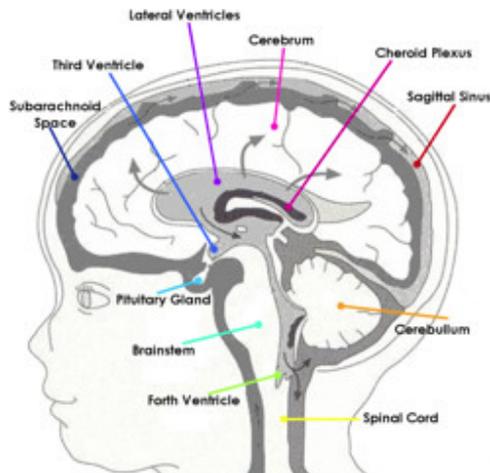


WHAT IS HYDROCEPHALUS?

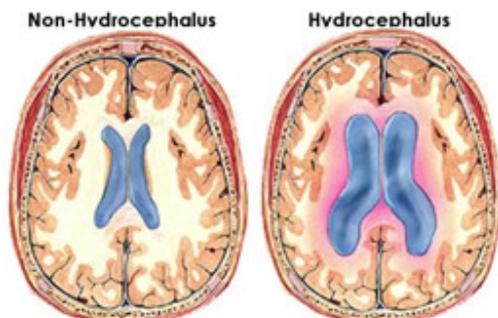
Hydrocephalus comes from two Greek words



The term Hydrocephalus comes from the two Greek words: 'hydro' which means water, and 'cephalus' which means head. In years past, it was commonly called 'water on the brain'. Put simply it is a condition where there is too much cerebrospinal fluid in the cranium.

Cerebrospinal fluid (CSF) is found within the brain and the spinal cord. It is a clear, watery substance that flows through a channel into the space (subarachnoid space) around the brain and spinal cord, where it also functions as a cushion. The CSF is absorbed back into the bloodstream via mushroom-like structures over the brain called and replenished. A small amount of CSF is produced by the spinal cord. The CSF contains nutrients and proteins necessary for the nourishment and function of the brain and carries waste products away from tissues in and around the brain.

The fluid is produced within hollow channels in the brain called ventricles, primarily within the lateral ventricle. In each ventricle is a specialised structure (which looks like small flower-like tufts) called the choroid plexus, which is responsible for the majority of CSF production. This CSF is produced at a constant rate.



The brain maintains a balance between the amount of cerebrospinal fluid that is absorbed and the amount that is produced.

Hydrocephalus occurs when there is an imbalance between the amount of CSF that is produced and the rate at which it is absorbed. This can be caused by a blockage in the pathways through which the fluid travels or from an overproduction of fluid or a difficulty in absorbing the fluid that is produced. Because the brain is enclosed within the skull, the extra fluid has no escape which causes it to build up. This then causes the ventricles to enlarge and the pressure inside the head to increase, resulting in an enlarged head and increased pressure symptoms.

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TYPES OF HYDROCEPHALUS

Hydrocephalus can be identified in one of two ways - Congenital and Acquired.

Congenital

Congenital Hydrocephalus results from a complex interaction of genetic and environmental factors and is present at birth. It is important to remember that the term genetic does not imply that it is hereditary. Often the exact cause of congenital Hydrocephalus cannot be determined. Though it might not be recognised and diagnosed immediately, congenital Hydrocephalus is often diagnosed before birth through routine ultrasound. Hydrocephalus diagnosed in adulthood may have existed since birth and can still be considered congenital and may be referred to as compensated Hydrocephalus.

Acquired

Acquired Hydrocephalus develops after birth as a result of neurological conditions. This type of Hydrocephalus can affect individuals of all ages and may be caused by head trauma, brain tumour, cyst, intraventricular haemorrhage or infection of the central nervous system.

Within both of these areas, congenial and acquired, Hydrocephalus can be described as communicating or non-communicating. Communicating Hydrocephalus occurs when the flow of CSF is blocked after it exits the ventricles. This form is called communicating because the CSF can still flow between the ventricles, which remain open. Non-communicating Hydrocephalus - also called "obstructive" Hydrocephalus occurs when the flow of CSF is blocked along one or more of the narrow passages connecting the ventricles.

There are two other forms of Hydrocephalus which do not fit exactly into the categories mentioned above and primarily affect adults: Benign External Hydrocephalus and Normal Pressure Hydrocephalus.

Congenital Hydrocephalus

This means that Hydrocephalus is present at birth. It is important to remember that this term does not imply that it is hereditary. Often the exact cause of Congenital Hydrocephalus cannot be determined but known causes can include:

Aqueductal Stenosis (non-communicating)

The most common cause of congenital Hydrocephalus is an obstruction called aqueductal stenosis. When the long, narrow passageway between the third and fourth ventricles (see 'What is Hydrocephalus' diagram) is narrowed or blocked, perhaps because of infection, haemorrhage or a tumour. Fluid accumulates "upstream" from the obstruction, producing Hydrocephalus.

Neural Tube Defect or NTD (communicating)

An open NTD, where the spinal cord is exposed at birth and is often leaking CSF, is often referred to as Spina Bifida (see 'What is Spina Bifida'). This kind of NTD causes part of the cerebellum and the fourth ventricle to push downward through the opening at the base of the skull into the spinal cord area, blocking CSF's flow out of the fourth ventricle and producing Hydrocephalus.

Arachnoid Cysts (non-communicating)

Arachnoid Cysts may occur anywhere in the brain. In children, they're often located at the back of the brain and in the area of the third ventricle. These cysts are filled with CSF and lined with the arachnoid membrane. Some arachnoid cysts are self-contained, while others are connected with the ventricles or the subarachnoid space. The fluid trapped by the cysts may block the CSF pathways, producing Hydrocephalus.

Dandy-Walker Syndrome (non-communicating)

In Dandy-Walker syndrome the fourth ventricle becomes enlarged because its outlets are partly or completely closed, and part of the cerebellum fails to develop. Dandy-Walker syndrome may also be associated with irregular development in other parts of the brain and sometimes leads to aqueductal stenosis. In some instances, two shunts are placed in the child's ventricles - one in the lateral ventricle and another in the fourth ventricle to manage the Hydrocephalus.

Arnold-Chiari Malformation (communicating)

There are two types of Arnold-Chiari malformation. Both types occur in the bottom of the brain stem where the brain and spinal cord join. The lowest portion of the brain is displaced and is lower than normal pushing down into the spinal column. (For further information see "What is Chiari Malformation")

Acquired Hydrocephalus

This means that Hydrocephalus has occurred after birth and can be caused by:

Intraventricular Hemorrhage (communicating)

An intraventricular haemorrhage, which most frequently affects premature newborns, may cause an acquired form of Hydrocephalus. When small blood vessels alongside the ventricular lining rupture, blood may block or scar the ventricles or plug the arachnoid

villi. The arachnoid villi is located in the second layer covering the brain which allows CSF to be absorbed. When the CSF can't be absorbed, Hydrocephalus results.

Meningitis (communicating)

Meningitis is an inflammation of the membranes of the brain and spinal cord. Caused by a bacterial or (less frequently) viral infection, meningitis can scar the delicate membranes (meninges) that line the CSF pathway. An acquired form of Hydrocephalus may develop if this scarring obstructs the flow of CSF as it passes through the narrow ventricles or over the surfaces of the brain in the subarachnoid space.

Head Injury (communicating)

A head injury can damage the brain's tissues, nerves, or blood vessels. Blood from ruptured vessels may enter the CSF pathway, causing inflammation. Sites of CSF absorption might then be blocked by scarred membranes (meninges) or by blood cells. The CSF flow is restricted and Hydrocephalus develops.

Brain Tumours (non-communicating)

In children, brain tumours most commonly occur in the back of the brain (posterior fossa). As a tumour grows, it may fill or compress the fourth ventricle, blocking the flow of CSF and causing Hydrocephalus. A tumour somewhere else in the brain might also block or compress the ventricular system.

Ventriculitis (non-communicating)

Ventriculitis is a disease causing inflammation and or infection of the ventricles. It is most common in infants and is often an extension of meningitis.

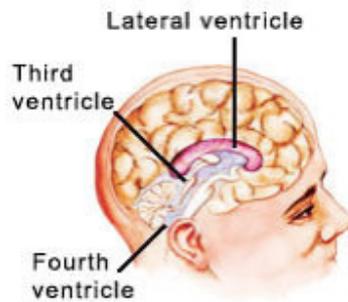
Choroid plexus papilloma (communicating)

A Choroid plexus papilloma (CPP) is a rare, slow-growing, tumour that is commonly located in the ventricular system of the choroid plexus (see 'What is Hydrocephalus' diagram). It may obstruct the cerebrospinal fluid flow, causing increased intracranial pressure and Hydrocephalus.

Prematurity (communicating)

Babies born prematurely are at risk of Hydrocephalus as their brain is still developing. The area which lies just beneath the lining of the ventricles in the brain is particularly important in this development as the activity in this area has a plentiful blood supply. The blood vessels are very fragile at this time and can easily burst if the baby suffers too large a swing in blood pressure or becomes severely ill from other causes. If these complications occur, then the baby may be at risk of developing a haemorrhage. This can lead to a blood clot developing, which in some cases is big enough to break through the wall of the ventricle. Should the clot block the flow of CSF, the baby will develop Hydrocephalus. The blockage may be temporary or permanent. Even if a blood clot does not develop, the blood cells from the haemorrhage can cause blockage and Hydrocephalus can occur.

Benign External Hydrocephalus (communicating)



Benign External Hydrocephalus (also referred to as External Hydrocephalus) occurs when an accumulation of CSF is found outside the brain, which usually presents itself at birth or soon thereafter. The infant's head size will increase, but scans show no international difficulties in the ventricles or pathways. This condition usually corrects itself within 18 months of age.

Normal Pressure Hydrocephalus (Non-communicating)

Normal Pressure Hydrocephalus can happen to people at any age, but it is most common among the elderly. It may result from a subarachnoid haemorrhage, head trauma, infection, tumour, or complications of surgery. However, many people develop Normal Pressure Hydrocephalus even when none of these factors are present for reasons that are unknown. (For further information see 'What is Normal Pressure Hydrocephalus')

WHAT IS NORMAL PRESSURE HYDROCEPHALUS (NPH)?

What is Normal Pressure Hydrocephalus?

The brain and spinal cord are surrounded by a clear fluid called cerebrospinal fluid (CSF). This fluid is produced and stored in cavities in the brain called ventricles. It circulates around the brain, moving from ventricle to ventricle. The purposes of the fluid are to cushion and protect the brain and spinal cord, to supply them with nutrients, and to remove some of their waste products. Any excess fluid drains away from the brain and is absorbed by other tissues.

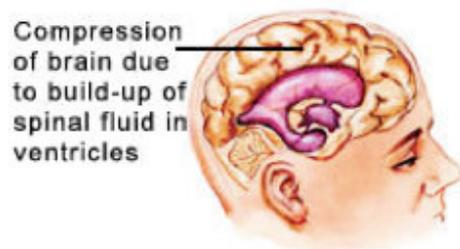
Hydrocephalus is a condition in which there is too much CSF in the ventricles. This occurs when the natural system for draining and absorbing extra CSF does not work right. The ventricles enlarge to accommodate the extra fluid and then press on different parts of the brain, causing a number of different symptoms. Hydrocephalus has many different causes. Some people are born with the condition, while others develop it during their lives.

Normal pressure Hydrocephalus (NPH) is a type of Hydrocephalus that occurs in adults, usually older adults. The average age of people with NPH is older than 60 years. NPH is different than other types of Hydrocephalus in that it develops slowly over time. The drainage of CSF is blocked gradually, and the excess fluid builds up slowly. The slow enlargement of the ventricles means that the fluid pressure in the brain may not be as high as in other types of Hydrocephalus. However, the enlarged ventricles still press on the brain and can cause symptoms. (The term “normal pressure” is somewhat misleading.)

The parts of the brain most often affected in NPH are those that control the legs, the bladder, and the “cognitive” mental processes such as memory, reasoning, and problem solving, and speaking. This decline in mental processes, if it is severe enough to interfere with everyday activities, is known as dementia. Other symptoms include abnormal gait (difficulty walking), inability to hold urine (urinary incontinence), and, occasionally, inability to control the bowels.

Note: The symptoms of NPH can be similar to those of diseases such as Alzheimer's and Parkinson's. Experts believe that many cases of NPH are misdiagnosed as one of these diseases.

What causes NPH?



Normal Pressure Hydrocephalus can occur after a head injury, bleeding around the brain (due to a blow to the head), stroke, meningitis (infection of a protective layer of tissue around the brain), or brain tumour. It can also happen after surgery on the brain. How these conditions lead to NPH is not clear. In most cases, the cause of NPH is never known.

What are the symptoms of NPH?

At first, the symptoms of normal pressure Hydrocephalus are usually very subtle. They worsen very gradually.

Symptoms of dementia include:

- Memory loss
- Speech problems
- Apathy (indifference) and withdrawal

- Changes in behaviour or mood
- Difficulties with reasoning, paying attention, or judgment

Walking problems

- Unsteadiness
- Leg weakness
- Sudden falls
- Shuffling steps
- Difficulty taking the first step, as if feet were stuck to the floor
- “Getting stuck” or “freezing” while walking

Urinary symptoms

- Inability to hold urine
- Inability to hold stool, or faeces (less common)
- Frequent urination
- Urgency to urinate

The following symptoms can be related to increased pressure in the brain:

- Headache
- Nausea
- Difficulty focusing eyes

When to Seek Medical Care for NPH

Some people think that memory loss; difficulty finding words, walking problems, or urination problems are normal parts of aging. In many cases, however, these are symptoms of treatable conditions. Any of these problems, or changes in mood or behaviour, warrants a visit to your health care provider.

How is NPH Diagnosed?

The symptoms of Normal Pressure Hydrocephalus can occur in Alzheimer's disease and Parkinson's disease. However, the combination of dementia-like symptoms, walking problems, and urinary problems should alert your health care provider to the possibility of NPH. Making the distinction is very important because the treatments for these conditions are quite different. Tests are available that can diagnose NPH. At any point in this process, your health care provider may refer you to a specialist in brain disorders (neurologist or neurosurgeon) to complete the evaluation and begin treatment.

What is the Treatment for NPH?

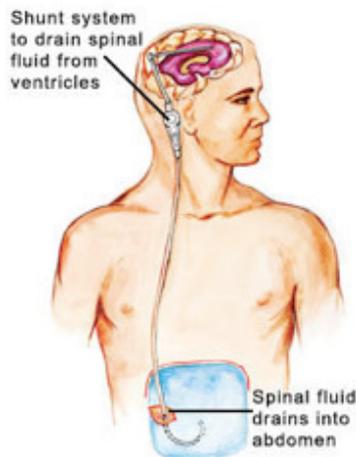
Normal Pressure Hydrocephalus generally cannot be cured. It is a long-term condition. However, many people with the condition obtain substantial relief through surgical treatment. For those who are not candidates for surgery, treatment consists of measures to relieve mood and behavioural problems, cope with physical problems such as incontinence and walking difficulties, and maximize physical, mental, and social functioning.

Surgery for NPH

Occasionally the cause of the Hydrocephalus can be treated directly through surgery. For example, a brain tumour blocking drainage of the CSF can be removed. In most cases, however, the underlying problem is not known or cannot be treated. The treatment in these cases is a shunt operation.

A shunt is a thin tube that is implanted in the brain by a neurosurgeon. It is inserted into the ventricles to drain excess CSF away from the brain. The tube is routed under the skin from the head to another part of the body, usually the peritoneum (the lower belly). The shunt is equipped with a valve that opens to release fluid when the pressure builds up. The fluid drains harmlessly and is later absorbed by the bloodstream. The pressure setting on the valve sometimes must be readjusted. The newer shunts allow adjustment without another operation.

A shunt operation is not a cure. It does not treat the underlying cause of NPH. It can, however, relieve the symptoms. The shunt remains in place indefinitely. If properly implanted, the shunt often is not obvious to other people.



Shunt operations do not work for everyone with NPH. Many people who undergo a shunt operation have substantial symptom relief. In some, the symptoms improve and then start to worsen again. Others benefit little, if at all. Even the experts are not able to predict perfectly who will benefit and who will not. Many surgeons perform a spinal tap before surgery to test whether the symptoms get better with removal of fluid. In some cases, the person is hospitalized for a few days while fluid is drained slowly through a small tube called a catheter. This is another way of checking whether removing extra fluid will help symptoms.

The earlier the NPH is diagnosed, the better the chances that the surgery will help. In general, people with milder symptoms have better outcomes with this surgery. Like any surgery, the shunt operation can cause complications. Such complications include infection of the shunt and blood clots around the brain. Your neurologist or neurosurgeon will discuss the pros and cons of this operation and whether it might work for you.

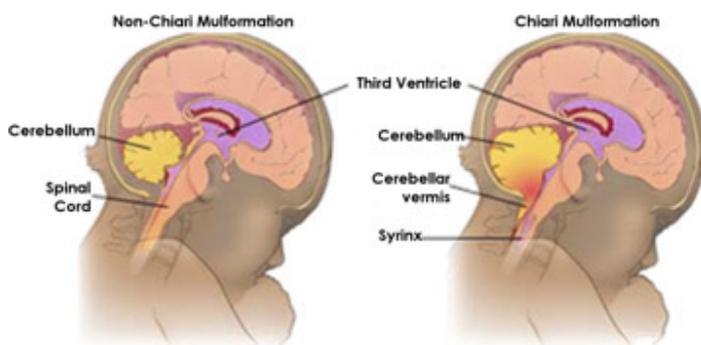
Another operation is sometimes used instead of shunt placement. In Endoscopic Third Ventriculostomy, an endoscope (thin tube with a lighted camera on the end) is used to create a small hole in the floor of the ventricles. The hole provides another way for CSF to drain from the brain.

Prevention of NPH

There is no known way to prevent NPH. A healthy lifestyle, including not smoking, maintaining a healthy weight, and regular exercise, may help avoid conditions such as high blood pressure, heart disease, diabetes, and stroke that might contribute to NPH. Wearing a seatbelt and safety helmet when indicated can help avoid head injury, another cause of NPH.

For further information on Shunts and Endoscopic Third Ventriculostomy please see “What is a Shunt” and “What is Endoscopic Third Ventriculostomy”

WHAT IS CHIARI MALFORMATION?



Also known as Arnold Chiari Malformation, Chiari malformation affects the part of the brain called the cerebellum (see ‘What is Hydrocephalus’ for further information). There are several different forms of Chiari Malformation but most cases are congenital, meaning they are present from birth.

Although Chiari malformation can be present at birth, there may not be any symptoms until adulthood. For this reason, Chiari malformation is often not diagnosed until adulthood. There is a higher incidence of diagnosis in women than in men, the reasons for which are unknown.

What are the symptoms?

The most common symptom of Chiari malformation is a headache, which begins at the back of the head (neck) and radiates upward. The pain is often made worse or can be brought on by coughing, sneezing or straining. These activities are known as valsalva maneuvers.

Visual problems such as nystagmus (involuntary eye movements), double or blurred vision may occur. Balance difficulties, vertigo and dizziness also may be present. Some people may have cranial nerve compression. This can result in apnea (cessation of breathing), gagging, swallowing difficulties, facial numbness or syncope (temporary loss of consciousness).

Symptoms may present as muscle weakness, particularly in the upper extremities, coordination problems, and gait abnormalities. Imaging of the spine may reveal a fluid collection inside of the spinal cord, known as a syrinx. Some individuals may have Hydrocephalus, a build-up of fluid in the ventricles of the brain.

Is there a Treatment?

The first step after diagnosis is to consult with a neurosurgeon who has experience treating and managing this disorder. Be aware that you may need to travel and you may wish to consult with more than one specialist.

If symptoms are mild and not progressing, your doctor may recommend conservative management. Supportive care such as headache and pain management, physical therapy or a reduction in activities can help manage symptoms.

An operation may be recommended. This is referred to as a posterior fossa decompression. The surgeon makes more room in the back of the head by removing small pieces of the skull bones. This reduces compression of the brain stem and allows the tonsils to move back into their natural position. The specific surgical techniques will vary among surgeons; no consensus yet exists on the best variation on this surgical procedure.

Is this condition hereditary?

Researchers investigated the genetic implications of the Chiari malformation with or without syringomyelia. A genetic prevalence has been identified in some families. Researchers continue to search for the gene(s) that are responsible for producing the Chiari malformation.

MRI scanning is recommended for family members who have signs or symptoms of the disorder.

WHAT ARE THE EFFECTS OF HYDROCEPHALUS?

[This page is available in a printable PDF format for your convenience.](#)

Hydrocephalus involves accumulation of cerebrospinal fluid (CSF) in the ventricles of the brain, with an increase in the pressure inside the head.

Pressure

There are two sources of this pressure. One is that of the CSF itself, but a much higher pressure is produced by the heart in order to pump blood to the brain. If the CSF pressure rises, it eventually interferes with the blood supply to the brain, depriving it of oxygen and glucose which it needs in constant amounts to continue to function. Initially this causes tiredness, irritability and drowsiness, but if it progresses then loss of consciousness will result as the brain begins to shut down.

The immediate effects of this interference with the blood supply disappear if the CSF pressure is returned to normal, such as by ventricular tap or insertion of a shunt. However, in most cases the process has been continuing for some time before diagnosis of Hydrocephalus is made. During this time the interference with the blood supply leads first to a 'dying back' of the very fine blood vessels in the brain. Even this process is largely reversible if prompt action is taken, but at this time there is often insufficient clinical evidence to suspect Hydrocephalus. The next stages involve progressive damage to the actual nerve cells in the brain and to their eventual destruction, and this cannot be reversed.

One effect of raised CSF pressure may be seen in the eyes, and this is why your doctor sometimes looks for 'papilloedema'. This is caused by pressure on the blood supply to the back of the eye. It is important to realise that it may not always be present, even when the pressure is high. If CSF pressure remains high for too long, damage to the optic nerves can become permanent resulting in blindness, though fortunately nowadays this is uncommon. Another appearance, particularly in babies, is the so-called 'sunset' eye sign, where the eyes are fixed in a downward position. This is due to CSF pressure affecting important nerves running from the brain which control eye movement.

If untreated the rise in CSF pressure can cause other serious problems in the brain, unrelated to blood supply. Many of our vital functions, such as heartbeat, breathing etc, are controlled from the brain stem, a structure joining the spinal cord to the brain. Very high CSF pressure can compress this sufficiently to cause the heart and breathing to stop. Once again, this is uncommon as signs of raised pressure are usually recognised before this. A similar problem might sometimes arise, particularly in those with Spina Bifida,

due to compression of the cerebellum, a part of the brain lying at the back of the head. This can also give rise to breathing, speaking and swallowing difficulties.

Areas and Associated Functions Affected

Because of the areas of the brain most affected, functions associated with thought and learning, as well as with co-ordinated skilled movement, begin to deteriorate. The precise effects differ between individuals and are further complicated by other abnormalities, as well as by the pre-existing degrees of ability and personality of each person affected. It is not surprising therefore that while, for instance, learning disorders are common amongst those with Hydrocephalus, and their exact effects vary considerably.

Learning

There can be learning difficulties associated with Hydrocephalus such as problems with learning difficulties, behaviour, motivation and visual problems.

Much is said and written about intelligence, and particularly about IQ (intelligence quotient) in people with Hydrocephalus. In fact this is far more complicated, and a good deal less informative, than many believe. The IQ is made up of several components which can be thought of as verbal and non-verbal, or performance-related tests. People with Hydrocephalus generally score better on verbal IQ than on performance IQ and this is thought to reflect the distribution of nerve damage in the brain as described above. Certainly, during periods of rising CSF pressure, such as in untreated cases or when a shunt is blocked, the effect on performance IQ is more marked. Generally speaking, people who have had Hydrocephalus since birth or childhood have, as a group, a lower average IQ than a comparable group without Hydrocephalus, but it is important to realise that there is a wide range in each group, and some people with Hydrocephalus have very high scores.

Practical Implications

Hydrocephalus can also result in subtle effects, giving problems with co-ordination, motivation, organisational skills and language. Physical effects such as visual problems, or early puberty in children, may also occur.

The practical implications of these features of Hydrocephalus are that there may be subtle problems of co-ordination of hand movements with what the person sees, as well as a degree of clumsiness, which make it difficult to perform certain tasks or do certain jobs. With regard to learning in the home or to education in school, there may be real problems with concentration and reasoning which require a sympathetic but skilled approach. For instance, it will often be necessary to teach simple everyday tasks like getting out of bed, washing one's face, dressing and going downstairs as separate short items rather than all at once, and to keep them consistent and repetitive. This does not indicate 'stupidity', but is caused by damage to the nerves in the brain which normally allow us to learn very quickly how to do a complex series of things. Much can be done to help, and the following chapters of this book give parents and teachers practical advice on how to help

children overcome many of these difficulties. Professional advice should be sought where needed.

Many of these effects can be reduced through teaching strategies or with treatment where relevant.

Psychological Development

Psychological development in children and adolescents with Hydrocephalus may proceed normally, but sometimes the changes associated with puberty (breast development, body hair growth etc) appear much earlier than expected, and the intrusion of psychological aspects of sexual development into a mind which is emotionally still very immature can cause distressing problems (see 'Precocious puberty', Again, specialist advice should be sought if necessary. Other effects of Hydrocephalus may also be seen, and some of these are difficult to explain. For instance, some people are very seriously distressed by everyday noises such as vacuum cleaners or washing machines.

Sensitivity to Noise

Many people with Hydrocephalus are very sensitive to sudden high-pitched sounds or very loud noises, e.g. amplification. Young children react by crying and may become very distressed although many become less sensitive over time. Some adults report feeling sensations in the shunt and others have an echoing feeling in the head, others feel panic, nausea and may burst into tears.

Seizures

Approximately one third of people with Hydrocephalus have seizures at some time in their lives. A rise in intra cranial pressure due to shunt blockage may trigger an Epileptic fit. Fits sometimes occur after shunt revision. It is often just an isolated incident, but some people go on to develop Epilepsy. Epilepsy is usually treated with anti-convulsing drugs and is the same for people with or without Hydrocephalus.

Premature Puberty

Some children with Hydrocephalus may develop early puberty. It is seen more often in girls than in boys. Preparation of the child for the onset of periods and sexual development needs to be handled sensitively.

Eye Problems

Eye problems may be the first sign of raised pressure in the brain or shunt blockage, so it is important to monitor the eyes. Visual assessments and ocular assessments, which monitor the eye movements and examine the back of the eye, are recommended.

There is a high incidence of eye problems in patients with Hydrocephalus, such as strabismus (squint), nystagmus (fine wobble of the eyes), papilloedema, (swelling of the

optic disk), optic atrophy and blindness. All Hydrocephalic children are at risk of losing vision and developing a squint. Squints can cause problems with judging distances, speed of approaching vehicles etc.

Language

In some children with Hydrocephalus their ability to use language is often ahead of their ability to understand it. Their vocabulary can be good because they are able to imitate what they hear. If they do not understand fully what is said their response may be inappropriate. A child with a language problem will pick out words they understand and guess the rest or give a stock answer.

Speech

If the child has a problem with forming sounds he/she may need to be referred to a Speech Therapist.

Weak Upper Limb Control and Hand Function

Problems with upper limb control and hand skills are common in people with Spina Bifida and Hydrocephalus. The majority have weak muscle power in their upper limbs. It is important to encourage the use of both hands, especially if one hand is weaker than the other. Loss of sensation in the hands results in an inability to discriminate between differences in water temperature or the temperature of objects such as radiators, kettles etc. Problems with fine finger movements are shown in everyday tasks such as fastening buttons, threading needles, catching balls, screwing lids on jars and using scissors, as well as handwriting. For many everyday tasks and handwriting, it is necessary to stabilise trunks and shoulders and maintain a good sitting position. The non-dominant hand should be used as a support e.g. to hold the copybook as the child uses the dominant hand to write.

Visual Perception

People with Hydrocephalus often have problems with visual perception. Although they recognise objects, they find it difficult to understand their position and relationships. A squint or other eye problems can exacerbate the problem. Some experience loss of depth perception or have difficulty in judging distance or speed. There may be a difficulty with scanning visual images, with consequences for reading, writing and drawing.

Difficulty in discriminating between different shapes has implications for learning to read and write, also problems with shape, size, direction, volume and position can cause difficulties with maths and practical tasks. Figure ground discrimination i.e. identifying an object from its background, may show up in problems with crossing a road, maps, diagrams and artwork in school.

Visual perception difficulties also means that judging slopes, height of kerb, width of doors or space in a room may prove problematic. It also affects placing objects accurately

i.e. a glass left near the edge of a table and even feeding - difficulty in getting spoon or cup accurately to the mouth. Dressing and undressing e.g. getting clothes on inside out, upside down etc may be difficult too. Sometimes people with Hydrocephalus are not aware of signals given by facial expressions in others.

Perceptual difficulties are not the only problems associated with Hydrocephalus. Some people with Hydrocephalus may have problems with decision-making, logical thinking, organisational problems, and inability to follow verbal instructions, short-term memory difficulties and passive behaviour. All of these have major implications for adult life.

Spatial Awareness

Spatial awareness is the ability to understand the surrounding space and judge distance, height, width, size, volume. Problems with spatial and visual perception are inter-related. It can affect the way people move about, e.g. a wheelchair user may bump into tables, graze doorways or clip people's heels. Fear of tilting a wheelchair backward to climb a kerb or fear of the drop may also be apparent. People with Hydrocephalus may have a fear of being left in a room alone, of venturing outside, or of long corridors. Manual tasks might be carried out poorly e.g. matching buttons to buttonholes, getting an arm into a sleeve, laying a table, making a bed. Their handwriting might also be quite poor and illegible - letters uneven or poorly spaced, mixture of upper and lower case, due to visual perception dysfunction.

What does this mean?

Reading a catalogue of the effects of Hydrocephalus can be very alarming. However, it should be realised that some people with Hydrocephalus may have very few of these problems. Also, many of those which have been described are found either in untreated Hydrocephalus or when the treatment fails, and when successful treatment has been promptly introduced they often improve or sometimes disappear. On the other hand, the more subtle learning and reasoning problems are usually present in some degree and are very important where a child's development and education are concerned.

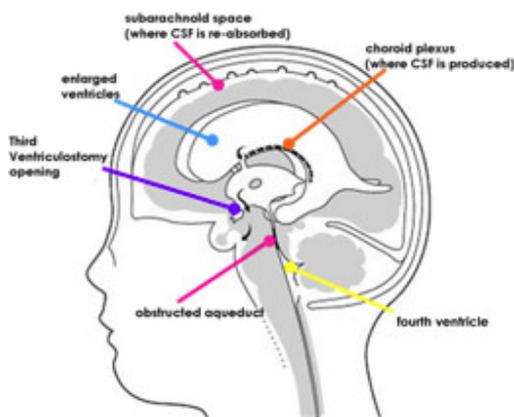
Many of these effects can be reduced through teaching strategies or with treatment where relevant. For further information on specific areas of concern see our Continence, Learning & Teaching, Health Body/Health Mind and Living Your Best Life sections at www.sbhi.ie

It must be stressed that the effects of Hydrocephalus vary from one individual to another and some people will have very few, if any, problems.

HOW IS HYDROCEPHALUS TREATED?

Treatment for Hydrocephalus aims firstly to ease the CSF build-up, and then to ensure that the same situation does not recur. Commonly surgical intervention is required by diverting the excess fluid by placing a synthetic tube (shunt) into the ventricle. Less common is a surgical procedure called Endoscopic Third Ventriculostomy (ETV) which may be a useful alternative to shunting in some cases of Hydrocephalus. For more specific information see “What is ETV?” and “What is a Shunt”

What is Endoscopic Third Ventriculostomy (ETV)?



Endoscopic Third Ventriculostomy (ETV) is a one-time procedure; an opening is created in the floor of the third ventricle using an endoscope placed within the ventricular system through a burr hole. This allows the movement of cerebrospinal fluid (CSF) out of the blocked ventricular system and into the interpenduncular cistern (a normal CSF space) thereby shortcutting any obstruction. ETV is used to treat certain forms of obstructive Hydrocephalus, such as aqueductal stenosis.

The objective of this procedure is to normalise pressure on the brain without using a shunt. ETV is not a cure for Hydrocephalus, but rather an alternate treatment.

Although open ventriculostomies were performed as early as 1922, they became a less common method of treating Hydrocephalus in the 1960s, with the advent of shunt systems. Despite recent advances in shunt technology and surgical techniques, however, shunts remain inadequate in many cases. Specifically, extracranial shunts are subject to complications such as blockage, infection, and over-drainage, often necessitating repeated surgical revisions. For this reason, in selected cases, a growing number of neurosurgeons are recommending endoscopic third ventriculostomy in place of shunting.

The ultimate goal of ETV is to render a shunt unnecessary. Although Endoscopic Third Ventriculostomy is ideally a one-time procedure, evidence suggests that some patients will require more than one surgery to maintain adequate opening and drainage.

Who Is a Candidate for ETV?

Recent studies point to three factors most responsible for successful ventriculostomies:

- Age (the individual should be over six months old)
- The prior presence of a shunt
- A diagnosis of non-communicating Hydrocephalus (obstructed ventricular pathways)

New Technologies

The revived interest in ventriculostomy as a viable alternative treatment approach is largely due to the development of a new technology called neuroendoscopy, or simply endoscopy. Neuroendoscopy involves passing a tiny viewing scope into the third ventricle, allowing images to be projected onto a monitor located next to the operating table. The neurosurgeon thus has a clear view of the inside of the ventricular system during surgery.

How Is Success Defined?

“Success” in terms of this procedure is usually considered (by patients and doctors alike) to be avoiding a shunt in a patient who would otherwise require one. Most doctors would categorise endoscopic third ventriculostomy as successful if a patient later shows clinical evidence of normal intracranial pressure (ICP) and structural evidence of stable or decreased ventricular size. If a patient was previously shunted, the shunt must be either removed or proved non-functional to demonstrate success.

What Are the Potential Complications?

With new technologies, such as high-resolution MRI allows doctors to clearly perceive the absence of flow through a stenosed or occluded aqueduct, while neuroendoscopic procedures offer unprecedented views from within the ventricular system.

The most common complications of endoscopic third ventriculostomy are fever and bleeding. There can be an increase in CSF temperatures, sometimes causing fever due to the equipment used during this procedure. Attempts to perforate the ventricular floor can lead to bleeding, as can damage to ventricular walls or perforation of the basilar artery. Large bleeds due to vessel injury under the third ventricle may occur but they are rare.

Short-term memory loss is another potential complication of endoscopic third ventriculostomy, since the procedure may affect the areas responsible for memory. However, given time, an individual usually recovers from any short-term memory loss.

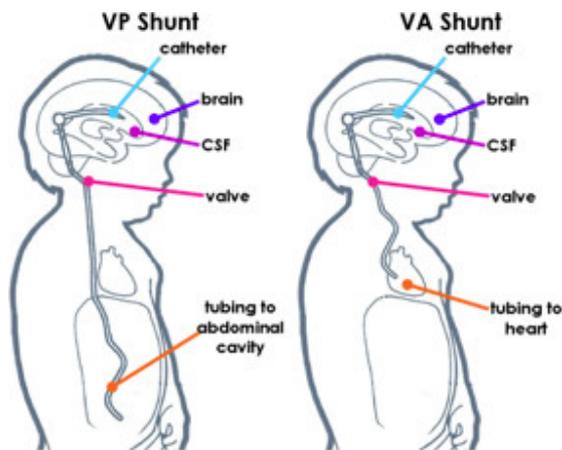
Because the area of the third ventricle where the opening is made is responsible for some hormonal function, there is also a possibility of sexual dysfunction this is often short-lived. Diabetes insipidus is another transient complication.

Although endoscopic third ventriculostomy can ideally lead to the much-desired result of a shunt-free life, doctors caution that this procedure is not appropriate for everyone. Still,

for those who meet the criteria, endoscopic third ventriculostomy offers the possibility of freedom from shunt dependency.

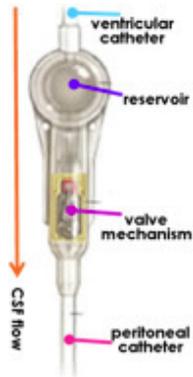
WHAT IS A SHUNT?

A Mechanical Device Which Transports CSF



A shunt is a mechanical device designed to transport the excess CSF from or near the point of obstruction to a re-absorption site and it is implanted under the skin. A shunt is a tube that diverts the excess fluid from the expanded brain cavity (ventricle) to another part of the body. This procedure re-directs the fluid to another body cavity such as the abdomen. This is called a VP shunt (Ventricular-Peritoneal shunt). In some cases, the fluid is diverted one of the chambers of the heart. This is called a VA shunt (Ventricular-Atrial shunt).

A shunt is usually composed of three parts: a silicone catheter that enters the enlarged ventricle; a one-way valve that only allows flow away from the ventricle; and tubing which enters the cavity that is to receive the fluid. Each valve is designed to operate at a set pressure, so that a high-pressure valve will allow less fluid to flow through it than a low-pressure valve. A variety of valve designs are available and efforts are constantly underway to improve them.



Newborns and infants often are implanted with a fixed shunt, when they are older and in need of a revision, the doctor may then decide to replace the valve and reservoir unit with a programmable one.

Although, shunting systems represent a major medical breakthrough, some are still left vulnerable to complications, most notably obstruction or infection of the shunt. However, most people diagnosed with Hydrocephalus live full and active lives.

SHUNT COMPLICATIONS

Shunts remain the mainstay of treatment for Hydrocephalus and, in the majority of cases, this remains an effective treatment.

However, they can never perfectly mimic normal physiology and, like any mechanical device, they are prone to malfunctions of various sorts.

Knowing what symptoms to watch for will help you become more at ease. If you suspect there is a problem with the shunt, you are advised to have it checked by the neurosurgeon rather than ignore it. It is better to have a false alarm checked than to leave it unattended. Remember, although shunt complications can be very serious, they can almost always be treated successfully when they are discovered early.

Types of Complications

In most cases, shunts are intended to stay in place for life, although alterations or revisions might become necessary from time to time.

Possible complications of shunts in the treatment of Hydrocephalus may include, but are not limited to:

- Mechanical failure
- Infections
- Obstructions

- The need to lengthen or replace the catheter.

Generally, Hydrocephalus shunt systems require monitoring and regular medical follow-up. When complications do occur, usually the shunt system will require some type of revision.

Shunt malfunction is usually a problem with a partial or complete blockage of the shunt. The fluid backs up from the site of the obstruction and, if the blockage is not corrected, almost always results in recurrent symptoms of Hydrocephalus.

Shunt infection is usually caused by a person's own bacterial organisms; it is not acquired from exposure to other children or adults who are ill.

Over-draining occurs when the shunt allows CSF to drain from the ventricles more quickly than it is produced.

Under-draining occurs when CSF is not removed quickly enough and the symptoms of Hydrocephalus recur.

Signs & Symptoms of a Shunt Complication

Shunt blockage, along with shunt infection, remains the most common cause of a shunt malfunction. In the vast majority of cases of shunt blockage prompt investigation and revision of the shunt is associated with full recovery and discharge from hospital within a few days. In rare situations shunt blockage can be fatal, particularly when the diagnosis is delayed.

Symptoms of shunt malfunction vary considerably from person to person, but tend to be similar each time for a particular person.

Infants	Toddlers	Children & Adults
Enlargement of head*	Enlargement of head*	Headaches*
Full or tense fontanelle*	Fever	Vomiting*
Swelling or redness on shunt tract*	Swelling or redness on shunt tract*	Fever
Fever	Vomiting*	Swelling or redness on shunt tract
Irritability	Headache*	Irritability
Seizures	Sleepiness	Ataxia*
Sunset eyes (eyes looking downward)	Seizures*	Personality changes
	Irritability	Visual disturbances*
		Decline in academic performance*
		Decline in motivation*
		Confusion*
		Seizures*
		Sleepiness*

Incontinence*

Pay Particular Attention to Symptoms Marked *

People, who were diagnosed and treated in adulthood, including those with Normal Pressure Hydrocephalus, tend to revert to the symptoms they experienced before initial treatment during a malfunction.

Less common symptoms include seizures, abdominal swelling and cranial nerve palsies. If a shunted child becomes unwell, it's important that the possibility of a shunt complication is considered as soon as possible.

Although the early symptoms of shunt malfunction or infection in children—fever, vomiting and irritability—are similar to many childhood illnesses; you will learn to determine the symptoms associated with shunt complications in a particular individual.

ANYONE WITH A SUSPECTED SHUNT BLOCKAGE (OR MALFUNCTION OF THIRD VENTRICULOSTOMY) NEEDS TO CONTACT THEIR SPECIALIST NEUROSURGICAL UNIT WITHIN 4 HOURS OF ACUTE SYMPTOMS DEVELOPING FOR ADVICE

Protocol for Suspected Shunt Complications

For those living WITHIN County Dublin:

UNDER the age of 16

1. Go directly to Accident & Emergency Department at Children's University Hospital, Temple Street (The team are on call 24 hours a day 7 days a week) on 01 878 4200
2. Give the A & E medical staff your Shunt Alert Card
3. Ask the A & E medical staff to contact the Neurosurgical Team as a matter of urgency. Do Not Let Them Leave A Message With The Neurosurgical Team – Make Sure They Speak To A Member Of The Team
4. Inform the Next of Kin

OVER the age of 16

1. Go directly to Accident & Emergency Department at Beaumont Hospital (the team are on call 24 hours a day 7 days a week) on 01 809 3000
2. Give the A & E medical staff your Shunt Alert Card
3. Ask the A & E medical staff to contact the Neurosurgical Team as a matter of urgency. Do Not Let Them Leave A Message With The Neurosurgical Team – Make Sure They Speak To A Member Of The Team
4. Inform the Next of Kin

For those living OUTSIDE County Dublin:

UNDER the age of 16

1. Go directly to your nearest Accident & Emergency Department.
2. Give the A & E medical staff your Shunt Alert Card
3. Ask the A & E medical staff to contact the Neurosurgical Team at Children's University Hospital, Temple Street (The team are on call 24 hours a day 7 days a week) on 01 878 4200 as a matter of urgency. Do Not Let Them Leave A Message With The Neurosurgical Team – Make Sure They Speak To A Member Of The Team
4. Inform the Next of Kin

OVER the age of 16

1. Go directly to your nearest Accident & Emergency Department.
2. Give the A & E medical staff your Shunt Alert Card
3. Ask the A & E medical staff to contact the Neurosurgical Team at Beaumont Hospital (the team are on call 24 hours a day 7 days a week) on 01 809 3000 as a matter of urgency. Do Not Let Them Leave A Message With The Neurosurgical Team – Make Sure They Speak To A Member Of The Team
4. Inform the Next of Kin

ANYONE WITH A SUSPECTED SHUNT BLOCKAGE (OR MALFUNCTION OF 3RD VENTRICULOSTOMY) NEEDS TO CONTACT THEIR SPECIALIST NEUROSURGICAL UNIT WITHIN 4 HOURS OF ACUTE SYMPTOMS DEVELOPING FOR ADVICE

Diagnosing a Shunt Complication

Diagnosing shunt complication is not always straightforward. Commonly there will be an alternative explanation for the symptoms for example ear infection, common colds etc. In fact, parents can be as successful at diagnosing shunt blockage as GPs and paediatricians.

Whilst additional investigations such as CT scan, plain X-rays and a shunt tap may be decisive, a definitive diagnosis is sometimes only possible through surgery.

Shunt Alert Cards



A small information card stating the type of shunt a person has and the symptoms of malfunction. Mainly for use in emergency situations, is available through SBHI or your Family Support Worker.

Referral Procedure

If you have not been seen by a neurosurgeon in the last 5 years and had your shunt checked, you will need to be re-referred to Beaumont Hospital for those over 6 years of age and Children's University Hospital, Temple Street for those under the age of six via your GP or Family Support Worker.

Baseline Scans

Even though you are not experiencing any problems with your shunt; it is advisable that a baseline scan is taken when you are well. This will help to determine treatment, should you develop any pressure problems, ie the consultant will know the size of your ventricles when well. If you have not had a scan in the last 5 years, you may need a referral - see referral procedures above.

Eye Examinations

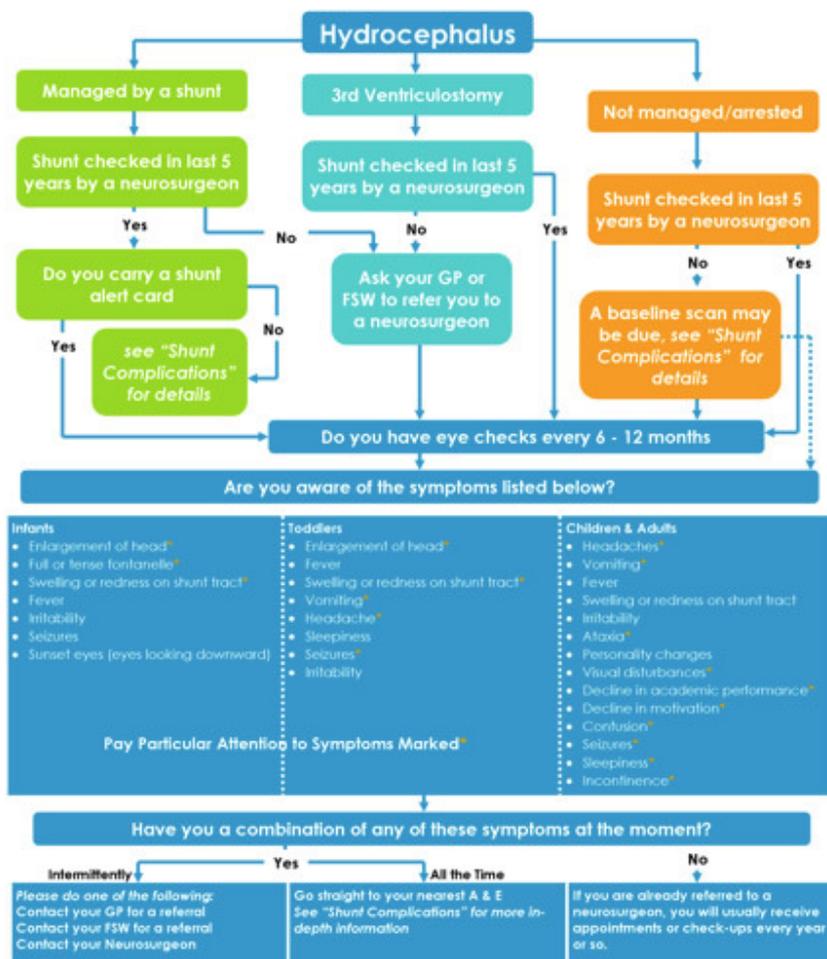
Individuals with a shunt are advised to have eye checks every 6 months. Raised intracranial pressure may cause pressure at the back of the eyes. Eye checks therefore assist early diagnosis

SHUNT ALERT CARDS



A small information card stating the type of shunt a person has and the symptoms of malfunction. Mainly for use in emergency situations, is available through SBHI or your Family Support Worker.

SHUNT MANAGEMENT



HYDROCEPHALUS & SPINA BIFIDA

Spina Bifida is a relatively common condition, which affects about one in every 1000 children born per year in Ireland. Ireland has one of the highest incidences of Spina Bifida births in the world. Spina Bifida is the most common neural tube defect (NTD) which causes incomplete development of the spinal cord. Translated, it literally means 'split spine'. While it is a Hydrocephalus is a complication of Spina Bifida occurring in approximately 90 % of cases, it is by no means exclusive to Spina Bifida. For more information, visit our Spina Bifida page.

HYDROCEPHALUS & EPILEPSY

About 1:3 children with Hydrocephalus will develop epilepsy which will be treated by a neurologist. (Ref: www.asbah.org)

Although epilepsy is commonly associated with shunt-treated Hydrocephalus, its relation to the shunting procedure and the criteria identifying postoperative epilepsy remain controversial. The complications of CSF shunt surgery seem to play a relatively minor role in the development of epilepsy.

For many children no cause is identified. Where causes are known they range from genetic and inherited conditions, head injury, brain infections (meningitis/encephalitis), developmental brain disorders, birth injuries, cerebral palsy, Hydrocephalus and more rarely tumours

HYDROCEPHALUS & HEADACHES

It is not uncommon for people with Hydrocephalus to experience headaches. This information will discuss headaches and Hydrocephalus in an attempt to give a better understanding of the issues.q/

Individuals with Hydrocephalus shunted or not, are frequently troubled by headaches. A diagnosis of the cause of headaches can be difficult and complicated, and, as with the management of any chronic pain, it requires tremendous patience on the part of the person with Hydrocephalus and the GP or Consultant.

Possible Causes of Headaches

Dr. Harold L. Rekate, Chief of Paediatric Neurosurgery at the Barrow Neurological Institute in Phoenix, Arizona, suggests five different reasons for headaches in a person with Hydrocephalus:

- Intermittent proximal shunt obstruction. This is often referred to as the classic ‘slit ventricle syndrome.’ Frequently the headaches last from 10-90 minutes and resolves on their own. Often occurring in the late afternoon, they can happen at any time. The headache can be severe, and may be associated with vomiting, photophobia (aversion to light), and it can resemble, to some extent, a migraine.
- Small ventricles when the shunt fails and the ventricles can’t grow to accommodate cerebro spinal fluid (CSF). This is more severe in people whose headaches come and stay; are present mostly in the morning, and can be associated with double vision. Their headaches are usually progressively more severe.
- Intermittent failure of the shunt can produce a variety of headaches. The length of time that failure occurs is indeterminate and not predictable.
- Extremely low shunt pressure can cause headaches that are similar to spinal headaches. In these cases, headache complaints are minimal when the patient is lying down but become more severe when the patient sits up or stands.
- Migraine, a common affliction, can also occur in a person with Hydrocephalus. Often there is a positive family history. Varying degrees of neurological dysfunction, headaches, vomiting, difficulty with vision and impairment of consciousness (including stupor) have been documented. Migraine attacks in shunted children and adolescents can create a disconcerting clinical situation for the patient, the family and the physician.

Dr. Gordon McComb, Head of Neurosurgery at Children’s Hospital in Los Angeles, identifies similar reasons for headaches, but he narrowed them down to just three causes: migraine, shunt failure and low pressure.

Mechanics

Brain volume, blood volume and CSF volume determine intracranial pressure (ICP). If one of these goes up, pressure in the brain will rise unless one of the others compensates by decreasing. In Hydrocephalus, this balance is distorted and an unnatural condition takes place. Under normal conditions, a person should have one ounce of spinal fluid in the ventricles and about four ounces of spinal fluid around the outside of the brain. When all the components of the brain are functioning, without a shunt, the brain has the ability to be elastic. That is, an increase in volume means an increase in pressure (and vice versa), the brain is compliant, or able to adapt. When a shunt is in place, the brain’s ability to compensate for things like coughing, or straining at stool, disappears.

Additionally, when we enter REM sleep, about 80-90 minutes after we fall asleep, plateau waves and high intracranial pressure (CIP) develop. In people with shunts who undergo ICP monitoring overnight, those changes are dramatic. The things that cause

pressure to go up create huge changes in the ICP of people who have been shunted. Under REM sleep, the normal rise of the ICP pressure is absent and is accentuated by the fact that there is no compliance. That is, there is no extra spinal fluid in the brain to be able to be displaced. The placing of a shunt creates an unnatural situation. The brain fills the intracranial space while the shunt drains essentially all of the available CSF from the ventricles. The result is a large brain in a fixed (NOT elastic) solid skull, with very little room for changes in intracranial pressure. If changes in cerebral blood flow occur, resulting in increased blood volume in the intracranial space, then increased intracranial pressure will result, possibly causing a headache.

Headaches can be related to the altered pressures inside the skull once the shunt is placed. They can occur when the intracranial pressure is too high, and also when the intracranial pressure is too low. And what's too high for one person can be too low for another.

Treatment

Children and adults with Hydrocephalus have headaches, just like everyone else. It is the frequency and severity, suggests Dr. McComb, which determines the possible relationship between Hydrocephalus and headaches. "If the headaches are getting progressively worse, many times it's (due to) an intermittent malfunction of the shunt. We change the proximal end of the shunt and that's it. (The upper end of the shunt is the proximal end, and the bottom end is the distal.) "Just because a CT scan does not show enlarged ventricles does not mean that the shunt is not working. In a given percentage of cases, the ventricles are going to remain the exact same size whether the pressure is normal or elevated," adds Dr. Rekate. With slit ventricle syndrome, argues Dr. McComb, small ventricle size is not the problem. The problem occurs if the shunt clogs and the ventricles don't dilate (get larger). If this happens repeatedly, and headaches accelerate, it often means that there is a blockage of the shunt that builds up and then releases, and builds up and releases. Again, replacing the proximal ventricular catheter, the part of the shunt that is plugged, often takes care of the problem, and relieves the headache.

One of the things that both Drs. Rekate and McComb recommend is sketching out a plan of action. This involves a patient-doctor conference where a time line and course of action are established. "We'll set up parameters and if these parameters are exceeded, then we'll go ahead and fix the shunt. So, if the headaches occur at such and such a frequency and continue getting more frequent, the criteria have been put into place to change the shunt." Both physicians suggest that it is very important to put all of the various pieces together to get a perspective, as well as to individualize the care of each and every patient.

Drs. Fred Epstein and Rick Abbott, of Beth Israel Hospital in New York City, and Jeffrey H. Wisoff, of New York University Medical Center, suggest that difficulties in the diagnosis and treatment of headaches arise when there have been no changes in ventricular size and headache symptoms are of a more chronic, non-progressive nature. This can be caused by intracranial hypotension (low) or intracranial hypertension (high). They and their colleagues recommend Intracranial Pressure Monitoring (ICP) for severe, persistent cases where CT or MRI demonstrates no enlargement of the ventricular

system. ICP monitoring involves hospitalizing the patient for a day or two, inserting the monitoring device and continually measuring the pressure inside the brain. The patient is alert and active so that pressures can be recorded in relation to body position and activity. If the pressure changes can be correlated with the patient's symptomatology, the shunt can then be revised with either a higher or lower pressure valve. Dr. McComb suggests that another way to test shunt function is to inject a tracer into the shunt and do a flow study.

The cause of many headaches can be related to the altered pressures and functions inside the head once a shunt has been placed. "Unfortunately," say Dr. Rekate, "The perfect valve is one you don't have to put in." Today, most of the valves are pressure differential valves which react to the pressure above versus the pressure below. The valve can't tell the difference between 300 and 100 because the pressure differential is the same. Research continues on flow regulated valves as well as shunts that are programmable.

Dr. Jack Walker, past President of the American Society of Paediatric Neurosurgeons, suggest that in some cases when intracranial compliance is extremely low, treating patients with migraine therapy will often produce an improvement because of the stability provided to the intracranial vasculature by such medication. "Dilation of cerebral vessels and increased blood flow may not occur as often due to the vasoactive drugs and stabilization of the patient's intracranial blood flow. Relief of the symptoms may occur even though the symptoms were not caused by a true migraine mechanism."

The criteria for establishing the diagnosis of migraine includes "Recurrent headaches with symptom-free intervals, as well as nausea, vomiting, abdominal pain, hemicrania, throbbing pulsating pain, complete relief after rest, aura and a family history of migraine," states Drs. Hector James and Thomas Nowak of Children's Hospital of San Diego. When a protocol of shunt testing scans, and ICP monitoring, and perhaps shunt revision with a valve change have failed to alleviate the condition, management with medications for migraine may be indicated. Propranolol, Periactin and Inderal are just a few of the medications prescribed for migraine control.

Conclusion

Hydrocephalus is not a disease; it is the brain reacting to a blockage. Placement of a shunting device is currently the most common way to control this blockage. However, as noted above, shunting creates an unnatural condition. While a number of people shunted for Hydrocephalus have few or no problems with their shunts, the limited statistics that are available suggest that more than 50% will need some kind of revision. Because headaches can be an indication of malfunction or obstruction, establishing a mutually respecting relationship with your neurosurgeon and your medical team, is the best way to insure continued, comprehensive care.

The occurrence of headaches in children and adults with Hydrocephalus, especially if recurring, can be a complicated problem that requires tremendous patience thorough medical attention and an agreed up plan of action.

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Hector E. James, MD and Thomas P. Nowak, MD, Department of Neurosciences, Children's Hospital of San Diego, "Clinical Course and Diagnosis of Migraine Headaches in Hydrocephalus Children."

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SUPPORT & RESOURCES

Family Support Service

The aim of the Family Support Service is to work with our members, their families and carers, by providing guidance and information in an environment which is conducive to their needs.

The Family Support Worker (FSW) will visit individuals and/or families in their own home, in hospital, in school or in the work place. The nature and delivery of our service is a direct response to the needs of our members, their families and carers.

We provide information, support and guidance from the time of diagnosis, which can occur during pregnancy or at the time of birth, through to adulthood. We also provide healthcare professionals, education professionals and those working within the disability sector with information, resources and guidance, ensuring that our members receive the best possible provisions from their multidisciplinary team.

The role of the FSW is very diverse and is guided by the needs of our members, their families and carers. Our aim is to work with our members, their families and carers by providing guidance, advocacy, emotional and practical support. For further information visit the [Family Support](#) page or email the Family Support Team at familysupport@sbhi.ie.

Youth and Respite Service

The Youth and Respite Service provides services nationally to people with Spina Bifida and/or Hydrocephalus, their families and carers.

Its aim is to provide and develop respite and youth services that are conducive to the changing needs of our members.

We encourage our members to enjoy a healthy, social, active and fulfilled life, to avail of all education and employment opportunities and to promote the development of a progressive society that is inclusive, aware and accessible to all. For further information visit the [Youth and Respite](#) page or email the Youth and Respite Team at SHINE@sbhi.ie.

Health Service Executive

Disability Services

The HSE provides a range of services for people with intellectual, physical and sensory disabilities or autism. These services include basic health services as well as assessment, rehabilitation, income maintenance, community care and residential care.

Some services are provided directly by the HSE. Many of the community, residential and rehabilitative training services are provided by voluntary organisations with grant aid from the HSE.

For further information visit

http://www.hse.ie/eng/services/Find_a_Service/Disability_Services/ or phone the HSE information line on 1850 24 1850

Disability Assessment of Need

On June 1 2007, Part 2 of the Disability Act 2005 became law for children under 5 years of age. Under Part 2 of this Act, children with disabilities have a right to:

- an independent assessment of their health and educational needs arising from their disability
- an assessment report
- a statement of the services they will receive
- make a complaint if they are not happy with any part of the process.

Who can apply for an assessment?

Any parent who feels that their child aged under 5 may have a disability can apply for an assessment. An application can also be made by a guardian.