Condition Insight Report (CIR)

Hydrocephalus

Created 12/12/2022

Version 1.0

Overview

What is the condition usually called/ any abbreviations used?

Hydrocephalus

Brief overview of the condition

Hydrocephalus is a build-up of fluid in the brain. The excess fluid puts pressure on the brain, which can damage it.

If left untreated, hydrocephalus can be fatal.

Different types of hydrocephalus can cause specific symptoms.

There are 3 main types of hydrocephalus:

•**Congenital hydrocephalus** – hydrocephalus that's present at birth

•**Acquired hydrocephalus** – hydrocephalus that develops after birth

•**Normal pressure hydrocephalus** – usually only develops in older people

Presenting Symptoms

The damage to the brain from hydrocephalus can cause a wide range of symptoms, including:
•Headaches
•Vomiting
•Blurred vision
•Difficulty walking

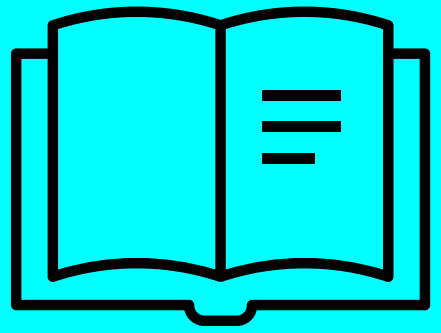
Hydrocephalus present from birth
Congenital hydrocephalus is when a baby is born with excess fluid in their brain.
It can be caused by a condition such as spina bifida, or an infection the mother develops during pregnancy, such as mumps or rubella (German measles).
Many babies born with hydrocephalus (congenital hydrocephalus) have permanent brain damage.
This can cause several long-term complications, such as:
•learning disabilities
•speech problems
•memory problems
•short attention span
•problems with organisational skills
•vision problems, such as a squint and vision loss
•problems with physical coordination
•epilepsy

Hydrocephalus that develops in children or adults
Acquired hydrocephalus can affect children or adults. It usually develops after an illness or injury.
For example, it may happen after a serious head injury or as a complication of a medical condition, such as a brain tumour.

Normal pressure hydrocephalus (NPH)
Normal pressure hydrocephalus (NPH) is an uncommon and poorly understood condition that most often affects people over the age of 60.
It can sometimes develop after an injury or a stroke, but in most cases the cause is unknown.
Mobility problems, dementia and urinary incontinence are the main symptoms of NPH. But because these symptoms happen gradually and are similar to those of other, more common conditions, such as Alzheimer's disease, NPH can be difficult to diagnose.

Fluctuations

- **Living with a shunt is not a cure, people often experience worse days than others, with severe head pain, ‘brain fog 'or mental fatigue.**
- **Some people report this varies according to the weather. People often report being in stressful situations affects their cognitive abilities.**
- **Basic physical ability is usually constant.**
- **Energy levels, pain, dizziness and nausea can fluctuate**



Click here to read all about Shana’s story living with hydrocephalus.

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY	TIMELY	ACCEPTABLE STANDARD	REPEATEDLY
Do they have any symptoms which could cause a safety consideration?	For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?	How have they adapted to completing tasks over time – is this different to what might be considered ‘normal’?	Are they able to repeat a task as often as required? Is this the same every day?
Often people who have been diagnosed with hydrocephalus may have learning difficulties and poor concentration. This may impact their ability to safely complete activities such as cooking and completing journeys.	Someone with Hydrocephalus may have poor short-term memory and organisational skills, making it difficult to complete tasks in a timely manner. They may feel they have adapted, however, it is imperative to establish how long a task takes them.	If the person was diagnosed with hydrocephalus at birth they may feel they have adapted to doing tasks in a certain way. As poor co-ordination is a common symptom, you must ensure tasks are being completed to an acceptable standard.	Energy levels can often be reduced due to this condition and consequently someone may be able to complete a task, but this has a detrimental impact on how they feel after.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

There is often nothing to suggest a person has hydrocephalus, it is very much a ‘hidden’ condition. Also, people with hydrocephalus may not be aware of the impact of their behaviour on other people or recognise the full impact of their cognitive issues, so not mention them.

Customer Care

- Create a quiet, relaxed environment
- Ask short concise questions
- Allow time for the questions to be processed and a reply to be constructed
- Avoid interrupting where possible
- Allow carers/relatives to prompt and support
- Ask open questions about ability to learn new tasks

Diagnosis and Treatment

A diagnosis of hydrocephalus is usually based on:

• Answers to the doctor's questions about signs and symptoms
•A general physical exam
•A neurological exam
•Brain-imaging tests

Brain imaging may include an ultrasound, MRI or CT scan.

Shunt

The most common treatment for hydrocephalus is the surgical insertion of a drainage system, called a **shunt**. It consists of a long, flexible tube with a valve that keeps fluid from the brain flowing in the right direction and at the proper rate.
One end of the tubing is usually placed in one of the brain's ventricles. The tubing is then tunnelled under the skin to another part of the body — such as the abdomen or a heart chamber — where the excess fluid can be more easily absorbed.
People who have hydrocephalus usually need a shunt system for the rest of their lives. They require regular monitoring.

Endoscopic third ventriculostomy

Endoscopic third ventriculostomy is a surgical procedure that can be used for some people. The surgeon uses a small video camera to see inside the brain. The surgeon makes a hole in the bottom of one of the ventricles or between the ventricles to enable cerebrospinal fluid to flow out of the brain.

Other treatments
Some people with hydrocephalus, might need additional treatment, depending on the severity of long-term complications of hydrocephalus.

Care teams might include the following:

•**Neurologist,** who specializes in the diagnosis and treatment of neurological disorders
•**Occupational therapist,** who specializes in therapy to develop everyday skills
•**Developmental therapist,** who specializes in therapy to help someone to develop age-appropriate behaviours, social skills and interpersonal skills
•**Mental health professional,** such as a psychologist or psychiatrist

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Someone with Hydrocephalus may struggle with both the physical and cognitive element of cooking. If they have dizziness or fatigue this could impact standing tolerance and co-ordination difficulties may impact upper limb use.

Also, if there are cognitive delays due to their conditions, there may be risks present in the kitchen that they are unable to manage without support.

Remember in PIP…

The claimant needs to be able to complete this activity safely. Can they tell food is cooked? Are they safe with knives or around flames? Are they easily distracted? Do they require prompting? Also, does their co-ordination impact their ability to chop food? Do they have seizures?

Activity 2: Taking nutrition

If someone has poor co-ordination this may impact their ability to cut up food and bring it to their mouth.

If they have a learning disability, they may not prioritise the need to eat or recognise hunger.

Remember in PIP…

It should be adequately probed if a claimant can safely eat. Do they need supervision? Are they eating things that would not be considered food/edible? Do they require prompting throughout the duration of the meal? Is there history of choking? Are they spilling food due to poor co-ordination?

Activity 3: Managing therapy and monitoring a health condition

Someone with a hydrocephalus may be having ongoing therapy such as speech and language therapy or physiotherapy. It must be explored if they need assistance with this within the home environment. They may also have other conditions that require the use of regular medications. If they have short term memory loss, this may impact ability to manage medications.

Remember in PIP…

If they do take medication, do they remember to take it? Do they prioritise their health? Do they need prompting? Do they complete any therapy in the home environment which may require assistance? If so, how long for?

Functional Impact

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Activity 4: Washing and Bathing

People with hydrocephalus may struggle to maintain personal hygiene or recognise the requirement to wash regularly if there are learning disabilities as a result. They may also have difficulties physically washing due to dizziness, fatigue or poor co-ordination.

Remember in PIP…

Do they understand the requirement to wash and keep clean? Do they need prompting to wash to an acceptable standard? Would prompting suffice or is the cognitive impairment to the extent they require assistance? Also, could they safely access an un-adapted bath? Do they experience dizziness? Is there a history of falls? Do they have seizures?

Activity 5: Managing toileting needs and incontinence

People with hydrocephalus may experience incontinence. Learning disabilities may mean they need prompting to manage their toilet needs and dizziness may impact their ability to sit and stand from the toilet.

Remember in PIP…

Can they physically sit and stand from the toilet and clean themselves after? Do they require any aids? Do they need prompting to clean themselves after using the toilet?
If they have incontinence, can they manage this themselves?

Activity 6: Dressing and undressing

If there are learning disabilities secondary to hydrocephalus, the person may require prompting and support to select appropriate clothing or change clothing. Short term memory loss may also impact this. Poor co-ordination may make it difficult for someone to physically dress without assistance.

Remember in PIP…

Do they understand the requirement to change their clothing regularly? Do they need prompting to dress to an acceptable standard or appropriate to the weather/environment? Would prompting suffice or is the cognitive impairment to the extent they require assistance? Can they physically manage buttons? Do they have to sit to dress?

Functional Impact

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Activity 7: Communicating Verbally

People with cognitive difficulties often have extensive difficulties communicating their needs and wishes. This may include not being able to speak or only having a few words, signs or gestures.

Remember in PIP…

The claimant must be able to both express **and** understand verbal information? How do they communicate in education or at home? Does information need breaking down for them to process it?

Activity 8: Reading and understanding signs and symbols

People with cognitive difficulties often have difficulties with word recognition, fluency, or below average cognitive ability. Their difficulty is with reading and comprehension. Up to 80% of people with learning disabilities have difficulties learning to read.

Remember in PIP…

Complex written information is considered more than one sentence. If they report the ability to read, can they understand what they have read? What support do they have at school? What can they read? Can they manage magazines, internet or text messages?

Activity 9: Engaging with others face to face

Lots of people with cognitive difficulties will lack awareness of social boundaries and may lack social and emotional skills. This may lead to vulnerability and difficulties coping and engaging with unfamiliar people. They may also be over familiar with others, putting them at risk of harm.

Remember in PIP…

We must consider someone's ability to safely engage. Although someone may like to engage with others, are they vulnerable? Do they go out alone? Who can support? Remember in cases where vulnerability is evidenced, prompting would not be appropriate and social support, as a minimum, would apply.

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Ability to budget may be impacted by poor short term memory, cognitive delay and poor organisational skills.

Remember in PIP…

The context of complex and simple budgeting. Can they understand change in a shop? Could they manage household finances? Could they plan for a future purchase? Do they have someone appointed to manage their finances?

Activity 11: Planning and following a journey

Some people with hydrocephalus will struggle to plan new routes, but also be restricted by difficulties with short term memory loss, poor organisational skills and cognitive deficit which impacts their ability to safely complete familiar journeys.

Some people may also experience seizures impacting their ability to safely plan and follow journeys.

Remember in PIP…

We must explore both familiar and unfamiliar journeys. How do/did they get to and from education? How do they travel now? Can they go out alone? If not, why not? Are they safe? Could they manage a diversion? How would they plan a new route? Do they have road safety awareness?
Also, do they experience seizures?

Activity 12: Moving Around

Some people may experience dizziness, poor co-ordination and fatigue as a result of their hydrocephalus which impacts their ability to mobilise reliably.

Remember in PIP…

If someone reports fatigue or dizziness, ensure you explore their ability to mobilise. Where can they walk? How far is this? How long does it take? Can they repeat? Does pace reduce? Do they require aids? Have they had falls?

Additional reading or other resources

EXTERNAL

Hydrocephalus - NHS (www.nhs.uk)

Hydrocephalus Fact Sheet | National Institute of Neurological Disorders and Stroke (nih.gov)

Shine - Spina Bifida & Hydrocephalus (shinecharity.org.uk)

Hydrocephalus | Headway

INTERNAL

Learning Disability-CIR

Spina Bifida-CIR