



Spina Bifida Hydrocephalus  
Queensland

# CHILDREN WITH HYDROCEPHALUS

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## DISCLAIMER

This booklet is designed to provide general information about the topics covered to assist interested parties. It is compiled from information written by staff of the Association, as well as from various publications by authors not related to the Association. Accordingly, whilst the Association believes the information is the most accurate and up-to-date available, the Association accepts no responsibility for the information from other sources. There is still much to be learnt about hydrocephalus and its causes. As further developments occur, the information may prove to be incorrect or incomplete. For this reason, and because the information is of a general nature, you should always obtain specific advice about matters affecting you.

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## SBH Queensland Services

### SBH Queensland

- Provides a contact point for information and services specific to spina bifida and hydrocephalus
- Empowers people with spina bifida and hydrocephalus to achieve their full potential
- Promotes the value of people with spina bifida and hydrocephalus
- Strives for excellence in the development and provision of programs to people with spina bifida and associated hydrocephalus

### What SBH Queensland can offer you and your child

SBH Queensland offers a range of services for children with spina bifida and hydrocephalus aged 0 to 18 years. These services consist of:

- The library and other information resources
- Support and counselling for new parents
- Support at Lady Cilento Children's Hospital spinal clinics
- Group programs such as: playgroups, mobility clinics and skill training groups
- Annual camp
- Lending of equipment for trial

### Eligible children may also receive individual services from the Education and Therapy Service

**Physiotherapy** - Assistance with mobility, wheelchairs, anything to help your child get around

**Occupational Therapy** - Assisting your child to develop essential skills for school and life

**Speech Pathology** - Focusing on your child's communication, speech, language and feeding abilities.

**Education Advisers** - Support for your school or early learning centre to help them understand and assist your child to reach their potential at school

# HYDROCEPHALUS

A clear, saltwater-like liquid called cerebrospinal fluid surrounds the brain. This fluid protects and hydrates the brain, carries away wastes from brain cells and contains important chemicals and nutrients. Each day an adult brain produces about a pint of cerebrospinal fluid, which flows in a continuous circuit through the brain cavities (ventricles), and over the surface of the brain and spinal cord until the body absorbs it.

Hydrocephalus is the result of a blockage in the flow of CSF through these pathways or the poor absorption of CSF by the body. Also rarely, the brain produces too much CSF to be absorbed. This blockage causes a build up of pressure in the ventricles, which then expand and push against brain tissue and the bones of the skull. In an infant the plates of the skull are not yet fused together. This enables the plates to shift and accommodate the excess cerebrospinal fluid and thus lessen the amount of damage to the brain.

In some babies born with hydrocephalus the condition is arrested if the blocked passage opens or the fluid is channelled elsewhere. If it continues to develop there is continuing pressure on the brain, which if untreated will cause brain damage.

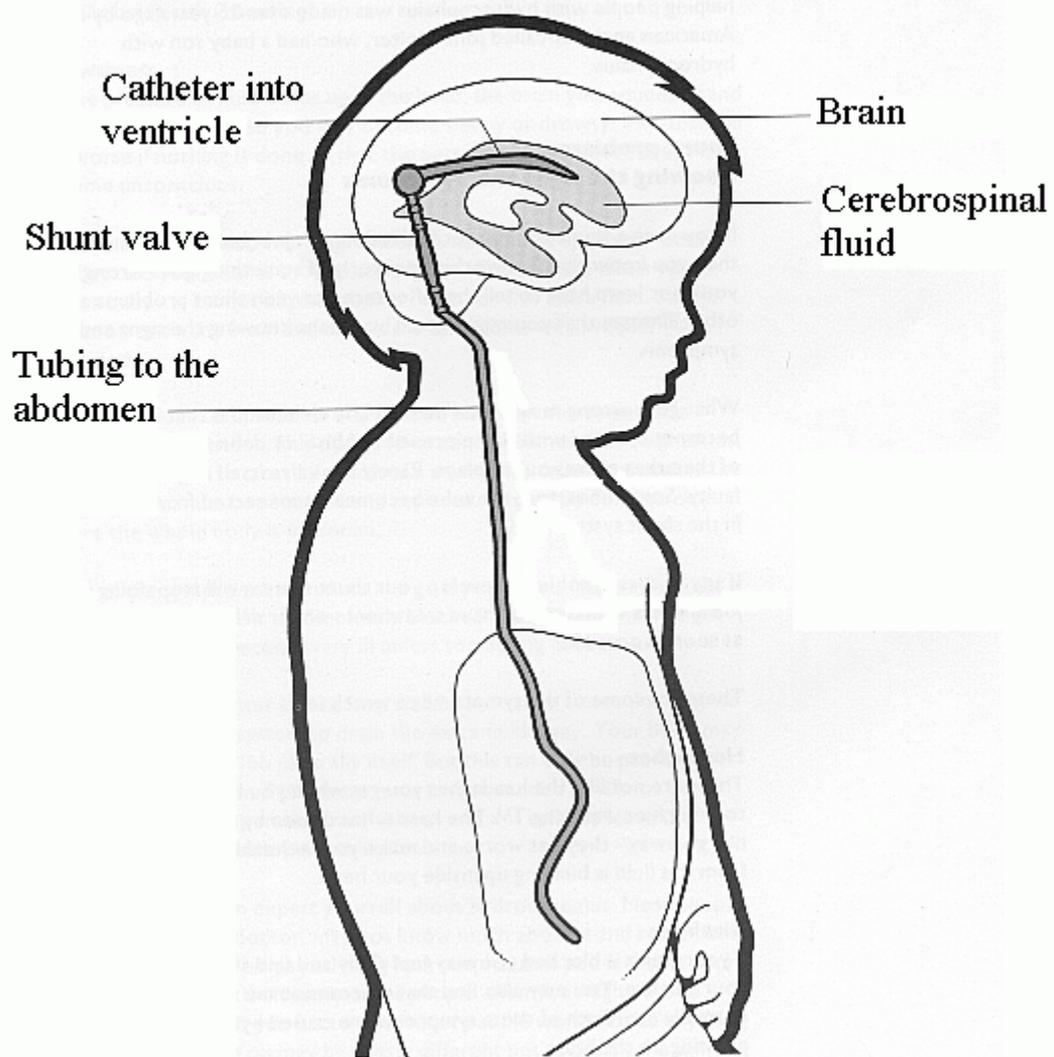
Hydrocephalus is usually treated by insertion of a "shunt". A shunt is a device, which is designed to drain excess cerebrospinal fluid from the brain and carry it to other parts of the body. A one-way valve is used, which usually sits outside the skull, but beneath the skin, somewhere behind the ear. (See diagram) A relatively new surgical procedure called endoscopic third ventriculostomy has been a successful treatment for some people with hydrocephalus. Not everyone with hydrocephalus will require a shunt or surgery.

Although a shunt generally works well, it may stop working if it disconnects, becomes blocked, or it is outgrown. If this happens the cerebrospinal fluid will begin to accumulate again and a number of physical symptoms will develop. It is important to get medical attention if any of the following symptoms appear.

## SYMPTOMS OF A MALFUNCTIONING SHUNT

- ◆ HEADACHE
- ◆ VOMITING
- ◆ FEVER
- ◆ IRRITABILITY AND PERSONALITY CHANGES
- ◆ DETERIORATION IN PERFORMANCE - school work, gait, balance, and concentration
- ◆ LETHARGY AND DROWSINESS
- ◆ DIZZINESS and in more severe cases
  - ◆ VISION DISTURBANCES and
  - ◆ SEIZURES

### SHUNT SYSTEM TO DRAIN CSF INTO ABDOMEN



*Diagram reproduced from "Spina Bifida and You"*

# LEARNING DIFFICULTIES

Although most children with hydrocephalus are within the normal range of intelligence, most experience specific learning difficulties.

Teaching a student with hydrocephalus requires all the normal teaching skills. Teachers must possess good communication skills and a willingness to work as a team with parents, therapists and students. They must also have the ability to use cooperative learning techniques and to modify teaching strategies and curriculum where necessary.

The recognition of problems and a fulfilling educational experience for these children will involve:

**Observation:** Parents are often the most skilled in this as they spend most time with their children. It is essential that parent's observations are noted and considered.

**Specialist Medical and Therapy Reports:** These may reveal certain problematic areas and, therefore, need to be carefully read and analysed with regard to the impacts at school and home.

**Discussion:** Difficulties may be revealed or identified by parents and professionals talking together. Discussions should include doctors, therapists, psychologists, other teachers and other professionals involved with the child's wellbeing.

## In The Classroom

- John does not remember today what he appeared to know last week.
- Susie talks a lot but is often off the point. She does not listen effectively and the other students find this irritating.
- Toby seems interested and starts tasks willingly, but rarely completes anything. His writing is awful.
- Peter works well when the teacher or aide sit beside him but he gets distracted and produces little if left to work on his own.
- Melissa forgets due dates for work requirements.
- Sean finds it difficult to grasp fundamental mathematical and spatial concepts.
- George can learn effectively but this often takes longer than his peers.

The above statements often apply to students with hydrocephalus. Although they may sound like difficulties that can affect any student every once in a while, it must be realised that for hydrocephalus students these problems are pathological in origin and need to be addressed accordingly.

The problems can be grouped under the following headings: **attention, language, memory and learning, visuo-motor integration skills, planning and organisational skills.** What follows is a short description of how they manifest and some recommended strategies for educators when confronted with them. Remember that though most students with hydrocephalus will exhibit similar learning difficulties, the range and their severity in individuals will vary widely. The teacher's knowledge and experience of their students will be the best guide to the distinctive pattern of cognitive strengths and weaknesses exhibited by individual students.

## Attention

Most students with hydrocephalus appear interested and motivated to learn. However they are easily distracted and find it difficult to sustain attention until the completion of work. Some have difficulty identifying the most salient aspect of a task and focusing their attention. Instead they tend to get distracted to less relevant aspects.

Students with attention problems usually function best when:

- the work environment is quiet, well organised and clearly structured;
- a single activity is set and competing distractions are minimised;
- high demand working periods are brief and interspersed with more relaxing activities;
- instructions are clear and step by step and repeated when required;
- adult assistance is available to redirect the student after lapses in concentration.

## Language

Students with hydrocephalus are often described as sociable and talkative with good vocabulary skills. However, they may have difficulty monitoring what they say for logic, relevance or appropriateness. This poor comprehension may be difficult to identify when associated with articulate presentation. Some 'over talk', perhaps to compensate for their limited mobility or to conceal their inability to do what is asked, may be evident.

Teachers can help by:

- encouraging the student to use language for communication of meaning rather than only to manipulate others or to conceal areas of difficulties;
- insisting that the student maintains a shared topic of conversation and redirecting them if they wander;
- routinely checking the student's understanding of the language they are using (for example, by asking the student to paraphrase what is said to them, particularly instructions).

## Memory and Learning

Immediate memory for auditory/verbal information may be intact, ie. the student has an age appropriate capacity to remember instructions or explanations immediately after they are given. However, there is a rapid loss of information over time and difficulty in retrieving the appropriate bit of information from long term memory when it is needed. Visual memory is weak and concepts grasped last week are later lost. Students with hydrocephalus can learn effectively however often take longer to learn and struggle with abstract concepts, for example, mathematics. During bad periods they may appear lazy or 'inert' and simply cannot function at the level they are capable of.

Students with memory learning deficit are helped by:

- reducing the amount of information presented at one time and allowing extra opportunity for rehearsal;
- emphasising key points in a logical sequence - information is remembered most effectively when it is processed in an organised and logical way. Extraneous information should be minimised;
- reinforcing conceptual learning through practical activities related to the student's interests and life experience.

## Visuo-Motor Integration Skills

Most students with hydrocephalus have difficulty with tasks requiring eye-hand coordination and motor planning skills. They may have difficulty with accurately interpreting what they see in terms of shape, size, space, and distance and then correctly matching their movements (gross or fine). Some students may experience confusion differentiating between left and right. Complaints about slow and untidy handwriting are common and written tasks are often not fully completed.

Assistance can be given by:

- allowing extra time for written work or assignments;
- providing alternatives, for example using an audio tape for creating writing activities;
- encouraging early and frequent use of a word processor for the presentation of written work;
- providing activities which allow the above skills to be practised.

## Planning and Organisational Skills

Most students with hydrocephalus find it hard to organise themselves, plan ahead and think flexibly. In addition, some may experience difficulty in understanding the passage of time or understand when matters are urgent. They may be unable to generate strategies for solving problems or to alter their approach if the first attempt is unsuccessful. They seem lost when confronted by a novel or multi-staged task and their work output falls off when they are expected to work independently.

Teachers can help by:

- breaking down complex tasks (eg. assignments, projects) into smaller steps, helping the student generate a plan of approach before they commence, reviewing progress after each component step has been completed and, in brief, providing signposts to guide the student's progress;
- encouraging organised work habits, eg. set homework times, the use of a diary, focusing on time management, use of written or pictorial check lists, use of colour coding to assist planning;
- encouraging the student to check and proofread their work.

The levels of educational achievement of students with hydrocephalus are in a wide range, from completion of university and vocational training programs to non-completion of secondary schooling. Whatever the potential of individual students, through awareness of the specific learning difficulties listed above and consistent strategies to intervene where necessary, educators will assist them reach their full potential.

# HANDWRITING

## TYPING & TECHNOLOGY

Hydrocephalus may affect a child's ability to concentrate and learn.

This is usually not so apparent at birth, and real difficulties may not arise until a child is of a pre-school age, or in fact not at all.

Initially, it may involve difficulties with small toys like Lego and trouble doing up buttons and zips in dressing. The child may not be keen to sit and play with fine motor toys or experiment with drawing or cutting activities. This kind of aversion to fine motor activity may indicate not only a dislike for but also a difficulty in handwriting, later on at school.

Handwriting, however, is much more than a fine motor activity and other factors need to be considered when looking at this skill development. These include:

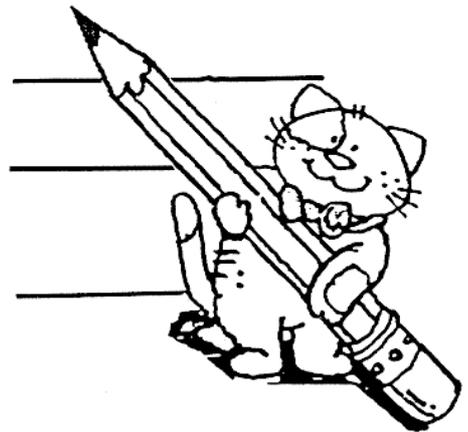
VISUAL ACUITY (how clearly can the child see)

VISUAL MOTOR INTEGRATION (eye-hand coordination)

WRITING TECHNIQUE (pencil grasp/pressure)

ESTABLISHMENT OF HAND DOMINANCE

INTEREST AND MOTIVATION



It is important to remember that the ultimate aim is for writing to be functionally useful both for the work required in primary school but more importantly for the volume of work provided in high school, and ultimately as a daily skill.

If it is determined that handwriting is not functional then an alternative means of written expression may need to be considered. It is reasonable, though, to assume that the child be allowed more time to develop the basic skills of handwriting before any recommendation for keyboards is made.

## KEYBOARDS

Primarily, lightweight electronic typewriters are used as a means of increasing a child's "output" with increased speed and reduced effort. They should **not** be used as a full time alternative to handwriting but a way of tapping into a child's creative expressive language, or in producing written work where writing is not essential to the task eg. Maths.

Typewriters are also still preferable as an initial tool for the training of keyboard skills, even in this day of computers, because:

- They can be specially/only for the child; no queuing for access
- An immediate input/ immediate output is provided
- They are lightweight and portable
- Families can also purchase one
- They have limited functions thereby, decreasing confusion

# SOCIAL DEVELOPMENT

The following is based on information supplied by the Hydrocephalus Association of America.

Positive social interactions are an important part of life. The social skills critical for social inclusion are numerous and for most our social learning is done automatically by seeing, copying and conditioning - we learn social skills incidentally, without formal instruction. However, many children with hydrocephalus have learning difficulties that make it difficult, or almost impossible, to pick up the verbal and non-verbal cues necessary for the acquisition of social skills.

Some of the most common problem areas are:

Talking over differences without getting angry

Persistence when facing frustration

Refusing requests politely

Taking turns while talking

Understanding social rules

Demanding immediate attention

Waiting when necessary

Difficulty perceiving non-verbal cues can create serious social problems. Children with learning difficulties often misjudge distance and spatial relationships. They get too close to other people, or they stay back too far. Getting too close will cause others to back off and find an excuse to escape. Staying back too far makes eye contact difficult, puts them out of reach of voice range and is likely to cause others to ignore them.

**These children may also have difficulty picking up other social cues, such as those from clothing, for example.** Someone dressed in a suit and carrying a briefcase tells us, "I am an authority". If a child doesn't pick up such cues, they might not figure out who is the authority, boss, teacher, or even the 'boss kid'. And, as a child, if you can't spot the leaders you may end up imitating the school 'nerd' with the high probability that you will then be socially scorned or ignored.

**Children who have a problem with non-verbal cues also often have difficulty perceiving intonation.**

For example, consider the youngster who hears that a party is being planned and goes up to ask if they can come. The 'child' responds, "Yeah, SURE, I REALLY want YOU". If the child shows up at the party, it is sure to be a heartbreaking experience. The child has heard the WORDS ("I want you"), but not the TONE ("I would rather die than have you at my party"). Errors such as these can be incredibly painful for children who are not attuned to such nuances as tone, rhythm or pitch.

Other important non-verbal cues are posture and facial expression. **If a child can't read faces very well, they will likely interpret things incorrectly.** These children may perceive only two kinds of facial expressions, 'happy' and 'mad', and perhaps 'sad'. This understanding is not enough to get along in the world. They need to perceive such subtleties as "quizzical", "reflective", and others, and are expected to learn them incidentally.

It is known that many youngsters with hydrocephalus may be slower in acquiring physical skills. With time, remediation and early intervention however, many of these skills are obtained. **But what about social skills?** If the child lags behind, will they eventually catch up on these skills on their own, or is intervention important at an early level? **Intervention is vital because even if the child does catch up on their own, it will probably happen over time and some skills may always be missing.** If undeveloped, social skills may come later but by then a youngster may be exhausted, reclusive or self-defeating in interactions with others, having had so many rejections that they refuse to continue to extend themselves socially.

We do not need to wait for this self-defeating behaviour to happen if we realise that many of these social skills can be taught. **These skills can be often be broken down into component parts and taught in stages.**

**By recognising and addressing the issue of social skills development, children with learning difficulties can make a move from potential social isolation to social inclusion and participation.**



## IN THE PLAYGROUND

When there is a child with a disability in your school, having that child fully involved in the classroom program is only half the story.

It is also the school's (and that means the whole school) responsibility to try to ensure that the child is as fully involved as is possible in playground activities as well, i.e. at lunchtime and playtime.

A child who, from Grade 1, has less opportunity to talk and play with schoolmates in the playground will have more difficulty developing appropriate social skills. With inadequate social skills, the problem obviously grows.

Play is important!

### WHAT TO DO

**Encouraging/facilitating appropriate play** - Sometimes it may be possible for a teacher-on-duty to suggest or encourage games in which the child with a disability can join in. This is not to limit the other children, but to encourage games which they can all enjoy.

Try to **tune in to whatever games are popular now**. It may only take a small modification to make it suitable for all the children.

**Ask the children for ideas** - both the child with the disability and his classmates. They will often have the best ideas about what games will work, or how to modify them.

These are just a few ideas to start with. Remember that the teachers in the schools are the ones who see the myriad of games which children play. **YOU** probably have lots of good ideas!

- Cubbyhouses - usually of bushes in the school ground.
- Imaginative play - each child making believe he is someone/something/somewhere else.
- Walking tiggly - instead of running to chase each other, a different type of gait is set (so not as fast moving). Alternatively you may add extra rules about using lines or markings on the ground to limit the pace or area of the game.
- Ball games - eg. handball (i) against brick wall so a missed ball does not take so long to retrieve and (ii) having a designated catcher, to retrieve missed balls. There are usually kids watching a game, so it is often easy to find a willing catcher. (Be careful not to give **too much** assistance).
- Modified ball games - eg. grip ball
- Sevenies - ball games against a wall
- Piggy-in-the-middle type games
- Simon says

- Traffic lights

*Green* - one step forward

*Red* - one step back

*Orange* - don't move

If you do the wrong thing you are out.

If the classmates are playing active games, then the child with a disability should too, whenever possible.

When this isn't practical, a sedentary activity such as *Where's Wally?* Books or board games may be good lunchtime activities.

It is sad to hear of children, especially young children, spending lunchtime in the library, even if it is their choice. It only magnifies the social isolation, so they feel even more uncomfortable trying to join in, in the playground.