Flashcards hydrocephalus



- **These flashcards contain information about working with people with hydrocephalus in low resource areas.**
- **These flashcards are made for the use of fieldworkers.**
- **These flashcards are based on the information about hydrocephalus from the RehApp.**



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The goals of the flashcards are:

- To meet the needs of people with disabilities and their families.
- To improve knowledge and skills of fieldworkers in providing basic (functional) rehabilitation services for people with disabilities and their families.
- To enhance participation in daily, family and community life.
- To improve the quality of life of people with disabilities and their families.
- To support you (as fieldworker) in the process of guiding a family by providing you with a resource you can keep with you on your phone (offline) or in your bag.

What can you do with these flashcards:

- To help guide your visits to families that have a family member with hydrocephalus.
- Make an inventory of the needs of the person with hydrocephalus and his/her family.
- Learn about the implications of a disability for the person and their family.
- Use them to do an assessment.
- Use them to set goals for a person with hydrocephalus.
- Use them to help you discuss interventions with the family.
- Use them to help you keep client records.
- Use them to help you monitor process.

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Note: These flashcards contain information about hydrocephalus. The content is organised according to the ICF domains. These cards don't replace the knowledge and skills of doctors and therapists. We advise you to seek their advice first.

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Hydrocephalus

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Card 1

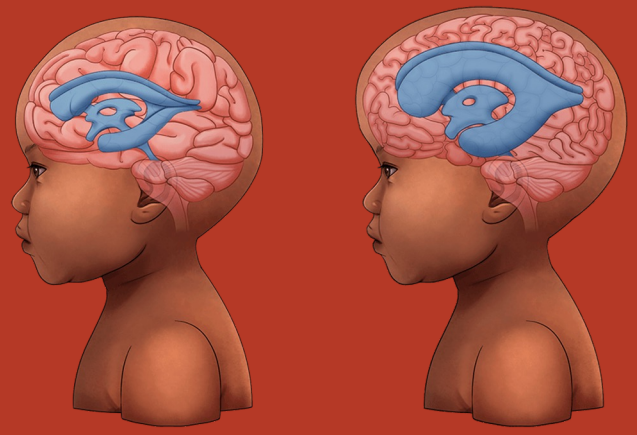
Introduction

What is hydrocephalus?

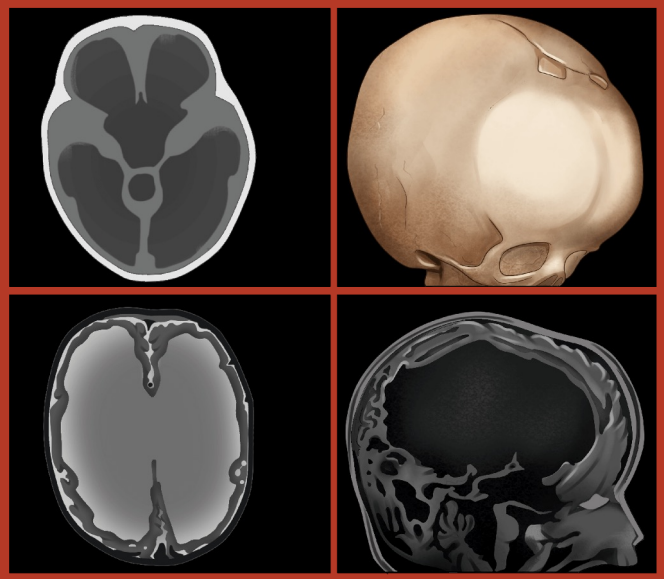
Hydrocephalus (sometimes called “water on the brain”) happens when there is excess fluid in the brain, which creates pressure on brain structures. Hydrocephalus is an **emergency situation**. It must be treated **as soon as possible by an expert surgeon to relieve the pressure and allow normal development of the brain.**

The cerebrospinal fluid in the brain and spinal cord (1) cushions and protects the structures, (2) delivers nutrition and (3) takes away waste products. However, when there is overproduction of the fluid (we often do not know why this happens), or the flow and absorption of the fluid is blocked, hydrocephalus occurs. This may happen in infants, children and adults.

Infants born with spina bifida have an 80% likelihood of having hydrocephalus, but there are also other causes.



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Card 2

Introduction



Possible causes of hydrocephalus

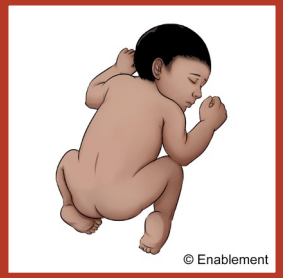
When hydrocephalus is present at birth, some causes are:

- ❑ Associated with spina bifida (see RehApp chapter on spina bifida)
- ❑ Infection during pregnancy affecting the growing fetus
- ❑ Complications of premature births such as bleeding in the brain
- ❑ Narrowing of brain structures causing a blockage to the normal flow of the fluid
- ❑ Malformation or abnormal development of the brain and skull

When hydrocephalus happens during childhood or adulthood it may be due to:

- ❑ Infections such as meningitis (most common)
- ❑ Bleeding caused by head injury, hemorrhagic stroke or after surgery
- ❑ Obstructions of the normal flow of the fluid in the brain and spinal cord
- ❑ Tumors in the brain or spinal cord

Hydrocephalus occurs more often in infants and in adults over the age of 60









Card 3

Introduction
How to recognise?

Signs and symptoms of hydrocephalus

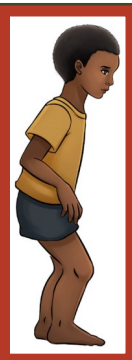
An infant with an unusually big head and bulging in the soft spots of the skull may have hydrocephalus. This means there is excess fluid, and as it increases the head gradually gets larger. The infant may cry, vomit and have seizures.

In children over 1 year, and adults, the skull bones are already fused, so the head cannot expand. Instead, the excess fluid puts increasing pressure on the brain. Older children and adults with hydrocephalus may complain of headaches, fatigue, vomiting, irritability, and problems of balance and walking. They may also have seizures.

Questions to ask: regarding infants are (1) what happened during pregnancy? (2) were there birthing difficulties? (3) what is worrying you about your child? (4) was there a recent child development check? With older children and adults, ask about any recent infections or high fever, head injury or disease. If the condition is mild, the hydrocephalus may not be noticed in the infant, but only later as the child's development is delayed.











Card 4

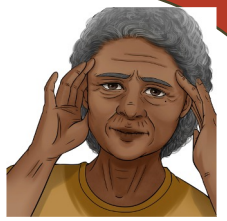
Introduction
How to recognise?



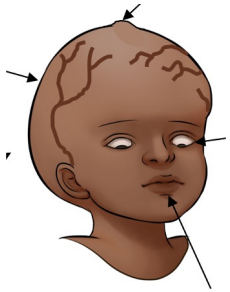


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Infants	Children / Adolescents	Adults / Elderly
Unusually large head size	Nausea, vomiting	Headaches, Neck pain
Rapidly increasing head circumference/size	Swelling of the discs in the eyes Blurred/double vision, sunset eyes	Blurred/double vision, or other visual difficulties
Bulging in soft spots of the head	Unsteady walking; poor balance	Nausea, vomiting
Veins visible on the skull	Unusually large head, stunted growth, develeopment delay	Unsteady walking, poor balance and co-ordination
Eyes fixed in looking down (called “sunset sign”)	Irritable, change in personality	Decline in memory, concentration
Poor feeding, vomiting	Poor appetite	Mild dementia (behaviour)
Irritability; high-pitched crying	Loss of control of urination	Loss of control of urination
Sleepiness	Drowsiness, disruption of sleep	Drowsiness; disruption of sleep.
Seizures	Seizures	Seizures
	Sexual maturation starts early	Difficulty in daily living skills















Body functions and structures:

Information and
Actions to take











Card 5

Introduction

Management of hydrocephalus

Non-Surgical Management: to manage the excess fluid production, a licensed specialist doctor may prescribe medications or do a medical procedure with a needle in the spine. These are temporary solutions only.

Surgical Management: is the best way to treat hydrocephalus. The surgeon places a shunt (a flexible tube) between the brain and the belly (usually) to drain the excess fluid from the brain. It remains in place for the person's life. For a few patients, the surgeon can make a new space in the brain for the fluid to drain into. This operation is called "EVT" and is highly specialised. Whichever method is done, most persons with hydrocephalus will require several operations during their lifetime, to keep the drainage open.

Nursing Management: always ensure good hygiene and nutrition. If the child has difficulties with eating, drinking, ask a health or rehabilitation staff for advice.

Rehabilitation Management: when the child is stable and willing to play, begin stimulating normal developmental activities like rolling, sitting, using their hands. With adults, encourage gradually regaining their daily living skills. As their energy level improves, encourage full participation in family and community life. Whether working with a child or adult with hydrocephalus, involve the caregivers **and family members.**



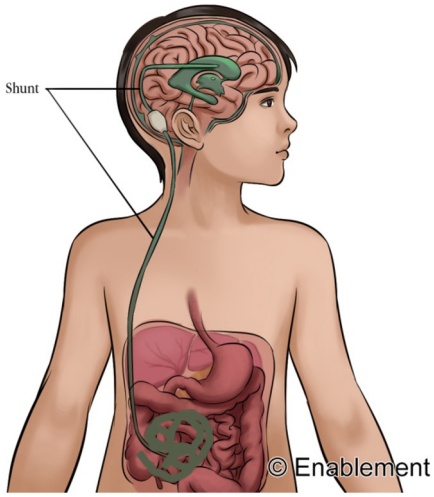


After surgery: signs to be aware of

Not every child with hydrocephalus needs an operation if the size of the head is not increasing rapidly. See card 7 to learn how to measure the head circumference.

However, if the size of the head increases rapidly, a surgical operation inserting a 'shunt' (a tube) may be needed before the pressure of the fluid causes damage to the brain. A tube is run from a liquid-filled hollow in the brain into the belly (abdominal cavity), draining the extra fluid from the brain to the belly.

Problems immediately after surgery: redness, tenderness, pain or swelling around the incision, abdominal pain, fever; and/or previous symptoms, like vision problems, sleepiness, irritability and nausea may reoccur. In this case, please take the patient to the doctor.



Problems with shunts and how to identify

Most children and adults with good working shunts can live normal lives. However, it's important to observe for any signs and symptoms that the shunt is malfunctioning. A problem with the shunt may occur suddenly or slowly.

Problems with the shunts: Shunts may become infected, blocked, twisted or break, in which case the shunt needs to be replaced in another operation. As a child grows, the shunt also needs replacing if it is too short.

Signs of shunt malfunction: vomiting, headaches, sleepiness, difficulty concentrating and confusion, seizures, irritability, swelling of the skin around the shunt, visual problems including, redness or the are eyes fixed looking downwards (sunset sign). If the shunt stops working, the fluid will build up again and cause brain damage. **It is a severe complication**.

If you notice or suspect a problem with the shunt, immediately go to the emergency room of a hospital and a specialist doctor for medical help.

Card 6

Body functions and structures

Card 7

Introduction

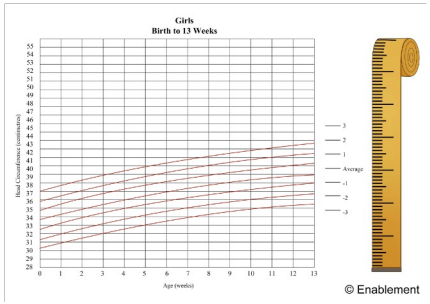
Monitor circumference of the head

In infants, the most obvious sign of hydrocephalus is an **unusually large head.** The bones of a baby's skull are not yet fused together, so the pressure caused by the extra fluid in the brain makes the head expand. Measure the child's head weekly and record it on the normal growth chart. If the head circumference is growing faster than normal, **contact the doctor immediately.**

How to measure the head circumference

1. The baby should be relaxed in the parent's arms. Place the measuring tape just above the eyebrow ridges, ears and around the prominent part at the back of the head. Measure the head at its widest circumference.
2. Read the tape measure at the side of the baby's head to the nearest full millimeter. Take the measurement three times and choose the largest measurement to record on the head growth chart.
3. If the head circumference increases faster than normal, the child may be developing hydrocephalus. The child must see a licensed doctor immediately.

You may use the "SHIP" passport to write down the measurements and other observations. See this website:
SHIP Passport Girls - IF Global
SHIP Passport Boys - IF Global



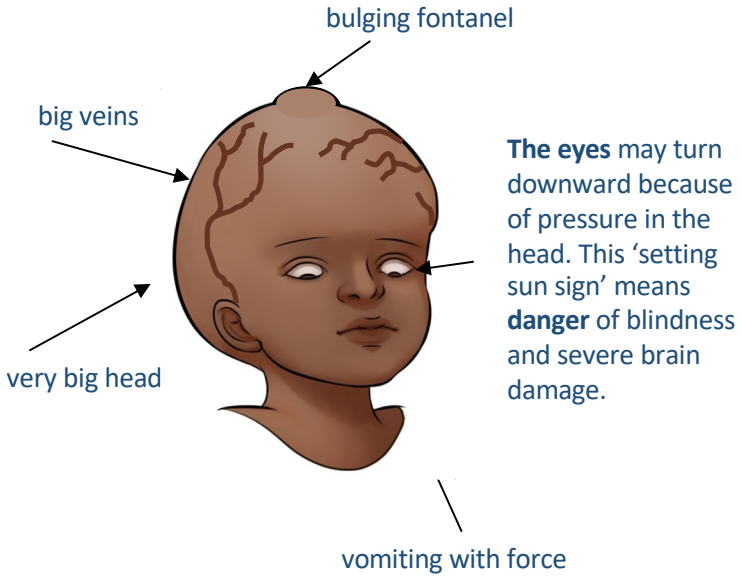


Actions to take



It is essential to refer to an infant with suspected hydrocephalus to a licensed doctor. Specialized doctors will confirm the diagnosis and decrease the pressure of the excess fluid in the brain, preventing further damage to the brain.

- Explain to the parents or guardians the importance of seeing a licensed doctor urgently.
- Record the head circumference regularly and monitor how fast it is growing.
- **Go to a medical doctor immediately** when the head is growing too fast, or the child has other signs as shown in the picture below



Card 8

Body functions and structures

Identifying hydrocephalus at different ages

Hydrocephalus may occur in children, adolescents and adults after head injuries, tumors, stroke, or some infectious diseases like meningitis, which affect the brain.

Field workers may find children with larger heads than usual or having other signs and symptoms, but who have not received any support. Sometmes the child is hidden by the family because of misunderstanding. shame or lack of information. Sometimes persons with hydrocephalus are only identified when they are malnourished or there are complications such as epilepsy, which require a visit to the doctor. Hydrocephalus can lead to many complications if not treated.

If you suspect a child has hydrocephalus, make sure they see a doctor and refer to other services as appropriate. The next cards have some activities and advice. This link also gives you ideas for teaching the child and family early stimulation and child development activities: Early Stimulation Activities | 2009 - IF Global. These will help to prepare the child for school.

If the person is an adult or elderly person, they must also see a doctor. The field worker can encourage them to improve their skills in daily activities by setting up a safe environment to practice and giving them assistance as needed, with the help of the family or neighbours. The Rehapp chapters on stroke and dementia provide many good ideas which you can try out. Also make sure the person receives the benefits and community services they need.







Card 9

Body Functions and structures

Intellectual disability

About two-thirds of children with hydrocephalus have normal or near normal intelligence if they are treated early and there are no complications. Some children will have learning difficulties, but extra stimulation and support before and during the school years will help them. If available, ask for specialist advice.



Vision, headache and noise in the ears

Children and adults may develop vision problems ranging from **decreased sight, blurred and double vision to severe loss of vision**. **T**he **"sunset sign"** (the pupil is covered by the lower eyelid and the eyes seem to look downward) indicates a possible infection.

Unusual headaches or **hearing a noise in the ears** (like a "whooshing" sound) may also be signs of problems.

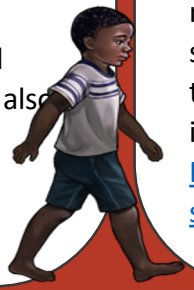
Report change in vision, hearing or headaches to the doctor. They may indicate increased pressure in the head, or that the shunt is not working correctly or needs replacing.



Movement and physical functioning

Children with hydrocephalus may have movement difficulties such as mild imbalance, incoordination or weakness and paralysis. The weakness is often on one side of the body (leg and arm), a weak trunk and poor head control. This means that large movements like sitting, crawling and walking and fine movements like grasp, pinch and holding items will be difficult.

Teach the family how to use play and the daily routine to practice movement and balance activities. A rehabilitation specialist can give you more specialized advice about how to progress the activities. They can also help to arrange for assistive products such as a wheelchair, crutches or leg splints according to the person's needs.



Epilepsy

Epilepsy or recurring seizures are common in people with hydrocephalus A person experiences a **seizure** when there is excessive and abnormal brain cell activity. The person may have uncontrolled movements, decreased responsiveness, and/or unconsciousness during the seizure. The Rehapp chapter on Epilepsy has more information.

Most children and adults with epilepsy take medication to control the seizures. It is important to take the medicines regularly as prescribed and not to make changes without seeing the doctor again. Inform the doctor if the frequency or type of seizures are changing. See this link for more information on how to respond to an epilepsy attack: [Epilepsy-nodding-syndrome-and-medication-tip-sheet_final.pdf (enablement.eu)]

Card 10

Body Functions and structures

Growth and Development

Puberty and body changes may come early in some children with hydrocephalus. If changes are noted before the age of 8 (girls) or age of 9 (boys), it is considered early.

Heights below the normal range, if not compatible with family stature, indicate slow **growth or stunting.**

Treatment is available for both conditions. Children should be referred to a specialist (endocrinologist) if available.

Support growth with early stimulation activities and good nutrition. If the child has difficulty to eat and swallow talk with a nutritionist or therapist.



Bladder and Bowel Control

Due to brain damage from hydrocephalus, children and adults have difficulty or lose control of their bladder (urination). They may also have difficulty to control their bowel movements (stools) and have constipation or loose stool. Reasons for this include weak muscles, lack of awareness of urination (poor sensation or awareness inside the body) or developmental delays including intellectual disability.

If there are unexpected changes in Bladder or bowel control, take the person to the doctor for advice.



Chronic Pain

Children and adults may have chronic pain. Even if they are taking medications prescribed by a licensed doctor, they may not get full relief from the pain. Physical activities such as play, relaxing activities and even exercise like walking or running may help some people.

Children and adults may also have abdominal pain, due to placement of the shunt or they may have headaches due to pressure changes. In these cases, it is urgent to see the doctor.

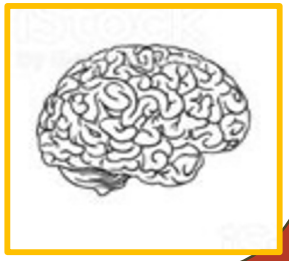


Dementia and Older Individuals

Dementia is not a specific disease, but a group of symptoms related to a decline in memory and thinking skills, as well as behaviour and personality changes that interfere with normal activities and relationships. These symptoms may develop due to hyrdrocephalus.

When the family tells you about these changes, report the situation to a specialist doctor. For advice.

The Rehapp chapter on Dementia has more information.













Activities and Participation:

Information and Actions to take







Get to know the child



All babies are unique. Play with the baby to discover what soothes them and what helps them to develop, learn and thrive.

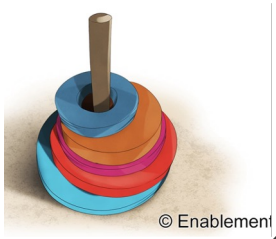
Babies and children learn through stimulation of their senses – taste, smell, touch, sight, hearing and movement. They ”learn” by playing, building up all the physical, mental and emotional skills needed that together help us become more independent in our daily life. Play is an essential part of child development.

Give all babies and children lots of opportunities for different experiences.

Get to know the child with hydrocephalus

These children may have altered sensations or movement. They may have difficulty with vision. Their development may be slower than other children on the same age. Be patient and repeat new actions and skills many times. If the head is heavy or big, support it using a hand, or a small pillow or rolled up towel or a head rest in sitting. until the child can control it.

Playing helps the child to learn new skills and begin to understand the space, noises, smells and objects in their environment.



Time to play

Play can happen at any time of the day, in any developmental position, when the child is being washed, dressed or getting ready for eating, as well as during a specific play time. Use bright colours, patterns and shapes and encourage the child to look at and follow these objects. Talk and make sounds with your child as you play, even if they don’t join you in speaking. Observe how the child communicates with their eyes, body, making noises or specific behaviour.

Some skills in development

- ❑ Holds on tight to your finger or toy
- ❑ Brings hands to mouth
- ❑ Develops head control in different positions
- ❑ Bring hands together
- ❑ Grasps and shakes toys
- ❑ Brings hands to feeding bottle
- ❑ Fixes eyes on parent’s face; follows objects with eyes (tracking)



Card 11

Activities and Participation

Card 12

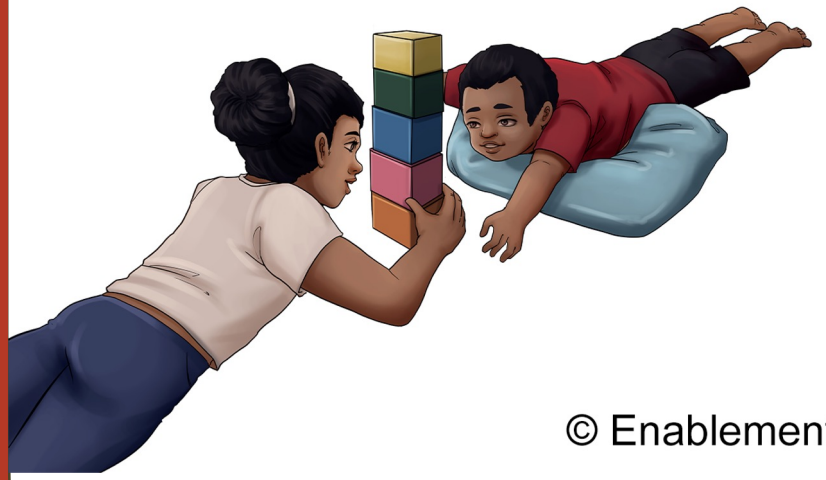
Activities and Participation

Tummy time

Babies should spend some time lying on their tummies. If the baby doesn't like it initially, you can lay them on the parents chest or thighs.

The benefits of tummy time are:

- ❑ Develops head control so the baby can hold her head up
- ❑ Strengthens back muscles for sitting up, kneeling, standing up and eventually walking
- ❑ Stretches all the muscles at the front of the body
- ❑ Learns to use their senses, like sight, hearing, smell, touch, taste, movement and body sense in a new position
- ❑ Preparation for crawling
- ❑ Promotes communication as you play together



Help the baby to roll

Twisting the body and head helps develop balance and co-ordination as well as muscle strength. Infants may need help to start rolling. Only give as much help as needed and use a toy or sounds to encourage the baby. Remember to support the head if it is heavy.

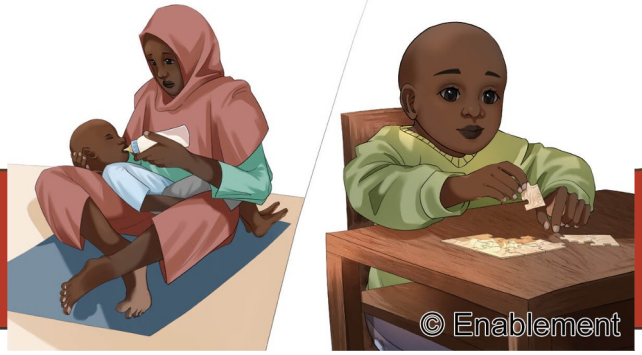
- ❑ Use your hand at the child's hip to lift it and encourage movement into side-lying using a toy or some noise
- ❑ Encourage turning the body and head and reaching for a toy
- ❑ Encourage the baby to roll to both sides
- ❑ Rolling from back to side lying and onto the tummy is usually more difficult for the child to learn
- ❑ Encourage rolling on hard, soft, and smooth surfaces and help the child learn about different textures



Feeding

Weaning to solid food

- ❑ Introduce a wide range of foods and flavours, especially vegetables, from about the age of 6 months
- ❑ Give the baby plenty of opportunity to use her hands during mealtimes
- ❑ Encourage holding the head up during eating
- ❑ If the child difficulties with eating and drinking, ask for specialist advice to prevent health problems



Skills to encourage in sitting

- ❑ Move on floor while sitting to get closer to a toy or person
- ❑ Reach to get a toy
- ❑ Transfer a toy from hand to hand
- ❑ Holds a toy in one hand while reaching with the other
- ❑ Picks up food to place in his mouth

These actions require balance, eye-hand co-ordination, muscle strength. They stimulate all the senses, communication and learning.

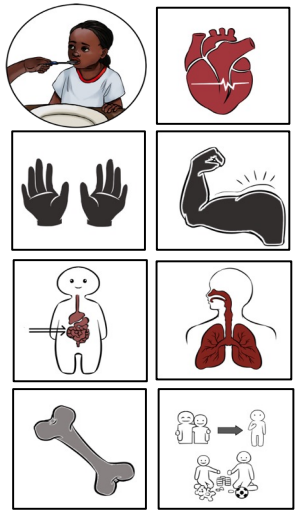


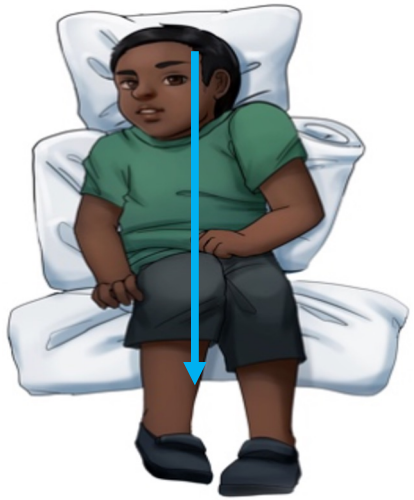
Sitting

In sitting we can freely use our hands for eating and playing. Sitting encourages deeper breathing and helps digestion of food. It makes seeing the world around us and communicating with others easier.

- ❑ When sitting, the back should be straight and aligned with the head
- ❑ To help sitting, place the small child on your lap facing you. At first, give a lot of support to the trunk and head. As the child becomes stronger, and feels safe, gradually decrease support.
- ❑ Practice sitting on the floor with the child's legs stretched out in a V-shape. As balance improves, place toys in different positions for the child to play.

If a person is not able to sit alone, provide support with pillows or a special chair.





Card 13

Activities and Participation

Card 14

Activities and Participation

Kneeling and crawling

Kneeling and crawling strengthen the trunk, hips and legs. The weight is born through the knees and hips, is preparation for standing and helps the bones of the hip joint to develop correctly.

Try putting a toy on a stool or table to encourage the child to use his arms and pull up into kneeling. Just give the amount of help needed. .

Movement help all parts of the brain and body develop.



Pulling up to standing

From kneeling, children usually start to pull up into standing, especially if they can see or smell something they want. Help them to stand if they are weak.

As children learn to move independently, they may have accidents with sharp objects, hot items, holes, steps or an open fire.
Remind parents to make a safe environment for their children.



Standing

- ❑ When the child can hold a table or chair to stand, encourage a few independent steps. To do this, the child has to lean how to balance on one leg then the other.
- ❑ Playing with a ball, kicking or throwing it, is good practice for balance and stepping, Give the child support at the hips or trunk initially until he/she is stronger and more confident. Also, help them to feel how to go from standing to sitting safely.
- ❑ Even children with very weak legs should practice standing because the weight bearing is good for the bones, joints and muscles. But you must give support, usually by holding the knees straight or using a slanted “standing board”.



Card 15

Activities and Participation

Handling the child with hydrocephalus

Support the child's head while holding, lifting and carrying a young child with hydrocephalus, as well as when you are playing together.

As the child grows up, lifting the child becomes more difficult and cause chronic back or knee pain for the caregiver. Suggest that two persons lift and move a young person or adult. A rehabilitation therapist can advise you on lifting techniques and help to get assistive devices such as a special chair or wheelchair.













Card 16

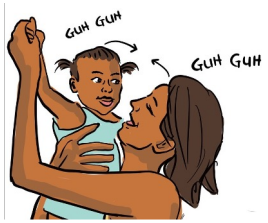
Activities and Participation

Language

Children need to hear, see and feel communication. Use body language, gestures, spoken language, songs and symbols. Children often understand more than they can speak. Encourage all sounds made by the child.

Encourage “talking time”. Talk to them about what you are doing, to encourages them to understand, make links between activities, movement, sounds and smells.

Read to the child and help them to develop interests.



Toilet training

Toilet training can start as with other children (18-24 months), but these children may take longer to learn how to manage.

Is the child ready: knows he/she is wet or needs to poo, can stay dry for 1-2 hours,

Some suggestions include:

- ❑ Place the toilet pot in same location each time
- ❑ Make sure the pot or toilet is safe and easy to use.
- ❑ For an older child with poor balance use rails or make a special chair
- ❑ When there are accidents, be supportive not critical.



Walking and independent mobility

Independent movement helps children to develop memory, finding their way around and decision-making. It helps their vision, language, cognition and social development

Most children should be independent in movement from around 18 months.



Cruising

When a child move around by stepping side to side and holding on to the furniture. They are practicing how to shift their weight from one leg to the other. Soo they will be able to take a step.



Card 17

Activities and Participation

Physical development – Gross motor skills (large movements of the body and limbs)

Children with hydrocephalus may have poor balance, muscle weakness, or difficulty with visual perception (size, shape, depth, space). They may be clumsy and unsteady.

Practice playing in rolling, crawling, sitting, walking and running according to their abilities. Children get bored with exercise, so make a game, use a toy or household object, or sing a song. Remmber to only give as much help as needed and have fun. There are many small opportunities throughout the day to practice.

- ❑ Move to reach, grasp and carry toys, pans or clothes
- ❑ Go up and down steps, curbs and stairs
- ❑ Stand on one leg when dressing
- ❑ Kick a large ball while sitting or standing
- ❑ Throw a ball (sitting and standing)
- ❑ Dance (sitting or standing)
- ❑ Tell a story with the arms (miming)
- ❑ Make an obstacle course (climb up, over, under, around objects)
- ❑ Begin to ride a tricycle or scooter board



Play indoors and outdoors, using natural objects moving on different surfaces and experiencing different conditions.

Upper limb skills – Fine motor skills (small movements of the hands and fingers)

The child needs a stable head, trunk and shoulders in order to focus on using the hands and fingers. Practice hand movement by sitting behind the child or use a supportive chair. A table in front will also support the elbows if necessary. Practice in other positions but try to make sure the head and shoulders are supported. Some activities are:

- ❑ Reach for a ball or objects of different sizes, shapes, weights and textures
- ❑ Encourage looking and reaching in all directions
- ❑ Find items in a small box of sand, rice or beans; such as a spoon, coin, small toy
- ❑ Finger drawing in sand, with paint on paper, hand cream on a mirro; then drawing with crayon or brush
- ❑ Puzzles, building block, put pebbles in a bottle, help turn the pages of a book, help washing vegetables



Card 18

Activities and Participation

Skills for life

Problems with vision, hearing or thinking and learning abilities may cause difficulties with daily activities like dressing, washing, writing or home tasks. The person may not be able to plan the order of the task or to get started on the task. Here are some tips.

- ❑ Observe which part of activities are difficult so you can decide how to give help.
- ❑ When teaching a daily task, always ask the child or adult to do as much of the action as possible, such as lifting the leg to put into trouser leg, or drying their hands after washing, etc.
- ❑ Only help as much as is needed to be successful; over many days of practice, gradually decrease the help given.
- ❑ Coach the caregiver to teach this way from easy to difficult.
- ❑ Remind them to be patient and that it takes a long time to learn activities so try to use the same steps each time.



Eating and drinking

If you are feeding or helping a person drink:

- ❑ Use a supported sitting position with chin tucked in.
- ❑ Take time to allow the the person to move the food in their mouth; and to breathe in between swallows
- ❑ Never feed someone with the head tilted backwards, because the throat relaxes and lets the food into the lungs instead of the stomach
- ❑ Encourage the child or adult to use their fingers to eat, before they can hold a spoon
- ❑ When drinking just give small sips from a spoon or use a straw; do not pour water into the mouth and throat because it will make the person choke.

In case of feeding difficulties, consult a specialist.



Cognition and learning

Children with hydrocephalus can have difficulty with learning, especially language and memory.

As the child is learning to become independent in an activiity, help them by:

- ❑ Do the activities in the same order of steps each time you practice: be consistent
- ❑ Do the tasks at the same time and in the same place: set up a daily schedule
- ❑ Prepare the activity and any materials needed in advance: be organized.
- ❑ Slowly offer choices: “do you want the yellow tee-shirt or green one”

Communication

Rhymes and songs with action are fun and useful ways to improve and develop language skills. If speaking is difficult or not possible, explore other ways for the person to express their needs or respond. Gestures, pointing, facial expressions, banging the feet, pointing to pictures, using the eyes, making sounds or sign language are all communication.





Card 19

Activities and Participation

School is important!

Work with the families and teachers to get the child in school at the same age as others. Do not wait because the child has poor balance or is slow to learn. A person with hydrocephalus needs to go outside, make friends, practice in new environments. This will help physical, intellectual, language and personality development.

The child needs opportunities to practice new activities by repeating again and again. Repetition, stimulation and seeing others do the same activities are important to develop each child's full potential in school and prepare him or her for adult life.



School and education

Going to school is a big step. Parents worry about letting their children go to school because of fear that the child may fall down, can't keep up with others, is not accepted or is bullied. Together, the parents and head teacher can make an individual education plan that includes classroom and social activities as well as self-care (toileting, washing, eating, etc). In between classes, some children need help to move around while others will need extra time and support in reading, writing, calculations or other subjects. There are many solutions to help the children to progress happily.

Actions to take

All children have the right to an education

- ❑ Explain to the family the importance of going to school
- ❑ Arrange for the parents and head teachers to meet and agree on an individual education plan and an emergency health plan.
- ❑ The school staff must learn about the medication the signs of increased pressure in the head (possible malfunctioning shunt) and how to manage seizures.
- ❑ The field worker may assist the teachers to organize some awareness activities for the other children.
- ❑ If required, teachers may want to set up a "buddy schedule" when a school mate helps the child.

Card 20

Activities and Participation

Sports

Children with hydrocephalus can usually participate in all school activities, including physical education.

Shunts are not easily broken because they are made from silicone. All the usual activities at school or in the home and community are possible.

When the child has difficulty in physical activities, such as walking, jumping or climbing, the activity can be modified according to their needs. Every child needs physical exercise as well as social participation with other children.



Transition to secondary school Preparation is the key to moving on to secondary school. Again, it is important to provide the school with information about hydrocephalus, and the specific problems experienced by the young person and how they cope with these, such as headaches, chronic pain or sensitivity to loud noises. The school must know the signs of seizures and shunt malfunction.

An **individual education support plan** is often required and there must be an **emergency health plan.**



Participation in daily life

Children with disabilities have to overcome many challenges in transitioning to independence. It is easy for families to over-protect children and young people. Although, sometimes, when support is lacking, children are neglected

Encourage families to teach their child to learn daily skills. Some examples of participation are:

- ❑ Pack away toys and tidy up
- ❑ Wash and arrange their own clothes
- ❑ Do household chores
- ❑ Play with other children, not only with adults
- ❑ Ask for directions or for help

Investing in life skills helps prepare the child and family for the future, as he or she becomes more self-aware, builds esteem, learns how to cope with emotions and stress, learns how to act in social situations, make friends and share responsibilities.







Leisure and pleasure

When an activity or sport is too challenging, a child may withdraw or avoid these situations. Some ideas to support participation are:

- ❑ Prepare the child through repeating small steps of the activities in safe environment
- ❑ Change the intensity of the activity, at least for some of the children or part of the activity
- ❑ Guide and encourage by touch or holding hands
- ❑ Create a new role within the activity for the child
- ❑ Avoid asking the child to do book work in the classroom while others are outside playing.
- ❑ Look for suitable activities with children of similar age, to practice social interaction

During adolescence friends are important to help develop self-identity and independence. Opportunities at an earlier age to make friends and respect the needs of others, will help the transition to adolescence.



Card 21

Activities and Participation

Card 22

Activities and Participation

Work

Having a job or other productive activity, and participating n community increases satisfaction and a feeling of belonging. Young people and adults with hydrocephalus can work just like everyone else, given jobs which match their skills and interests. Just as in the school, the person may meet challenges with the physical and social environments which need to be overcome in the workplace.



Actions to take

- ❑ Ensure the condition is well-managed , and colleagues know what to do in an emergency.
- ❑ Practice community orientation and safety skills (getting to the workplace, crossing a road)
- ❑ Analyze the selected work and provide appropriate job training and supports
- ❑ Lobby for changes in the physical environment
- ❑ Refer to a specialist for specific assistive products
- ❑ Help to request small changes (such as earphones to cut down on sound, work in a place without flashing lights, or only work part-time initially)

Community participation

Each person with hydrocephalus has an unique story to tell; and we can all learn a lot from listening to their stories, their challenges and solutions as well as their successes and joy in life.

Fieldworkers can play an important role in encouraging work, community participation and raising awareness with community members.



Actions to take

- ❑ Encourage and support participation in usual and special community activities
- ❑ Increase disability awareness in the community and among persons with disabilities and their families
- ❑ Lobby to remove barriers to information, services, shops, facilities and offices.
- ❑ Support persons with disabilities to make informed choices in their lives.











Personal factors:

Information and

Actions to take







Card 23

Personal Factors

Personal wishes and needs

Every person, with or without disability, has wishes and needs, including those persons who cannot speak or have intellectual diabilities. When setting goals and action plans, the person's own wishes and desires must take priority.

Actions to take

- ❑ When talking with families or making plans, always include the person with disability
- ❑ When a person cannot speak or has difficulty underestanding, use alternative ways, such as visual images, body language and facial expressions
- ❑ Plan for enough time for these discussions; be prepared for several sessions



Social skills and personal boundaries

Social skills include being aware of and able to manage your own emotions and behaviour and how people around you are responding. It includes being able to maintain relationship and understanding that people hae "personal space". Social skills are needed at home, school, work, when with friends or meeting new people, developing a love life, and having a family.

When a person has an intellectual disability or an adult has dementia, they may not understand social boundaries and act inappropriately, like hugging or hitting others. On the other hand, someone else may bully them, physically, or sexually abuse them, or take financial advantage of them.

Actions to take

- ❑ Discuss with the person, the family or caregivers how to teach social skills; this will take time.
- ❑ Teach them how to protect themselves.
- ❑ IIf the person has continuing difficulties, it is important to discuss with the family and look for solutions This probably includes asking friends and neighbours to watch out for the person, and to help keep him or her safe while maintaining the dignity of that person.



Card 24

Personal Factors

Mental support

Persons with disabilities and their familes experience many emotional ups and downs as they adjust their expectations and face repeated medical, social and economic difficulties. These may result in feeling sad, hopeless and depressed

Depression is an illness characterized by persistent sadness and loss of interest in activities once enjoyed, The person shows a gradual inability to carry out daily tasks, appetite and sleeping habits change, feels listless, worthless and has thoughts of self-harm or violence,

If the person's depression is growing worse or they talk about harming themselves or others**: refer to a licensed doctor urgently**

Actions to take

Be sensitive to emotional distress (exhaustion, anxiety, depression, anger). Frequent visits or "check-ins", even by text messaging, may help.

- ❑ Discuss solutions with the local health centre staff
- ❑ Visit more frequently than usual: listen patiently and be non-judgemental
- ❑ Encourage them to look at their strengths and what they have accomplished, as well as their difficulties
- ❑ Encourage seeking assistance from family and friends
- ❑ Alert the social network such as family, friends/peers, community members, health centre and others



Caregiver's role

The amount of care required may vary from mild to severe depending on the situation of the chld or adult with hydrocephalus. The caregiver, whether a close family member or other person, plays an essential role in maintaining the dignity, choices and quality of life of the person with disability,.

Indeed the caregiver needs to stay healthy, relaxed and keep their own interests and activities. This is good for both the caregiver and the person with disability.



Actions to take

- ❑ Help the caregiver identify their own social support network for when they are stressed, anxious or tired.
- ❑ Look for practical ideas to simplify the daily routine activities and improve their skills as caregivers, use an assistive product, or change the tasks in small ways.
- ❑ Discuss how to avoid overprotecting the person with hydrocephalus and demonstrate how to coach the person with disability to beome more independent.
- ❑ Provide realistic information on expected outcomes and the future, discuss accepting ourselves
- ❑ Work in collaboration with the caregiver to decide on priorities; without overburdening the care giver.

Card 25

Personal Factors

Peer counseling

Peer counselling is when emotional and practical support is given by people in similar situations. An experienced parent or caregiver can answer many questions on how to take care of the person with disability, sharing their knowledge and skills. However, each situation is unique and what the peer counselor experienced may be different from the situation of another parent. So usually, it's good to discuss the situation and prepare the "peer counselor" before introducing them.

Peer support can be given by an experienced individual to the parent or caregiver. It can also be done in a group situation with families or with other parents. Groups provide emotional and social support, practicall tips and pathways to school, work or solving other problems.

Actions to take

- ❑ Connect the parents to an experienced caregiver
- ❑ Connect the parents to support groups of parents of children with disabilities.



Spiritual support

Not only knowledge, skills and practical support are needed but also spiritual support.

Learning your family member has hydrocephalus is a life-changing event. The family may ask themselves why has this misfortune or burden come about? What have we done wrong? Talking with a religious leader – a priest, an imam, a rabbi- or praying with others in religious rituals may help.

Actions to take

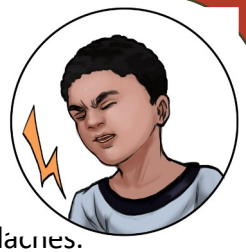
- ❑ Be aware of the support given by traditional or religious leaders, but make sure there is no harm made to the person's body like burns or cuts



Card 26

Personal Factors

Chronic Headaches

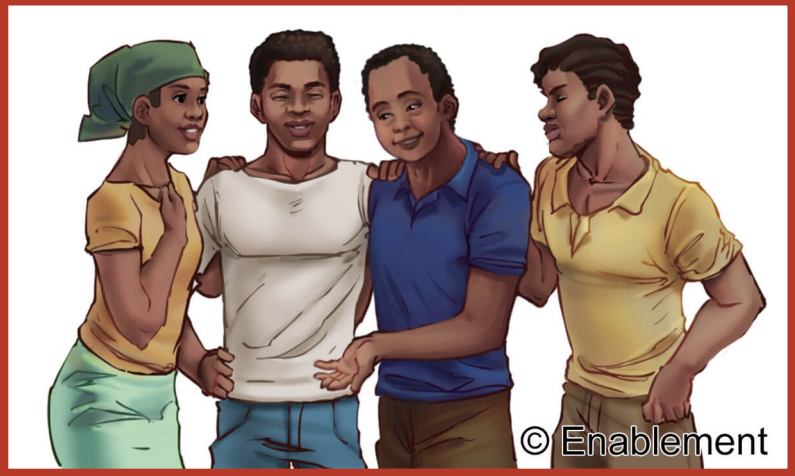


Many children and adults with hydrocephalus experience frequent headaches. making it difficult to concentrate and to participate in school and work activities. If the headaches are getting worse and accompanied by other signs of increased pressure in the brain, the person should follow up with the specialist doctor, because the shunt may have to be changed. Unfortunately, the reasons for headaches are complex and solutions are not easy to find.

Actions to take

- ❑ Seek advice from the doctor if the pattern of headaches change and anytime they cause excessive anxiety.
- ❑ If the doctor clears any emergencies, and the headache can be relieved by rest or medications, discuss with the school or workplace for arranging quiet places to rest. If a child needs to stay home, arrange for someone to help tutor or keep them up to date with school work.
- ❑ Identify physical activity (such as walking or gardening) or mental support (such as music) which seems to relieve the chronic pain, even if only to a small extent
- ❑ Look for advice from a peer or a chronic pain support group
- ❑ With the person's agreement, make sure that teachers and workmates are aware of the chronic pain, how it affects the daily performance, and the best way to help





Card 27

Personal Factors

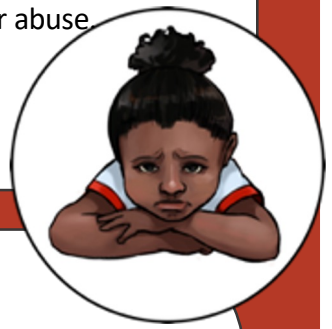
Puberty

Many young people are worried during puberty due to changes in appearance, hormones, feelings and emotions. This is also when adolescents want to become more independent of their parents.

Puberty starts early in some children with hydrocephalus, although the reason is not understood. Starting puberty before their peers is difficult especially for children with intellectual disabilities.. Growth also stops once puberty has ended, so these children may be shorter than their peers. Other children may bully or laugh at them, and they are more likely to experience abuse.

Actions to take

- ❑ Prepare parents or caregivers for the possible early puberty, so they can look after their child
- ❑ Explain to the child the changes that are happening in their body, emotions and behaviour, so that he or she can understand that puberty is a normal stage.
- ❑ Help them and their caregivers to find ways to cope with the changes, whether a boy or girl.
- ❑ Advise parents to share the situation with the teacher to look out for bullying, teasing or other abuse
- ❑ Ask for advice from a doctor or other professionals



Relationships

Persons with hydrocephalus, especially if they have intellectual disabilities, may find it difficult to adjust to sudden changes in plans and routines. They tend to want to have time for explanation and to prepare both their emotions as well as for their physical needs.

They have the same social and emotional needs as everyone else. They have desire for affection and attention and they wish to have friends, short-term relationships, lovers or life partners.

However, it is known that persons with hydrocephalus are less likely to have a partner, less likely to be sexually activ and may also have difficulty with sexual functions.

Actions to take

- ❑ Support them by listening and talking with them naturally, including them in regular group activities
- ❑ Help the person to find ways to cope with their emotions and understand their own behaviour and that of others.
- ❑ Learning about sexuality and love is a part of growing up;. Educate the young person in a way which is understandable and healthy
- ❑ Arrange for counseling in how to maintain different kinds of relationships

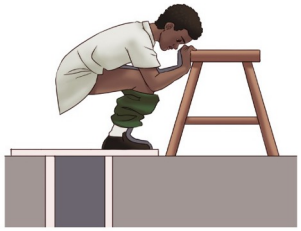










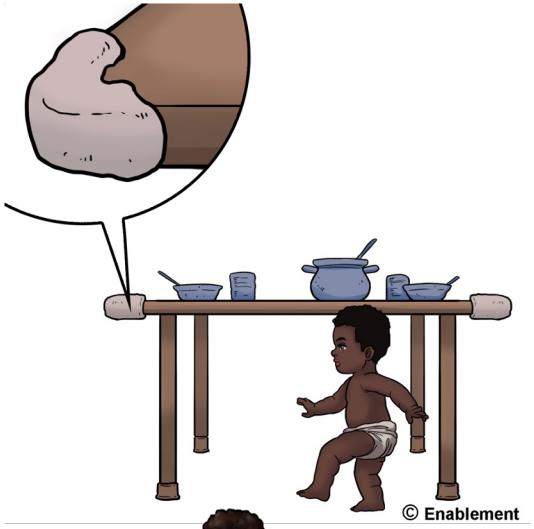




Environmental factors:

Information and

Actions to take









Card 28

Environmental Factors

Policies, Programs and Awareness

Hydrocephalus needs co-ordination among families, health, education and social services and communities. Early identification by health staff and support to arrange for specialist surgery and follow-up is essential. Children need to attend school, adults need to find jobs, and both need to participate in community activities.

Field workers must work with all the services to raise their awareness and provide support in various ways.

Healthcare

- ❑ Assure access to universal health care coverage to provide specialized care, referrals, operations and follow-up services, rehabilitation and assistive products
- ❑ Ensure healthcare coverage for general health needs of children and adults with disabilities
- ❑ Provide early stimulation and intervention programmes for all children with developmental delay or disabilities.

Education

- ❑ Invest in education at all levels and for children and young people with disabilities
- ❑ Promote educational rights of children with special needs including higher education or vocational training

Labor

- ❑ Prohibit discrimination in the workplace, including accessibility and assistive products
- ❑ Increase awareness of employers regarding the strengths of persons with disabilities in the work place and encourage their support.

Barriers to achieve quality of life

Lack of data

Data regarding the prevalence of persons with hydrocephalus is incomplete or missing. Children with hydrocephalus are often not registered at birth. Parents may not seek healthcare. Some children are hidden from view due to lack of information and superstition.

The result is limited research into the appropriateness and effectiveness of treatment for hydrocephalus.

Lack of knowledge, stigma and misconceptions

Healthcare workers may have no experience with persons with hydrocephalus. They have limited knowledge and skills to help them.

Literature and healthcare education may be outdated and not include the latest information or specialist services available.







Card 29

Environmental Factors

Family support

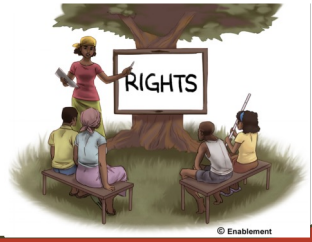
Having a family member with hydrocephalus changes the lives of all the family members. Parents and siblings may face unexpected challenges and a range of emotions



Actions to take:

- ❑ Evaluate the family dynamics and support the family members incuding siblings to accept the person with hyrdrocephalus
- ❑ Work with the family, health, education and social support staff to plan a holistic approach..
- ❑ Provide the family with information about where to get support at each stage of the person's life.
- ❑ Teach the person with disability and the families to advocate for themselves regarding their rights and responsibilities.
- ❑ Talk with the adolescent or adult with disability and the family separately about their expectations for independent living, self-management and community participation; help them to come to consensus on future goals.





Accessibility

- ❑ Look for solutions to physical barriers in home, outside area, school or work. Some examples are: stairs without railings or no ramp if the person uses a wheelchair, unsafe toilets, or very muddy roads.
- ❑ Identify when an assistive product may help









Actions to take:

- ❑ Consider what the problem are and identify how eliminate physical barriers
- ❑ Identify the postural or mobility device the person needs for stable posture or to move around more independently
- ❑ Ask a physiotherapist or occupational therapist for help or refer them to an organization that provides assistive devices.
- ❑ Use tele-rehab with your mobile phone to contact the therapists and show them the problems the person is having; they can help you decide exactly what assistive device the person needs. (make sure you have the person/family's permission to share photos or video)

Card 30

Environmental Factors

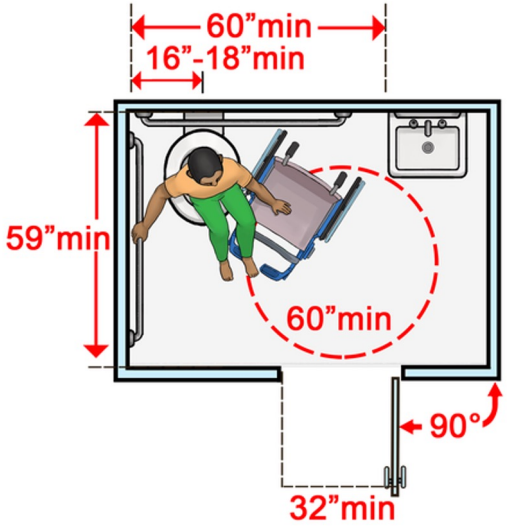
Learning environment

Here are a few tips but each child will need different solutions, and the teacher may find this difficult. It's important to try out what works best in the classroom.

- ❑ Ask the child to sit near the front of the class, with a clear view of board or screen and the teacher
- ❑ Check for physical barriers in the classrooms, resource room, toilet, washing and eating areas
- ❑ If the child is sensitive to noise and crowding or has headaches, arrange a quiet place for resting.
- ❑ The teacher should model, write and speak instructions
- ❑ Provide extra time for children to respond; be patient
- ❑ Make a visual timetable as well as a written one; and tell a story as the class gets ready to change their activity, this helps children prepare their emotions for the change in activity
- ❑ Create an environment with muti-sensory input; all children will enjoy and benefit.
- ❑ If older children have a mobile device, such as a phone, it will allow them to record a class or do their assignment verbally or as an interview instead of traditional written work.



Possible home modifications











Card 31

Environmental Factors

Traveling with hydrocephalus

Whether the person with hydrocephalus is traveling in a car, bus, or flying the ability to travel is important to broaden their horizons, inspire new ideas, improve self-esteem and confidence.

It's essential to prepare for any trip. In some countries, there is a disability card that ensures free transport for persons with disabilities Explore these options and support the family to obtain such services.

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Being independent outdoors

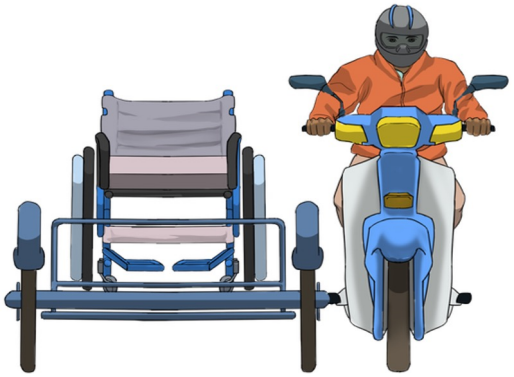
Some children and adults with disabilities spend most of their times inside the home. As fieldworkers, you can encourage the person with hydrocephalus to participate in outdoor activities as much as possible. You can also help with supporting new skills in different parts of the community



Actions to take:

- ❑ Identify the difficulties to go outdoors for any reason; don't forget how to manage toileting eating and drinking depending on the length of the trip.
- ❑ Practice the activities at home before the trip
- ❑ Evaluate the environment and how to get accessible transportation in each part of the trip
- ❑ Discuss and advocate with local officials about inaccessible public places and services, as well as difficulties with transport.





Card 32

Environmental Factors

Safety

Children and adults with disability are often abused or harassed. Girls and women with disability, as well as men and women with intellectual disabilities are often at risk because they cannot protect themselves or do not understand the situation.

Abuse happens in many ways: neglect, physical violence, psychological and emotional abuse, sexual harassment. Sometimes adults and elderly persons with disabilities lose control or benefits of their disability
Allowance or other finances.



Actions to take

- ❑ Teach young persons and adults about personal safety, what is “ok” and what is not appropriate.
- ❑ Raise awareness in the person’s social network: to be vigilant for abuse and harassment.
- ❑ Create awareness in the community for the rights of persons with disabilities.
- ❑ Teach the persons with disabilities and their families about justice, and how to stand up for their rights.

Livelihoods



Adults who have grown up with hydrocephalus, and have received appropriate h t like other persons. However, some persons who have symptoms such as chronic pain, wea ementia, find they cannot continue working, but they may be able to find meaningful activities at h

Families often have economic difficulties due to the medical treatment ne follow-ups. Organizations and support groups can help these families to augmen community income generating activities.



Card 33

Environmental Factors

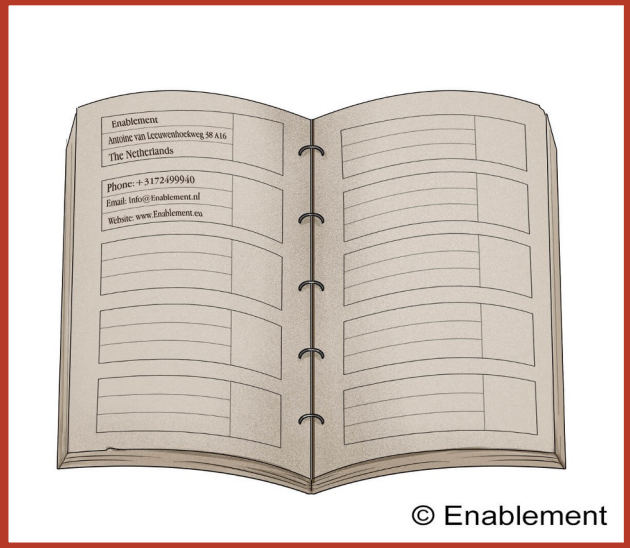
Service mapping

The availability of services and specialists in low resource areas is often limited. It is important that you identify and map available services at community, district, provincial and national level. Identify relevant stakeholders in the areas of health, education, livelihood, social services. Look for peers with similar experience and organizations of people with disabilities who can support and empower persons with disabilities and their families.

Actions to take

- Make a map of where relevant buildings, services, specialists and other stakeholders are located at community, district, provincial and national level together with their contact information, so you can contact them or refer in a timely manner.
- Stakeholders also include community leaders, religious and traditional leaders and healers.
- Make a resource directory (address book), with contacts, addresses and comments; add any additional useful locations, such as social services to obtain a disability card and/or allowance.





Card 34

Colophon

Published: 2023

When drafting the content of the Flashcards, several resources were particularly helpful:

Centers for Disease Control and Prevention. “Spina Bifida: Health Issues and Treatments for Spina Bifida”. Retrieved from: https://www.cdc.gov/ncbddd/spinabifida/treatment.html

Jallo GI, Kothbauer KF, Recinos VMR. (2018) *Handbook of Pediatric Neurosurgery.* New York: Thieme. Available t: https://shop.thieme.com/Handbook-of-Pediatric-Neurosurgery/9781604068795

Hydrocephalus Association. “About Hydrocephalus: A Book for Families.” Retrieved from: https://www.hydroassoc.org/docs/About_Hydrocephalus_A_Book_For_Families1.pdf

John Hopkins Medicine. (n.d.). “Toilet Training”. Retrieved from: https://www.hopkinsmedicine.org/health/wellness-and-prevention/toilettraining

Montgomery, N. (2022). “Measuring your baby’s head circumference, length, and weight. Retrieved from: https://www.babycenter.com/baby/baby-development/growth-charts-taking-your-babys-measurements_1620

National Hydrocephalus Foundation. (2018). “Facts About Hydrocephalus.” Retrieved from: https://nhfonline.org/facts-about-hydrocephalus/

NIH:National Institute of Neurological Disorders and Stroke. (2019). “Hydrocephalus Information Page.” Retrieved from:https://www.ninds.nih.gov/Disorders/All-Disorders/Hydrocephalus-Information-Page

Piatt, J. H. (n.d.). “VP Shunts”. Retrieved from: https://kidshealth.org/en/parents/vp-shunts.html

Reeves, M. (2016) *Hydrocephalus: Prevalence, Risk Factors and Treatment.* New York: Nova Science Publishers, Inc. (Congenital Disorders: Laboratory and Clinical Research Series). Available to purchase book at: https://novapublishers.com/shop/hydrocephalus-prevalence-risk-factors-and-treatment/

Shine Charity. (n.d). “What is Hydrocephalus?” Retrieved from: https://www.shinecharity.org.uk/downloads/pdf

Tecklin, JS (2015). Pediatric Physical Therapy 5th Ed. Lippincott Williams & Wilkins, Baltimore, MD. Available to purchase at: https://shop.lww.com/Tecklin-s-Pediatric-Physical-Therapy/p/9781975141578

Verhoef M, Barf HA, Vroege JA, Post MW, Van Asbeck FW, Gooskens RH, Prevo AJ. Sex education, relationships, and sexuality in young adults with spina bifida. Arch Phys Med Rehabil. 2005 May;86(5):979-87. doi: 10.1016/j.apmr.2004.10.042. PMID: 15895345.

Liliane Fonds (2022). Development Chart. Illustrations used Liliane Fonds | See the strength in every child

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Colophon

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