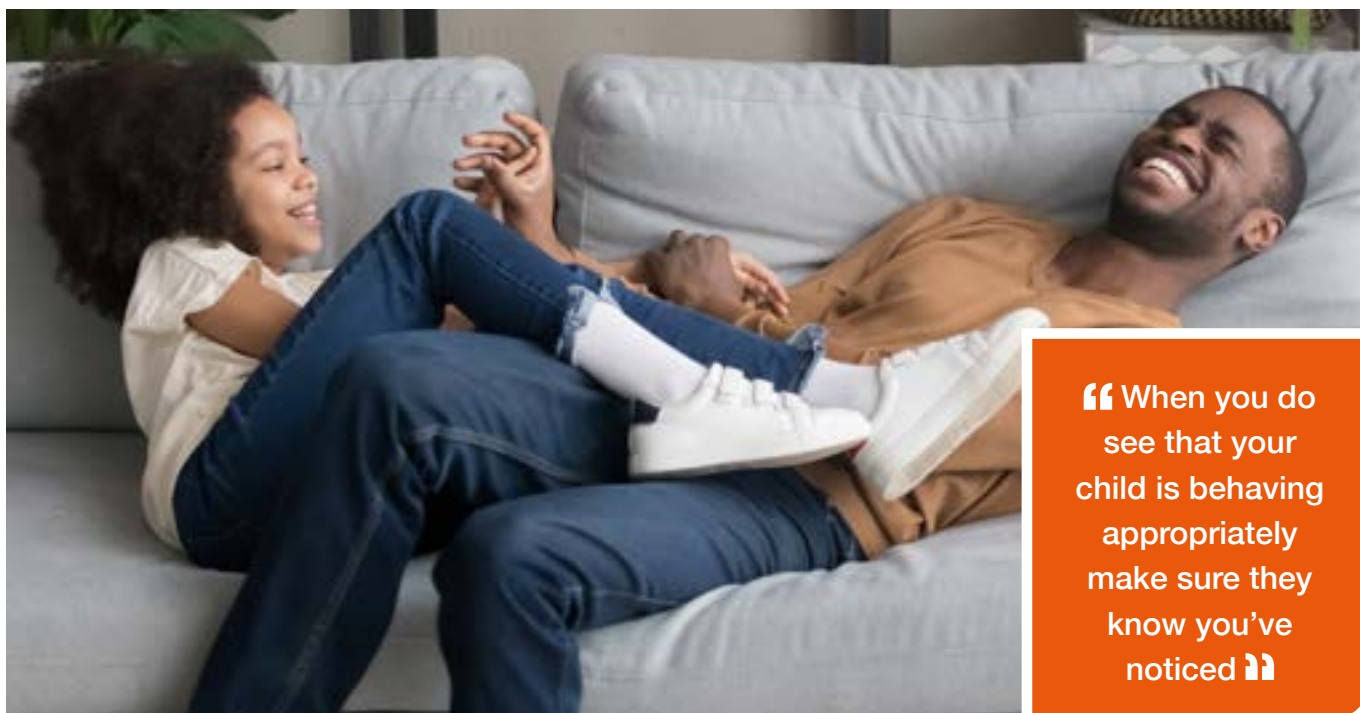
- **Is it attention?**
- **Do they enjoy the behaviour and your reaction?**
- **Do they get their own way?**
- **Do they avoid doing something they don't like or find difficult?**

You should now have some ideas about what triggers the behaviour, how it stops, and what the child gains from it, and are in a better position to try and change it.

Your child may have been practising this behaviour for several years, so it can take a long time to change. You and your child, and maybe school, will need to learn new behaviours to replace the one you want to stop.

### Strategies to help

- **Routine – the more established a routine, the less likely a child is to try to change it.** You may need a ‘going to school’ routine, a ‘what to do when you come home’ routine, a ‘bedtime’ routine, etc. In fact, wherever you notice a time that causes problems, try a routine. Routines are particularly important for children with working-memory difficulties. Repetition enables them to remember what to do and allows them to be more independent
- **Consistency** – this ties in to routines but also includes how we respond to a behaviour. If we always ignore a child or young person when they shout, then eventually they will stop shouting. If we only ignore it now and again then they will learn that it works sometimes and they keep trying, sometimes harder!
- **Look for the positive, ignore the negative – when you do see that your child is behaving appropriately, make sure they know you’ve noticed.** Descriptive praise can help a child to understand what they are doing well. Saying, “Behave sensibly,” or, “Play nicely,” means very little to a child, but, “I like the way you’re sitting at the dinner table,” has more meaning. Catching your child being good and then letting them know you’re pleased and proud of their behaviour makes a child feel good about themselves
- **Reward good behaviour, however small** – rewards can be anything that the child enjoys: a cuddle, five minutes playtime, music or just a smile. It doesn’t have to be a present or cost any money
- **Try to ignore inappropriate behaviour as much as you can** – if you have to intervene, do it as calmly and as quietly as possible. Don’t get into a discussion, or negotiate with your child, or try to explain in great detail why the behaviour was unacceptable. Children may not really know why they did something, so don’t keep asking why
- **Make instructions clear and positive** – such as, “This is what I want you to do...”, where you model the behaviour or describe it in more detail, rather than a negative such as, “Don’t do that”. Use as few words as possible and simple instructions like “Stop” and “Listen”.
- **Make time** – try to make some time every day which is just for you and your child. It could be built into a routine, for example, at bedtime when reading a story together and talking about what happened during the day. It is important that this time is guaranteed, no matter what, even if you don’t feel like it. If your child doesn’t feel like it, make it clear that this is special time and you are there if they change their mind
- **Be consistent when your child needs help in learning how to manage their own behaviour.** Some children with hydrocephalus need direct teaching of social skills because they may find social interaction, understanding language, reading emotions and body language very difficult, and may need to learn how to manage their own emotions



“ When you do see that your child is behaving appropriately make sure they know you’ve noticed ”



If you are finding your child’s behaviour very challenging, there are some helpful parenting courses available or you can speak to your GP about a referral to a health professional service such as CAMHS (Child and Adolescent Mental Health Services).



### Getting on well with other people

Sometimes it is hard to get on with other children at school. This can be very upsetting and can happen to anyone. If other children at school are making your child feel unhappy then support them to talk to an adult they trust. They really should not keep it all to themselves.

Explain to your child that it is important to take turns when they are talking to people. Help them to practise good listening so people know they are trying hard to listen to them. If your child finds it hard to understand what someone means, they should be encouraged to explain this to them so that they are aware that your child wants to understand.

Children with hydrocephalus often prefer to play on their own and can find it difficult to interact with other children their age. This could be because they have some difficulty in understanding what others are feeling or are unable to recognise that their actions have an impact on other people.

#### What you can do

- Encourage your child to interact with other children of a similar age as much as possible. This could be through after-school activities or clubs
- Encourage your child to do imaginative play such as dressing-up, drama and make-believe activities
- Social-skills training may be helpful for some children. If you think your child would benefit from more structured support, then ask for a referral to an appropriate specialist from your child's school or educational psychologist
- Some children with hydrocephalus may not display appropriate nonverbal behaviour such as body language, facial expression and eye contact. It may be helpful to teach your child 'what to do' and 'how and when to do it' using pictures and mirrors

### Supporting brothers and sisters

Sometimes it can feel like the brother or sister of a child who is facing health challenges has to grow up very quickly. Giving them the chance to talk about things can help them to deal with issues that are bound to crop up occasionally.



### Remember

- There will be times when brothers or sisters have to take second place for a while – don't feel guilty about it
- Siblings will sometimes be uncooperative and resentful – they are kids!
- You can't do everything, but you are doing your best



### Top tips to help brothers and sisters

- Reassure them that no one is to blame for their brother or sister's difficulties and talk with them about what hydrocephalus is and the effects it can have. Help them to figure out how to explain their sibling's challenges to their friends
- Involve siblings in discussions and plans for both the immediate and more distant future. Depending on your children's ages, they need to know for example, what would happen to them in case of an emergency situation
- Make sure that your son or daughter's school knows what is happening at home
- Try to spend some quality time every day with each child on their own. Enjoy some 'special time' which is just for them, e.g. a regular bedtime story and chat or a trip to the cinema once a month
- Acknowledge negative feelings as well as positive ones
- Enjoy outings with all the family – such as a picnic, swimming or bowling – which involves all of you
- Allow brothers and sisters to speak their mind, even if it's difficult
- Encourage the sibling to make contact with other siblings of children with hydrocephalus; this may be possible through Shine
- Involve a friend or family member to be a 'listening ear' if the sibling needs to talk

### Leisure and pleasure

- Some children with hydrocephalus may find everyday activities a little challenging due to difficulties with balance or vision, for example. If your child finds it a struggle to participate fully in playground activities or sports, they may sometimes withdraw and avoid situations that they don't feel competent in
- It may be worth looking for activities in your area that are specifically suited to supporting children with additional needs

- Sports and leisure activities play a vital role in helping to keep at a healthy weight and to develop good health habits. They are especially important in developing your child's confidence, social skills, physical abilities and ultimately their self-esteem and sense of achievement



### What you can do

- Try to find an activity that your child really enjoys and has some success in and encourage them to participate
- Make sure your child gets plenty of exercise in whatever way possible
- If you are concerned about your child's weight, request a referral to a dietician through your GP
- While bearing in mind your child's safety, learn to 'let go' and allow your child to enjoy a reasonable degree of 'rough and tumble' play and independent exploring. Shunts are very robust and very, very unlikely to break during ordinary play



**There's no such thing as bad weather. Put on the wellies and get out every day, whatever the weather.**

The next two parts are for your child to read to help them understand things from other people's perspectives. If necessary read them through with your child to open up discussion about strategies and tips that may be most helpful.



### Getting on well with your teachers

Lots of teachers may not know about hydrocephalus. They won't know what it's like to have hydrocephalus. They might think that you are not listening to them, or that you need to try harder. Teachers can get upset when they think you are not listening to them. This can make you feel angry with them. Some people with hydrocephalus can find it hard not to show people when they are angry. When we feel angry with teachers, we can end up getting into trouble.

Sometimes people stop trying so hard at school so that they don't feel silly when they get things wrong. This is understandable. Tell your teacher that you need their help. If you feel embarrassed about your friends knowing then ask to see the teacher during break time, in private.

It is important that you get good help from your teacher. You need to help them to understand that you are struggling. Teachers don't always know everything! They cannot guess what you are feeling. If they know you are trying very hard, they will want to help you more. If you prefer, ask another adult you trust to talk to your teacher about hydrocephalus.

There is special information for teachers to help them understand how hydrocephalus can affect your learning. They can get this from Shine. You could also show them this book.

### Getting help

**If you're finding things difficult, there are solutions.**

The most important thing is for you, your parents and your teachers to understand what you find difficult so you can work together to find out how you learn best.

**Think about all the things you have learnt easily – why did you find them easy?** Were you doing something practical? Were you listening to music? Did you get plenty of opportunity to practise? Was there something odd, funny or exciting about them? If you can work out how you've learnt things in the past this will give you valuable clues about how learning can be made easier in the future.

The Education Advisors at Shine will be happy to help. They may be able to come up with ideas your teachers or your parents haven't thought of.

### For you, mum and dad

Being a parent is the toughest job you will ever do and there's no course or training that can fully prepare you for the emotional rollercoaster that having a child sends you on!

Stress levels can be particularly high for parents of children who have additional difficulties, such as behavioural issues.

Probably the most important thing you can do for your child is to **be kind to yourself as parents**. It is natural that you will feel stress sometimes. All parents do! However, it is important to learn how to recognise when you are stressed and then manage it, in case it harms your emotional wellbeing and family relationships.

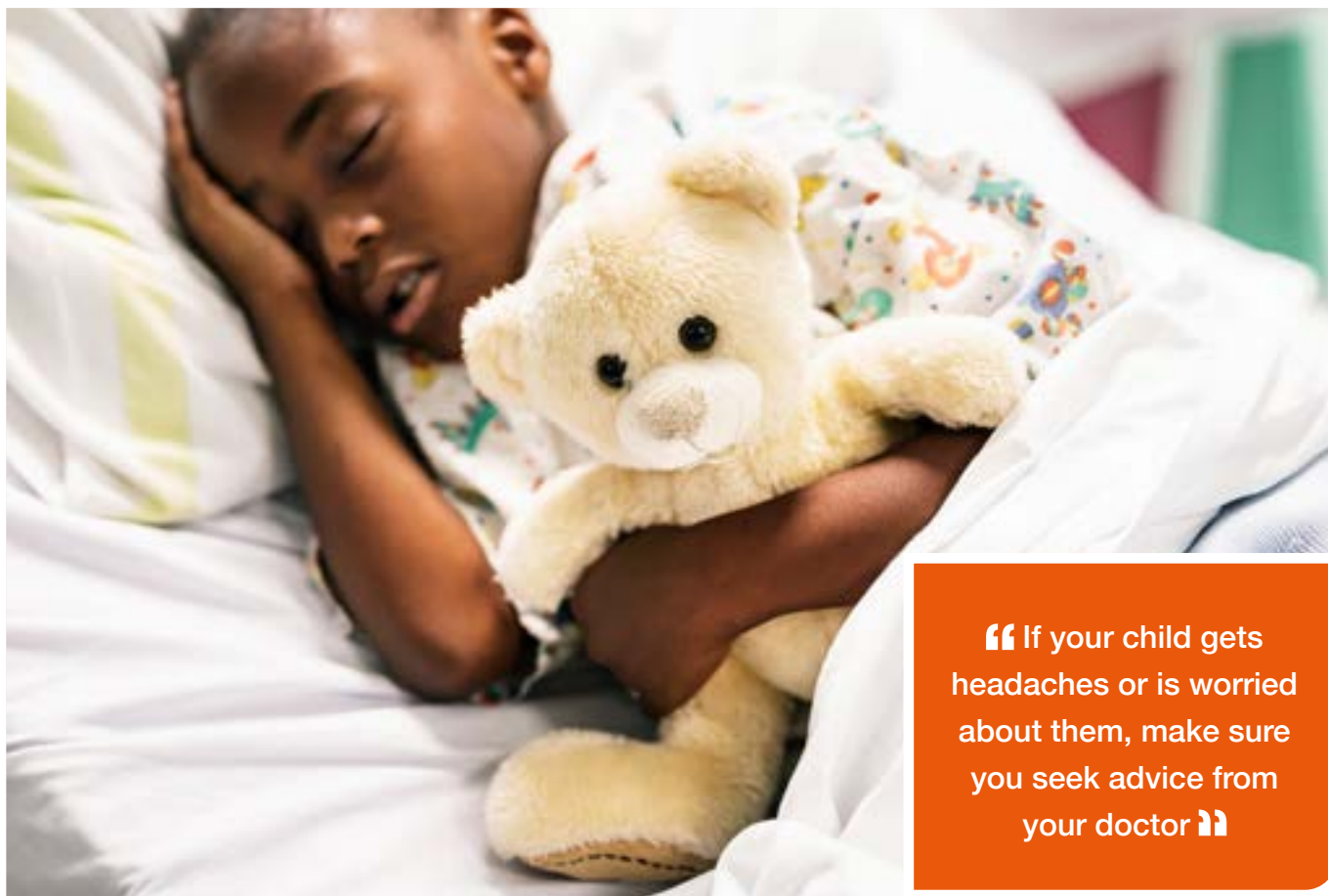
### Managing stress

#### How to help yourself

- **Recognise times when you are stressed and be open about this** – there is nothing wrong with admitting that you feel things are getting on top of you
- **Think about your coping style**. Parents tend to cope better when they:
- **Seek support from others** – let people help!
- **Feel well-informed about their child's condition** – so don't be afraid to ask questions
- Eat, sleep and do things they enjoy!
- **Ask for help** – this might be through talking to others, or may involve seeing your GP or a health professional if you feel your stress levels are very high or have been going on for a while
- **Take time to do things that you enjoy and give yourself some time for relaxation every day**. This can feel difficult but is so important. It doesn't have to be a big deal either, just sitting for five minutes to enjoy a lovely cuppa, a walk outside or a bubble bath in the evening are some ideas to try
- Try some simple relaxation exercises

#### Have realistic expectations:

- Nobody can be the perfect parent
- Everyone gets it wrong sometimes
- We can all only do our best
- You can't give if you have nothing left to give
- Parents sometimes feel anger, guilt and despair at times... **This is normal**



“ If your child gets headaches or is worried about them, make sure you seek advice from your doctor ”

## Coping with pain and hospitalisation

Hydrocephalus may cause frequent headaches which could make it very difficult for your child to concentrate and may be distressing.

Headaches can signal the build-up of intracranial pressure and this could worry your child that they may have to go into hospital, but headaches are also a normal occurrence and could be happening for other reasons.



### IMPORTANT TO KNOW...

If your child gets headaches or is worried about them, make sure you seek advice from your doctor. If the headache is not related to hydrocephalus, it may be helpful for your child to see a professional to learn strategies for coping with the headaches and anxiety.

Complications with the shunt may also occur which will be worrying for your child and may involve, sometimes repeated, hospital stays and surgery. They may miss school which could impact on schoolwork and friendships.

If your child is missing school for health reasons:

- Make sure that the school is involved in helping your child, e.g. sending work home or arranging a tutor
- Invite friends to your home to play and spend time with your child when they feel well enough

**Teachers also like to be made aware of changes in a child's needs or approaches that you have been advised of by health professionals.**

### Useful information to share with the Headteacher, SENDCo or class teacher on return to school after illness or a hospital stay

- Have any sensory difficulties emerged after the medical procedure?
- Are there any physical difficulties that might affect your child in school, such as access to classrooms or PE lessons?
- Are there any activities such as school trips that might be difficult?
- Does your child have difficulties with concentration or communication?
- Does your child have any therapy requirements, which might have an impact at school?
- Are any special devices or equipment required?
- Does personal care need extra supervision?
- Should prescribed medication be given at school?
- Does your child have seizures?
- Are there any safety precautions to be made?
- Do you have any particular concerns about the return to school?
- Are there brothers or sisters at the school, who may be affected by all the changes that have taken place?



You could ask your doctor to put you in touch with a specialist nurse and/or epilepsy parent support group and inform school as well so that appropriate support can be arranged.

### Adrenarche and puberty

Puberty is a difficult time for most young people, with changes to appearance, hormones and feelings. Most of us can remember the confusion, the mood swings and thoughts and feelings which were difficult to understand. Having the first signs of puberty before ten years for boys or nine years for girls is known as 'early puberty', while under the age of nine for boys or eight for girls is classified as 'precocious puberty'. Early/precocious puberty is common amongst children with hydrocephalus, and spina bifida with hydrocephalus.

The most up-to-date research found that for children with shunts (but without spina bifida), puberty started early or very early in around three-quarters of girls, and two-thirds of boys. For children with spina bifida, around half of girls and a third of boys experienced early puberty.

Starting puberty early can make this time harder to deal with, and for young people with learning challenges, it can be very hard indeed. As well as the difficulties of mood swings and coping with periods at a young age, children also have to cope with having physical changes, such as breast development or body hair, ahead of their classmates. They may also start to show sexualised behaviour, which might be difficult for the child and others to understand and deal with. Early puberty results in short stature in adulthood too, as we stop growing once puberty has ended, so the younger (and shorter) we are when puberty begins, the shorter we will be as adults.



### Epilepsy

Children with hydrocephalus are at increased risk of having epilepsy. It is possible that this could be very mild and may therefore be missed during conventional assessments. If epilepsy is present, it may lead to emotional issues surrounding self-image and confidence and may affect learning, concentration and physical activities. There are strategies previously mentioned that will help your child if this is the case. If you suspect that your child has epilepsy or 'absences', you must seek advice from your GP and request an assessment.





Most girls with bladder problems find these are much worse, with more leakage around the time of their period as the hormones relax the pelvic floor, crucial for keeping the bladder neck closed.

**Adrenarche is a normal part of development, which happens when the adrenal glands mature. It occurs before puberty, usually between the ages of six and eight.** The glands begin to produce hormones which can cause pubic and other body hair to begin to grow in some children, cause mood swings or tearfulness, and change the smell of sweat to produce ‘body odour’.

The first signs of puberty include development of breast buds or breast tenderness in girls, and enlargement of the testes and reddening of the scrotum in boys.

It is these changes, rather than the changes associated with adrenarche, that signal the beginning of puberty.

At the moment, we are not sure exactly why early puberty happens, because we don't understand fully how puberty is controlled in typically developing children. **The organ responsible for coordinating puberty and all the hormones which control reproduction, the pituitary gland, is found at the base of the brain, just below the third ventricle.** It's thought that increases in pressure in this area, either before shunting, or during shunt malfunction, can change the pituitary gland and bring about early puberty. Early puberty is also seen in children without

shunts but with third ventriculostomies (ETVs), which would support this theory.

### What you can do

Measure your child's height every few months. You can measure arm span if it's difficult to measure height accurately. Ask for a referral if growth is especially rapid, your child is very young and you think they are about to enter puberty.

It is possible to delay precocious puberty for a few years, by giving a hormone similar to the one which kick-starts puberty. This blocks the action of the body's natural hormones. By putting off the changes for a few years, it allows the child to mature and grow as usual so that when puberty is allowed to begin, the child is better able to cope with the changes.

Timing can be difficult. By the time parents spot the earliest physical changes, puberty is underway. **However, the growth spurt that heralds puberty usually begins around six months before puberty begins,** so spotting this can provide a bit of time to arrange to see your paediatrician, or get a referral to an endocrinologist (a doctor specialising in hormones) to see if puberty could, or should, be delayed. It may not always be possible or desirable to delay puberty, but getting the opinion of a health professional could be helpful.



“ Gaining the right support and forward planning is key to your child having a positive experience of secondary education ”

## Transition to secondary school

**Preparation is key to finding the right secondary school for your child with hydrocephalus.**

Secondary school is very different from primary school and there are many additional demands on children. Schools are generally much larger, and unlike primary where they are taught in one classroom and with the same teachers, most will involve several classrooms and teachers each day. There is an expectation that your child will become more independent in their learning and be responsible for managing their timetable and getting themselves around the school.

This is big change for any child but can be particularly challenging for a child with hydrocephalus who may have difficulty with planning and organisational skills, or may tire easily when moving around a large school. Gaining the right support and forward planning is key to your child having a positive experience of secondary education.

**Here is a checklist to help you and your child make the right choice at this important time.**

### Top tips

**1 Talk to your child about what their ‘ideal’ school would be like**

Make a list of what your child likes or really dislikes about their current school. This might include subjects on offer, class sizes, the layout of the school or concerns about travelling to and from school. This involves your child in the planning, although you will need to make the final decisions.

**2 Make a list of all suitable schools in your area and visit as many as possible**

Secondary schools have open days or open evenings in the Autumn term, but you can often gain a better idea about a school by arranging a visit during normal school hours, if possible.

If there are no schools which can meet your child’s needs within your area, look further afield to nearby local authorities.

**3 Make a shortlist of schools to discuss with your child**

If possible, talk to other parents of children with extra needs who go to the schools. Make a list of questions with your child and ask for meetings with the special educational needs and disabilities coordinator (SENDCo) so you can discuss your child's needs and ask your questions.

**4 Get to know your local secondary school admissions process**

You are not choosing one school, but listing the schools you would like your child to attend. If your child has SEN Support then your Local Authority Admissions Guide will explain how to apply and lists the admissions criteria for schools in your area.

**5 Make sure you have lots of evidence about your child's special educational, health and social care needs**

Collect and share as many professional assessments as you can because the local authority and schools will rely on evidence in order to plan for your child's needs.

**6 Once you have chosen a school, discuss an appropriate 'transition plan' with the school and your child**

Good transition planning gives a clear handover to a new educational setting and their services so that your child

and you will feel confident in who you are working with and where you need to go if you are in need of help.

It may help your child to have a full map of the school, which details where toilets and classrooms are. If it will help your child, ask for a list of school staff, their roles, names and, if needed, their photos. Request a detailed timetable for your child to have before starting school, daily checklists, a list of the school rules and any other information your child might need to ease anxiety of the transition. It may be appropriate to have photos of the classrooms and other areas of the school to make your child social story that they can refer to in order to reduce any anxiety.

**7** Request the maximum support possible at the start of a new school placement with a view to adapting or reducing the support if it is not required.

**8** Communication is key to keeping a good relationship with the school. Ask the SENDCo and class teacher for regular meetings to plan targets and to discuss what is working well or not.

**9** Make a 'personal passport' with your child for use in school. Medical Alert cards are also useful in a big school environment where not all teachers and support staff will know your child and their additional needs.

