Ageing Well With Spina Bifida and Hydrocephalus

This information manual has been developed by SBH Queensland as part of an educational program to promote healthy ageing for people with Spina Bifida and Hydrocephalus. This project has been made possible through a grant from the Metro North Brisbane Medicare Local.

The objectives of the Project have been:

- To increase awareness and understanding amongst health providers and community agencies in the Metro North region about what living with SBH means and provide strategies to assist adults with SBH to age well.
- Equip adults with SBH and their families with knowledge, skills and resources to navigate their local community services (health and otherwise) and maximise and maintain good health as they age.
- To develop digital and print resources to support awareness of SBH and promote practical strategies to assist adults with SBH age well.

SBH Queensland has been supporting people with Spina Bifida and Hydrocephalus since 1970. Since its inception, SBH Queensland has faced many challenges in supporting our clients.

The challenge to assist our clients to age well is an ever increasing issue as the ageing process and what it means for people with SBH is relatively unknown. Prior to the introduction of the shunt in the 1960s babies with Spina Bifida/Hydrocephalus did not survive into adulthood. We are now seeing the first wave of people living into their 40s and beyond. The ageing process raises complex issues for people with SBH and their families as they seek to ensure they maintain the best level of health possible and plan for any possible challenges in the future.

The manual provides a variety of information including the physiological basis of Spina Bifida and Hydrocephalus, health and ageing issues, independent living, community engagement, learning and cognition and mental health. All of these issues have the potential to impact on the person with SBH's means to face the challenges of the future and to maintain their independence and health as they age.

It is hoped that this information will better equip you to navigate the various issues which can help you get the best out of your future years.

ASSIST

SBH
Spina Bifida Hydrocephalus
Queensland

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METRO NORTH BRISBANE
Connecting health to meet local needs

This project has been made possible through a grant from the Metro North Brisbane Medicare Local.

The Metro North Brisbane Medicare Local believes in a community where good health is available to everyone. We improve access to health care for communities across Brisbane's north and Moreton Bay by providing innovative approaches to coordinate health care services.

Medicare Locals are a national network and gratefully acknowledge the financial and other support from the Australian Government Department of Health.

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SPINA BIFIDA

What Is Spina Bifida?

Spina Bifida is the most frequently occurring permanently disabling birth defect.

It affects the development of the spine and spinal cord and also alters development of the brain.

It is a complex impairment and many other organ systems are affected.

With Spina Bifida at least one spinal vertebra is only partly formed and the spinal cord at that point and below as well as the skin around the site are not properly developed.

Babies are usually born with a sac of undeveloped tissue on the back. The amount of damage to the spinal cord and nervous system varies from person to person.

Also, the alteration to the brain's development causes Hydrocephalus in about 90% of people with Spina Bifida.

What causes Spina Bifida?

Spina Bifida appears to be caused by a combination of genetic and environmental factors. Some factors, such as having a close family history of Spina Bifida or taking some anti epileptic medication are known to increase the risk, however 95% of children with Spina Bifida are born in circumstances where high risk factors are not apparent.

Genetic research, in particular, is beginning to piece together the puzzle.

What are the effects of Spina Bifida?

The effects vary considerably from person to person. Spina Bifida is commonly found in the lumbar and sacral spine. Because the lumbo sacral spinal nerves control muscles and feelings in the lower limbs, people with Spina Bifida have some degree of paralysis.

Most people need to use a wheelchair. Bladder and bowel functioning are also severely affected. Tethering is caused by tissue attachments that limit the movement of the spinal cord within the spinal column. Other common problems include curvature of the spine, decubitis, epilepsy, short stature, latex allergy, urinary tract infections, as well as many other problems caused by Hydrocephalus. Frequent hospitalisation are needed to treat these problems.

How common is Spina Bifida?

More than 10 million people worldwide have Spina Bifida.

In Queensland approximately 1 in 1,000 babies are born with Spina Bifida. With the use of folic acid this incidence is believed to be declining.

There are over 800 adults with SBH in Queensland who are linked with SBH Qld.

Is there a cure for Spina Bifida?

No. There is no cure for this condition because damaged nerve tissue cannot be replaced or repaired.

Is there a treatment for Spina Bifida ?

Multiple surgeries, other medical treatment, medication, physiotherapy, occupational therapy, neuropsychology, medical aids, assistive equipment and assistance at school and beyond are all required in the treatment of Spina Bifida.

Spina Bifida is not a condition that people outgrow. People have to learn to manage the effects of Spina Bifida as best they can and live with them. Ongoing medical care, surgical procedures, therapy and community support are all required to prevent and manage complications throughout a person's life.

Can Spina Bifida be prevented?

No, but the risk can be minimised if an expectant mother takes a daily supplement of 0.5mg of folic acid one month before conception and three months after. Folic acid is a B vitamin which is present mainly in leafy green vegetables. Research has shown that this regime reduces the incidence of Spina Bifida and similar birth defects by up to 70%. The National Health and Medical Research Council recommends that all women of child bearing age consume a 0.5mg daily folic acid supplement.

Anyone with a family history of Spina Bifida have a higher risk and should consult their doctor about a higher dose of folic acid.

What does the future hold?

There are many unknowns to do with Spina Bifida. Medical research dealing with the ongoing problems associated with Spina Bifida is relatively new. Prior to the 1960s few children with Spina Bifida survived due to the inability to treat Hydrocephalus. Now the first group of people with Spina Bifida and Hydrocephalus is reaching adulthood and we are starting to see what effect Spina Bifida has on their lives.

Although the future of how ageing will affect each individual is unclear, we do know that proactive management of physical and mental health will maximise each person's quality of life well into adulthood.

SBH Qld is a community association of people with Spina Bifida and Hydrocephalus, their families and other supporters, which works to improve the lives of people with Spina Bifida and Hydrocephalus. Staff provide information and advice, support and therapy to people and families affected by Spina Bifida and Hydrocephalus and to other organisations working with them.

HYDROCEPHALUS

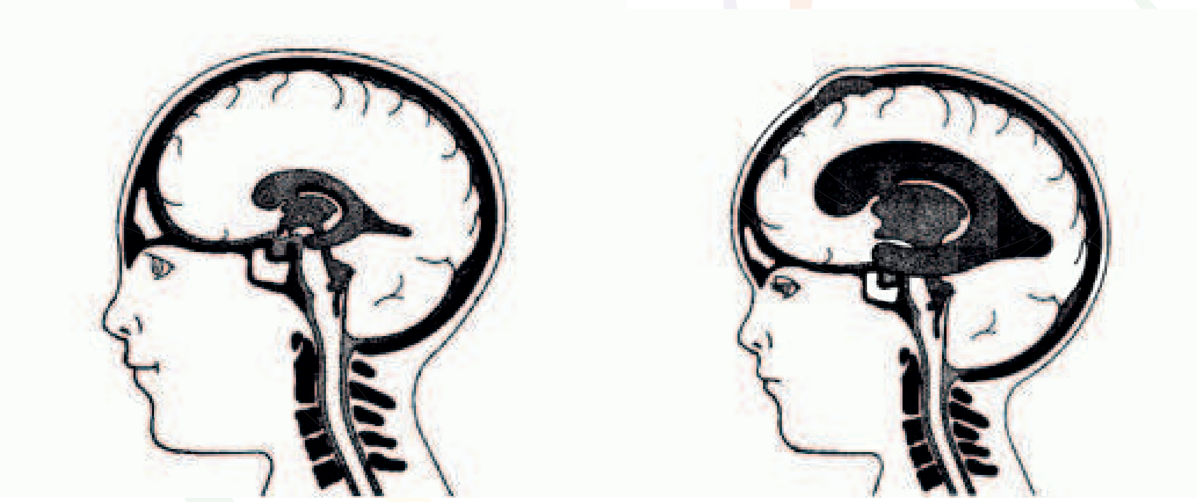
What is Hydrocephalus?

Hydrocephalus is the result of a blockage in the flow of cerebrospinal fluid (CSF) through the pathways of the ventricles of the brain, causing pressure on the brain.

A clear, saltwater-like liquid called (CSF) surrounds the brain. This fluid protects and hydrates the brain, carries away waste from brain cells and contains important chemicals and nutrients.

Each day the brain produces about 500mL of cerebrospinal fluid. The CSF flows in a continuous circuit through the brain cavities (ventricles), and over the surface of the brain and spinal cord until it is absorbed by the body.

When CSF is constantly being produced, but cannot get out, it accumulates and causes raised pressure inside the brain. When there is a blockage, the ventricles swell or enlarge and the brain tissue is stretched and squashed.



Normal Ventricles

Hydrocephalic Ventricles

Diagram Sourced – Medtronic 2003 Living with Hydrocephalus.

Hydrocephalus and Spina Bifida

Hydrocephalus occurs at birth, in approximately 90% of people with Spina Bifida. Somewhere along the CSF pathways, the flow of cerebrospinal fluid has been obstructed.

How is Hydrocephalus Treated?

Hydrocephalus is usually treated by insertion of a “shunt”. A shunt is a device which is designed to drain excess cerebrospinal fluid from the brain and carry it to other parts of the body.

A one-way valve is used, which usually sits outside the skull, but beneath the skin, somewhere behind the ear.

Please refer to the shunt information sheet.

Types of Hydrocephalus and terms commonly used

External Hydrocephalus

Fluid builds up around the inside of the skull, rather than within the brain in the ventricles

Congenital Hydrocephalus

Means present at birth. In congenital Hydrocephalus it is usually impossible to determine the cause. It is assumed to be due to the baby’s development before birth that somewhere the CSF pathways have been blocked.

Acquired Hydrocephalus

Develops often as a result of ‘injury’ to the brain . Bleeding in the brain is the most common cause of Hydrocephalus. Infections such as measles or meningitis can also cause Hydrocephalus.

Arrested Hydrocephalus

At some time there has been increased pressure causing enlarged ventricles, but it did not continue to progress. It is the progression of pressure that causes the damage.

Normal pressure Hydrocephalus

Often occurs in older people. Dementia type symptoms may develop and often bladder control and unsteady gait develops.

SHUNTS AND THEIR SYMPTOMS

What is a shunt?

Hydrocephalus is usually treated by insertion of a shunt. A shunt is a device, which is designed to drain excess cerebrospinal fluid from the brain and carry it to other parts of the body.

A one way value is used, which usually sits outside the skull, but beneath the skin, somewhere behind the ear.

What are the symptoms of a malfunctioning shunt?

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

- Headache
- Vomiting
- Fever
- Irritability and personality changes
- Lethargy and drowsiness
- Dizziness
- Changes in vision
- Seizures

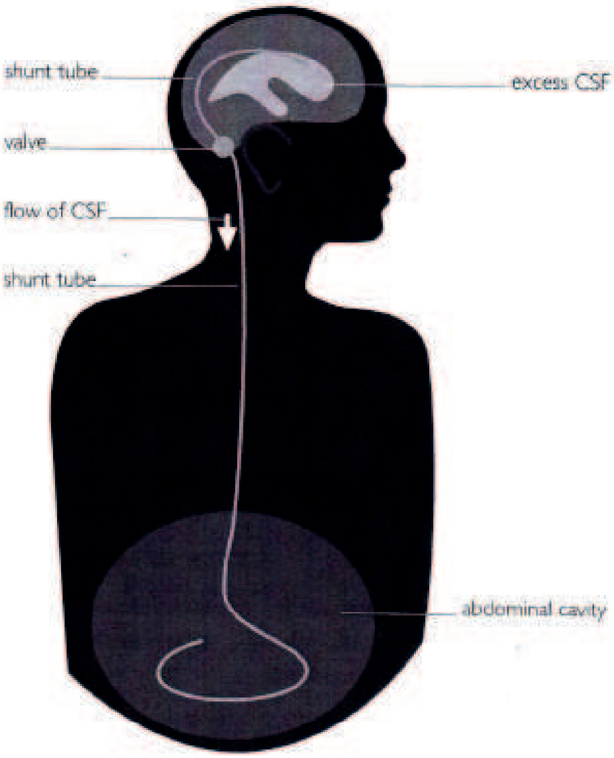


Diagram Sourced –
The Brain & Spine Foundation, Hydrocephalus & Shunts 2012

Shunt revision

As a shunt is often inserted in infancy, at some time, most adults with Hydrocephalus will have had a shunt revision. Shunts can become blocked, disconnected or outgrown by the person. A shunt revision is surgery to the shunt to 'fix' the problem if there have been symptoms experienced.

ARNOLD CHIARI MALFORMATION

The Arnold Chiari malformation, sometimes referred to as the Chiari II malformation or ACM, is an anomaly of the brain, which occurs in almost all people born with Spina Bifida and Hydrocephalus. It mainly involves the lower brainstem and lowermost portion of the cerebellum, but the anatomy of the whole brain is affected.

When the Chiari Malformation is present, the brainstem is elongated, and displaced into the opening of the base of the skull and top of the spinal canal. It is often kinked. The brainstem, cranial nerves and the lower portion of the cerebellum may be stretched or compressed. Therefore, any of the functions controlled by these areas may be affected.

The brainstem is the origin of many of the nerves which control the heart, breathing, blood pressure and help control swallowing, sneezing and coughing.

The cerebellum controls the maintenance of posture and coordination of muscle action, to produce precise, coordinated movements.

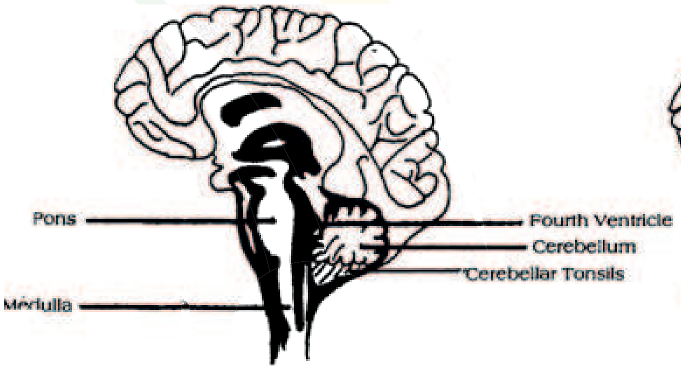
Symptoms in adults are:

- swallowing difficulties
- dizziness
- unsteady gait
- neck pain
- arm weakness

If any of these symptoms are present, medical advice is needed.

Treatment may involve decompressing the brainstem by surgically removing part of some of the cervical vertebrae and the lowest part of the skull.

Anatomy of Normal Brain



Anatomy of the Chiari Malformation

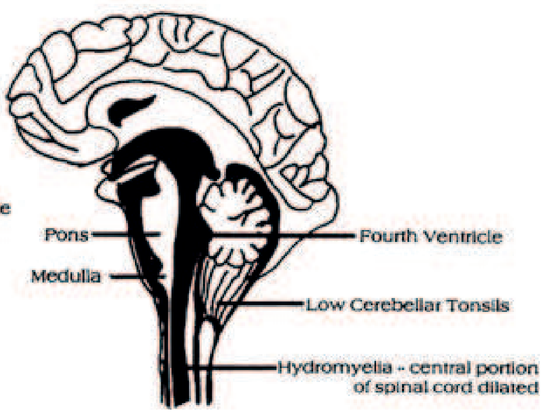


Diagram Sourced –
The Chiari Malformation, J.Frost RN.

MEDICAL IMPLICATIONS OF SPINA BIFIDA

Spina Bifida is a lifelong medical condition which requires ongoing monitoring and management.

The medical implications of having Spina Bifida may impact upon a person's normal routines such as work or study to varying degrees.

Doctors Appointments

Regular doctors appointments are required to monitor a person's health. Some of these appointments are only available on specific spinal clinic days which are dictated by the hospital.

In order to see specialist doctors, travel to major hospitals may be required. This may impact upon amount of time required off work or study.

Latex Allergy

- Many people with Spina Bifida have an allergy to natural rubber Latex
- Allergies may present as a rash or as a hay fever type reaction
- There is a link between increased exposure to latex and increased allergic reactions
- It is important to minimize exposure to latex

Continence Routine

- Most people with Spina Bifida are required to follow a continence routine
- It is important that regular toilet breaks are allowed

Operations

Spina Bifida is an ongoing condition which requires ongoing management. This management may involve operations and therefore time off work.

For some operations the person may be informed well in advance, however there may be operations which are required at short notice.

LEARNING AND COGNITION

What is cognition?

A simple way to define cognitive skills is to describe them as the underlying brain skills that make it possible for us to think, remember and learn.

These are the skills that allow us to process the huge amount of information we receive each and every day and respond appropriately to that information.

Difficulties with learning and cognition are more common amongst people with Spina Bifida and Hydrocephalus (SBH), particularly due to the impact of Hydrocephalus on brain function. Common cognitive difficulties experienced by people with SBH include:

- Attention and concentration
- Thinking and motor speed
- Short-term memory / new learning
- Understanding incoming information
- Expressing thoughts and ideas
- Perceiving and making sense of visual information
- Higher level or 'executive skills' such as planning, organizing, sequencing and monitoring

Can cognitive skills be improved?

Unfortunately, there is no quick fix or cure to cognitive difficulties. However, there are strategies to help minimise the impact of these problems on your daily life. Strategies can be grouped into two main approaches:

- Compensatory strategies – these aim to optimise function by focussing on using intact functions. In other words, using your strengths to compensate for your areas of difficulty
- Adaptive strategies – these aim to change the task or the environment in which the task is done to allow success with the task

So when you realise you are facing a particular problem due to problems with memory, concentration, planning or another cognitive function, ask yourself these key questions:

- What could I do differently?
- How could the task be changed?
- How could the environment or the circumstances be changed?

MEMORY

Aspects of Memory

Immediate or short term memory – encoding of information. Putting new information into your memory.

Delayed memory – retention and retrieval of information stored.

Long term memory – long term storage of information. Procedural e.g. cleaning your teeth and declarative e.g. memory of events or facts.

Prospective memory – remembering to use information when it's required.

Strategies to help immediate memory problems

- Make sure you are paying attention when you are trying to learn something new
- Focus on one activity or thing at a time
- Repeat information back to the person to ensure that you have understood it
- Keep distractions at a minimum
- Remember to use your strengths ie verbal or visual
- Elaboration – get more details
- Compatibility – how does this fit with what I already know?
- Self reference – how is this relevant to me?

Strategies to help delayed recall problems

- Use memory aids e.g. a diary, notebook or whiteboard and write it down
- Use checklists and reminders
- Keep organised ie do the same things at regular times
- Rehearse information that needs to be learned e.g. go over it in your head, or if written read it again and again
- Use clues/cues e.g. leave things that are needed in a prominent place such as leaving your bag near the door to remind you that you need to take it
- Ask others to prompt you when they notice that you have forgotten something

Strategies to help prospective memory

- When you think of something that needs to be done, try to do it immediately
- Set a timer or alarm that will go off when the most important tasks needs to be attended to e.g. phone reminder
- Place a note in a prominent spot
- When taking medication, use a segmented pillbox or set out the medication for the day and label it

Ideas for your environment

- Notepad beside the phone
- Large noticeboard for planning
- Special place such as drawer or basket for keeping items which tend to go missing
- Label or colour code cupboards
- Tying objects to places

Memory Aids

- Diary
- Notebook
- Lists and checklists
- Alarm clock, wristwatch alarm and timer
- Calendar
- Wall chart
- Tape recorder or dictaphone
- Smart phone
- Electronic organiser
- Pill reminder box
- Post it notes
- Memory book
- Mobile phone
- Apps

ATTENTION AND CONCENTRATION

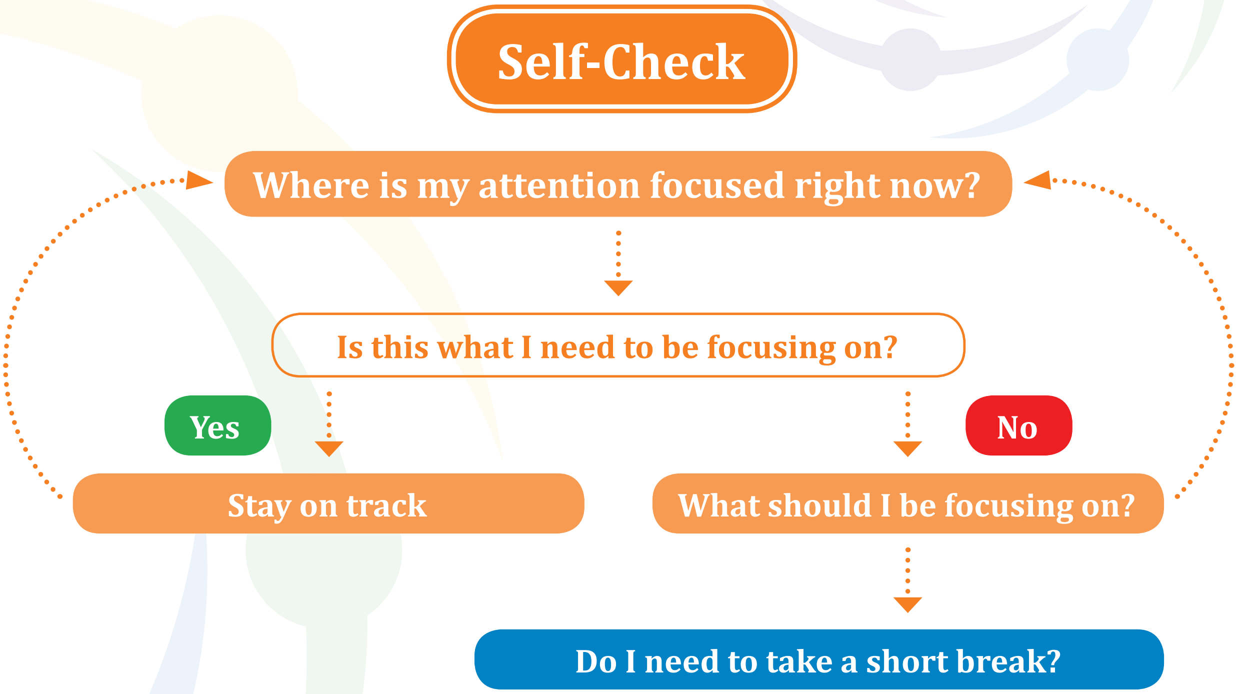
What do difficulties with attention and concentration look like?

- Difficulty concentrating while reading, listening or following conversation (sustaining attention)
- Becoming easily distracted from tasks e.g. starting something and then moving onto something else (selective attention)
- Forgetting things because we are caught up in thinking about something else (alternating or shifting attention)
- Having trouble managing more than one task at a time (divided attention)

Strategies for managing attention and concentration problems

Managing problems with sustained attention:

- Plan frequent breaks when completing long tasks
- Do important tasks at a time of day when you know you will be more alert
- Alternate between tasks of varying interests
- Break large tasks into smaller ‘bites’
- Set priorities and make plans
- Use to do lists to keep you focussed on your goals



Self-Check

Where is my attention focused right now?

Is this what I need to be focusing on?

Yes

Stay on track

No

What should I be focusing on?

Do I need to take a short break?

Managing problems with selective attention:

- Avoid distractions
- Turn off radio/TV
- Move to a quiet area
- Clear work space
- Choose a time of day when most alert to complete more challenging activities
- Verbal cueing
- Use technology e.g. audiotape
- Alternate between tasks of varying interest (physical or mental)
- Use strategies to keep you on track
- Make notes
- Use alarms
- Use checklists
- Environmental organisation e.g. set a time
- Symbol or reminder cards

Managing problems with divided attention:

- Structure activities so that they can be completed one step at a time
- Avoid activities for which there is a high demand to process information concurrently or make multiple responses
- Minimise disruptions

VISUAL PERCEPTION

Visual perception is the ability to gather visual information from the environment and integrate them with our other senses. It involves the ability to identify, sort, organize, store and recall visually presented information.

Visual perception problems which are common to people with Spina Bifida and Hydrocephalus include:

- Recognising faces
- Recognising objects
- Noticing details
- Finding things
- Writing and drawing neatly
- Following maps or plans, e.g. assembly instructions
- Negotiating gutters or stairs
- Avoiding obstacles
- Reading, giving or getting directions
- Visualizing objects or past experiences
- Remembering things visually
- Eye hand coordination e.g. in ball games

Managing visual perceptual difficulties

- Modify your surroundings e.g. object locations, use bright colours on corners and edges
- Magnify writing and or increase contrast
- Turn your head/body to make sure you scan the whole environment
- Visually scan whole document or map/plan
- Keep environment as simple and consistent as possible and reduce clutter
- Use a systematic and paced search to find a desired object
- Substitute other senses e.g. use touch to find an object in the fridge
- Avoid high risk situations e.g. climbing ladders, may need to avoid driving

INFORMATION PROCESSING

What do problems with information processing speed look like?

- Taking time to register information

  Example – Notice that things have started or changed.

- Taking time to process information

  Example – When someone is speaking, taking a while to understand what they are saying to you.

- Taking time to respond to information

  Example – Taking a while to respond to someone when they ask you a question, or having difficulties with moving quickly when needed.

Strategies to help improve difficulties with information processing speed?

- Allow yourself more time to complete tasks
- Structure activities to allow self-pacing
- Make others aware that it may take some time to process and respond to information. They may be able to assist with changing the expectation and setting realistic goals

  Example – Is it better to be fast or accurate?

- Get written copies of information
- Practice and repeat tasks to improve performance speed and accuracy
- Investigate whether there are any technology options to enhance speed

  Example – Using recording devices, video recorders, digital pens etc.

EXECUTIVE SKILLS

Executive skills refer to the higher level cognitive skills that allow us to plan, direct and monitor our thoughts and activities. These functions are localised in the frontal lobe structures of the brain and allow us to participate in goal directed behaviour that is appropriate to the given situation and circumstance.

Executive skills include

- **Initiation** – Getting started on a task in a timely fashion
- **Motivation and Persistence** – The capacity to follow through to completion of a goal
- **Goal Setting** – Being able to define what is the desired goal
- **Planning and Organisation** – To plan/ follow a path to the goal, keeping track of what step you're at; keeping track of information. The ability to estimate how much time one has and how to complete tasks on time.
- **Problem Solving** – Identify problems along the way and ways of addressing them
- **Flexibility** – The ability to revise plans in the face of obstacles, setbacks, new information or mistakes; to adjust to change either in task, environment, or for example when goals change
- **Self-monitoring** – To look at and reflect on ourselves and our behaviour
- **Self-regulation** – To alter our behaviour, thought, actions in response to above – the capacity to think before you act
- **Insight and Awareness** – To be aware of ourselves as well as the world at large. The ability take in the big picture, overall understanding of how things/situation works, foresee consequences
- **Metacognition** i.e. thinking about thinking – The ability to look at oneself in a situation and think about how you solve a problem and to question "How am I doing?" or "How did I do?"

Managing problems with initiation i.e. getting started on tasks

- Make sure that problems are not being confused with anxiety or depression (seek appropriate help if this is considered to be the cause)
- Make lists of tasks that need to be completed for that day and start at the top
- Set alarms for when to commence or continue a tasks
- Ask others to help keep us motivated or to provide gentle prompts
- Use positive self-talk "I can do this"
- Use rewards for a job well done!

Managing problems with persistence or motivation

- Write a list of everything you have to do
- Number the list starting with 1 being most important
- Start at #1 and KEEP going until it's done
- Ask others to help keep us motivated or to provide gentle prompts
- Use positive self talk "I can do this"
- Reward yourself

Managing problems with planning and organisation

- Most goals will have a number of mini steps so to keep things in order so you can see both what you have to do and see progress happening
- Use external aids such as whiteboards and calendars to plan activities (timeframe, equipment needed etc.)
- Use checklists and goal statements with step-by-step plans to organise events
- Have at least your next step set out ahead of you

Managing problems with problem solving

- Give yourself time to think
- Brainstorm to see if there are other options
- Talk to other people to gather other ideas
- It's OK to ask for help
- It's OK to try things and they not work out the first time

Managing problems with self monitoring/regulation

- Use self-talk and try to delay responses
- e.g. use STOP – THINK – DO

  STOP – what am i doing?
  THINK – is this appropriate?
  DO – what should I do instead?
- Count to 10
- Regularly check your work, go back often to see if you have made any mistakes (correct once these are noticed)
- Ask loved ones, or colleagues to provide you with feedback about your performance – take it as constructive advice, not criticism

Managing problems with insight and self awareness

- Get educated about the cognitive effects of Hydrocephalus, and make sure others are educated too
- Obtain formal assessment of your cognitive strengths and weaknesses, or conduct a self assessment
- Ask others for feedback

PERSONAL CARE

Looking after yourself as you get older may mean you need to re-think how you do some of the everyday tasks of daily life. How you get around, how you shower, how you manage things within the home can all have an affect on your overall health and well-being.

Mobility and Transfers

The affects of getting older may mean a change to the way you get around.

For walkers

- Know your limits and allow extra time to get places
- Take rest breaks as you need them
- Walking aids such as crutches and sticks may offer support and safety

For wheelchair users

Propelling yourself in a wheelchair on a daily basis over many years does have a significant impact on your body. As you get older, you may start to feel the impact on your joints, particularly your shoulders, and on your posture. (More information is available in the "Joint Health" information sheet about taking care of your joints.) It may be time to consider some equipment changes that can help to minimise the impact on your body of full time wheelchair use.

Some possibilities include:

- A higher and/or more contoured back rest to give you more postural support
- A lighter weight wheelchair frame to make propelling and lifting your wheelchair less challenging
- Using power assist attachments on your wheelchair to make it easier to manage long distances, slopes and rough terrain
- Use of a motorised wheelchair or scooter

Showering

People often get very "set in their ways" about bathroom routines or are limited in the ways they do things by the physical layout of the bathroom. As you age however you may no longer be able to transfer in and out of the shower or bath as you have been able to previously.

Equipment and ideas to make things easier in the bathroom:

- Use of a static or mobile shower chair
- Hand-held shower hose
- Non-slip matting if you stand in the shower (remember to consider if you need a latex free option)
- Long handled washing and drying devices

- Modification to the layout of the bathroom e.g. to provide a stepless shower area
- Support services – if you are no longer able to shower safely and independently, you may be eligible for assistance from a community service

These services can be accessed via **Community Care Access Point – Phone: 1800 600 300**

Household management

Cooking meals, cleaning the house, doing the shopping, taking out the rubbish... all these kinds of household tasks are hard for most people, but as you get older you may find them increasingly overwhelming.

Tips:

- Cook in larger batches and freeze individual serves for later
- Make sure your kitchen layout i.e. the bench heights, are suitable for you to minimise the effort needed to do things in the kitchen
- Make use of time saving gadgets and appliances e.g. robotic vacuums, clothes dryers, automatic vegetable slicers, online shopping
- Support services – you may be eligible for assistance from a community service to help with house cleaning

These services can be accessed via **Community Care Access Point – Phone: 1800 600 300**

CONTINENCE

Continence is the ability to exercise voluntary control over the bowel and bladder.

Many people with Spina Bifida are incontinent, that is, they are unable to control their bowel and bladder discharge resulting in involuntary loss of urine (urinary incontinence) or faeces (faecal incontinence).

People with Spina Bifida generally have what is termed a “neurogenic bladder and bowel” which means that there has been an interruption to the communication between the nerves of the spinal cord and the bladder and bowel. This results in the brain not being able to control the muscles that coordinate bladder and bowel function.

What happens if continence is not well managed?

Possible health impacts:

- Not managing bowel continence issues can lead to an overloaded bowel. This can result in kidney damage, UTIs, and can cause the bowel to become obstructed, which may be a life-threatening emergency. Episodes of ‘overflow’ (bouts of uncontrollable, explosive ‘diarrhoea’) is caused by chronic overloading and is treated by clearing out the bowel.
- Not managing bladder continence can lead to urinary tract infections and if ongoing, to kidney failure – refer to the Kidney Health information sheet.
- Being wet or soiled is linked to skin problems, particularly it can make you more prone to pressure wounds.

Possible social impacts:

- If you have lived with urinary and or faecal incontinence issues for all of your life, you are often less aware of “accidents”. Those around you, however, are most likely very aware. Incontinence can limit your ability to make friendships, engage in work or any other social activity.
- Complications with sexual activity.

Options for managing urinary incontinence

Urostomy – common management option prior to the 1970s. A urostomy is a surgical procedure that creates a stoma (artificial opening) for the urinary system. The stoma is generally created in the abdominal wall and it allow urine to pass directly into a collection pouch.

Clean Intermittent Catheterisation (CIC) – common management option from the 1970s onwards. This option involves passing a catheter directly into the bladder at regular intervals to allow for the drainage of urine. The catheter can be inserted through the urether or through a created stoma.

Continence pads – pads worn in the underwear are often used by people to manage the leakage of urine, either between catheterisations or if they manage their toileting normally but have occasional incontinence due to urgency.

Bladder augmentation – a surgical procedure which increases the size of the bladder by surgically attaching a portion of bowel to the bladder. By increasing the size of the bladder, its capacity to hold urine is increased. People usually continue to use CIC in conjunction with this procedure.

Artificial sphincter – An artificial sphincter is a device which consists of three main parts – a fluid filled cuff, a pump and a small balloon reservoir. The cuff is placed around the urethra to act like a muscle and control the flow of urine from the body. The artificial sphincter is inserted surgically. The cuff is released by pressing the pump which sits in the scrotum for the male and in the labia for the female. The fluid then moves from the cuff into the balloon reservoir. This is just like releasing your muscle. A catheter is then inserted and urine can flow out. The fluid from the reservoir slowly flows back into the cuff to tighten the urethra again. This allows you enough time to do your catheter before the cuff is tightened again.

Mitrofanoff procedure **(also known as “stoma procedure” or “Yang procedure”)** – a surgical procedure to create a passage from the bladder to the outside wall of the abdomen to allow for drainage of urine. Catheterisation is then done directly through the stoma in the abdomen wall. This procedure is particularly useful for those people who find it difficult to reach to complete direct urethral catheterisation.

Options for managing bowel incontinence

Regular toilet routine.

Use of enemas.

MACE procedure (Mitrofanoff Antegrade Colonic Enema) or Malone procedure – surgical procedure which creates a passage from the top part of your bowel to the wall of the abdomen. This allows for an enema solution to be placed through the stoma into your bowel to thoroughly wash out the bowel from the top downwards.

Anal irrigation (such as the Peristeen system) – a system of emptying the lower part of the bowel by slowly introducing warm tap water into the rectum. A catheter is inserted into the rectum and held in place by a balloon. A hand held pump pushes water through the catheter into the bowel. When the balloon is deflated and the catheter removed, the contents of the bowel are discharged.

Being prepared...

Plan ahead – check toilet locations – are there accessible toilets available? There is an app available that shows nearby locations with accessible toilets. Use toilets when you have a chance – even if this means going before your scheduled time.

Check your bag – have you got enough catheters, pads, undies and change of clothing, medications, deodorant or powder, a plastic bag for wet or soiled clothes?

Continence Equipment/Supplies

In Queensland, there are two types of subsidies available for continence supplies:

- Medical Aids Subsidy Scheme (MASS) – a state government scheme that subsidises the cost of continence aids. Applications can be made with assistance of a Registered Nurse or Occupational Therapist
- Continence Aids Payment Scheme (CAPS) – an Australian government scheme that provides a payment to assist eligible people who have permanent and severe incontinence to meet some of the cost of their continence products. Information and application forms are available at **www.humanservices.gov.au/customer/services/medicare/continence-aids-payment-scheme**

Housing options

- Private rental
- Home ownership
- Building a home
- Share houses
- Public housing
- Community housing
- Housing with shared support

Private rental

Many people rent their homes either directly from owners or through real estate agents. Rental costs vary according to the size of the property and the location. Rental websites, such as www.realestate.com.au can provide information about the average rental costs in a given town or suburb.

Assistance available to private renters

Residential Tenancies Authority – the RTA provides tenancy information, bond management, dispute resolution, investigation, policy and education services for people renting privately (tenants). You can contact the RTA for any information about the legislation, your rights and responsibilities when renting. They can be contacted at: 1300 366 311 or www.rta.qld.gov.au

Rent Assistance – financial rent assistance to people who receive a Centrelink payment and who are living independently in private rental accommodation. The fortnightly amounts payable depend on the amount of rent you pay, your marital status and whether you have any children or dependents. Find out more: www.humanservices.gov.au/customer/services/centrelink/rent-assistance

Bond Loans – a rental bond is money that you pay at the beginning of a tenancy that the lessor/agent can claim if you owe money for rent, damages or other costs at the end of the tenancy. Rental bonds are held by the Residential Tenancies Authority and are usually equivalent to four weeks rent. A Bond loan is an interest free loan to people who cannot afford to pay a full bond when moving into rental accommodation. Bond loans are available through the Department of Housing and are paid back on a monthly basis. For more information: www.qld.gov.au/housing/renting/bond-loan

RentConnect – this is a government service which helps people to find and apply for a place to rent. This can be a particularly useful service if you are having trouble finding a property which suits your needs e.g. one that is accessible enough, or if you do not have a rental history. More information is available at: www.qld.gov.au/housing/renting/rentconnect

Tenants Union of Qld – is a specialist community legal sevice that provides tenancy legal advice. They assist and represent renting housholds. A free statewide advice service for Queensland residential tenants is available. For advice: 1300 744 263
www.tuq.org.au

Making modifications to a private rental home to improve the accessibility of the property

When renting a home privately, it is necessary to request the written permission of the landlord to have any modifications carried out, even for minor jobs. The landlord has the right to refuse the completion of any modifications. If permission is granted, the lessor/agent should outline what changes have been approved and any terms to the agreement.

If this permission is given by the landlord, assistance to complete minor modifications may be available through the Home Assist Secure service. **Home Assist Secure** is a state government service for elderly people or people with a disability. They provide assistance with home maintenance, repairs and small modifications, such as the installation of step ramps or grab rails. For minor modifications, you usually pay the cost of materials and the service provider meets the cost of the labour.
www.hpw.qld.gov.au/aboutus/reportspublications/factsheets/pages/homeassistsecure.aspx

Home ownership

Assistance available for home owners

First Home Buyers Grant – The Queensland government offers first home owners a grant of $15000 towards the cost of buying or building a new house. Eligibility criteria and how to apply can by found by calling 1300 300734 or at: **greatstartgrant.osr.qld.gov.au**

Queensland Housing Finance Loan – The Queensland housing finance loan may be available for Queenslanders who can afford to buy or build a home but cannot get private finance from a bank or building society. This loan can be used to buy an established house, unit, town-house or duplex, or to build a house. More information:
www.qld.gov.au/housing/buying-owning-home/qld-housing-finance-loan

Modification Services – home owners are generally able to access **Home Assist Secure** for small modification jobs, in the same way as discussed above for private renters. For major modification projects, such as bathroom or kitchen adaptations or ramps, assistance can be found through government funded major home modifications services. These services are managed by different agencies according to your region. Information about which service to contact can be found by calling your local **Community Access Point on 1800 600 300**.

According to your eligibility and financial circumstances, these services generally subsidise up to 50% of the cost of the modification.

Public (or social) housing

The state government provides rental housing at a lower cost for people with low income and specific needs. It aims to provide safe, secure, affordable and appropriate housing for people who have difficulty meeting their housing needs in the private housing market. Public housing is provided through the Department of Housing and Public Works (many people still refer to this type of housing by its previous name, Housing Commission).

The rent for public rental accommodation can be a lot cheaper than private rental accommodation. The rent is dependent on income and for people on the Disability Support Pension it is about 25% of the pension.

Renting through the Department of Housing is relatively secure i.e. tenants are usually able to rent a dwelling indefinitely. If an application is approved, the applicant's name goes on a waiting list. Applicants nominate six suburbs they prefer to live in. Some areas are more popular than others and therefore may have longer waiting times. The demand for public housing is very high and the waiting time can be a number of years. So, if you think public housing may be a good option for you, submit an application and get your name on the list as early as possible.

Eligibility

To be eligible for public housing it is required that you meet certain criteria. These criteria depend on your residency, whether you own a property, age and your household income.

You can check your eligibility on the department's website:
www.Qld.Gov.Au/housing/public-community-housing/eligibility-for-housing

How to apply

To apply for public rental housing you need to complete an "Application for Public Housing Form" and provide other documentation. You can visit your nearest Housing Services Centre or check their website at:
www.Qld.Gov.Au/housing/public-community-housing/apply-for-housing

Public housing for people with disability

People with a disability can be housed through the Department of Housing's public housing program. People with any type of disability physical, intellectual, sensory or psychiatric, which affects their housing need, can apply to receive assistance to find appropriate housing. Many people with a disability have very specific housing needs, such as modified bathrooms, kitchen or access and the Department does try to meet these needs whenever possible. Your specific housing requirements may also impact on the level of priority your housing application receives, so be sure to give as much information about your disability and housing needs at the time of your application.

Therefore if you require specific home modifications, they can supply housing that will meet your needs or if you are already in public housing they will supply modifications to that home. An occupational therapist from the Department of Housing will assess your needs.

Community housing

Community housing is a service whereby the Department of Housing and Public Works funds non-profit organisations and local governments to provide housing and support.

Crisis accommodation

The Department of Housing and Public Works funds not-for-profit incorporated community-based organisations and local governments to provide short-term housing for people who are homeless or at risk of homelessness, in crisis and/or in need of transitional support in the move towards independent living.

Transitional accommodation

Transitional accommodation is provided through the **Community Rent Scheme** (**CRS**). The Department of Housing funds non-profit, community-based organisations to provide short to medium-term accommodation for people on the public housing wait list who have **qualified for public housing** and are on the waiting list and are in severe and immediate housing need.

Long term accommodation

Long-term Community Housing is a program designed to involve local government and non-profit community organisations in the provision of locally managed long-term rental housing for low income earners whose needs are not adequately met by other housing options.

The eligibility criteria are generally the same as for public housing and applications for community housing are made through the public housing system. It can be useful however to make yourself known to any local community housing organisations and let them know about the urgency of your housing situation. Community housing organisations can nominate potential new tenants when they have a housing vacancy.

Housing with shared support

Housing with shared support helps people with disability support needs to live in the community with ongoing support. This type of public housing helps groups of people with support needs to live together (or close to each other) so they can share services.

Eligibility for public housing with shared support

To be eligible to be a part of a shared support house you must:

- Complete an individual “Application for Public Housing Form” and be eligible for housing
- Have a disability funding support package (approved by Disability Services – 13 74 68)
- Agree to enter into a public housing with shared support arrangement with the disability support agency
- Agree to live together and/or in close proximity with other individuals in public housing for the purpose of sharing the support you will all receive

MONEY MATTERS

Money management can be difficult at the best of times and it is often complicated, especially if you are on a limited income. Keeping track of expenses, bill payments and entitlements and negotiating who or where you can go for help can be confusing and difficult to find.

Having Hydrocephalus can also impact on your learning and understanding and on your ability to judge, plan and stick to a budget. With the implementation of strategies and ongoing support, these difficulties can be minimised.

Money Management strategies

- Ask someone to help
- Ask someone to help you break information down into smaller parts
- Break your tasks (money handling , bill payments, budgeting) down into smaller steps
- Ask someone to check your steps
- Repeat back instructions so they become clearer
- Use memory strategies such as like diaries, checklists, notes
- Use IT technology, budgeting apps, planners, memory and reminder apps
- Use bill payments and direct debit systems

Budgeting

The dreaded "B" word! It's difficult and requires motivation, perseverance, persistence and diligence. But it can be done!! A budget is essentially looking at what money comes in and what money goes out. Before looking to manage your budget, you must first get a good handle on understanding what money you get in and then how you are spending your money.

Below are some links to websites that could be of assistance in helping you manage this further:

www.moneysmart.gov.au
www.humanservices.gov.au

iPhone™ and smart phone apps can be useful aids in assisting monitoring your budget and daily spending habits. Here are some budgeting apps that might help:

- TrackMySPEND
- Visual Budget
- Budget Tracker

Other Helpful ways to make your money go further

- Have a loose change jar – place your loose change in a jar and at the end of the week use it for a personal purchase. Or save it up and put it in the bank.
- Use a weekly cash allowance – give yourself a weekly cash allowance – place this in folding money in your wallet. This is your personal budget for the week – it can be helpful to actually see how much you have rather than using a plastic card all the time.
- Direct debit – have all your bills direct debited on your pay day. This way all the big things are out of the way and you know how much money you have left for yourself.
- Watch for the Hidden Costs of living – these are the costs we pay, but don't really think they matter, but of course they do. They are the small amounts that often add up the most! Examples are mobile phones and their ring tones, wallpapers and messages, online apps and games, iTunes™ Store, etc.
- Beware of contracts and plans. Often things like foxtel, gym memberships, phone contracts have you signing up over lengthy time periods which you are then contracted to for that time. Check the overall amount for affordability before your sign!
- Watch for door to door salespeople – if you are thinking something sounds too good to be true – it often is!
- Avoid fines – This sounds basic ,but fines can add up! Late library books / late DVD rentals all add up. If you drive – avoiding speeding, this is costly in many ways. Parking fines can also be a huge expense.
- Every time you use another ATM it can cost you up to $2 or more. Make sure you know where your own bank's ATM's to avoid fees or use EFTPOS, where there are no extra fees.

Pensions/Concessions and eligibility

If you are not working, the Disability Support Pension will be your main source of income. The eligibility criteria and other related concessions can be accessed by the Centrelink website. On this website is a useful tool called "The payment finder" which will help you look for possible further assistance and concessions. Some of these might be:

- Mobility Allowance
- Rent Assistance
- Continence Payment Scheme www.humanservices.gov.au

Some other subsidies you might also qualify for:

- MASS, CAAS and CAEATI www.health.qld.gov.au/mass
- Taxi subsidy, Parking permits and transport www.tmr.qld.gov.au/Travel-and-transport/Disability-access-and-mobility.aspx

Other Government Departments

Office of Public Trustee – they offer impartial financial advice and assistance to people with disabilities who may run into difficulties and have no other means of assistance: www.pt.qld.gov.au

Office of Adult Guardian – The Office of the Adult Guardian is an independent body, working to protect the rights and interests of adults who have an impaired capacity to make their own decisions: www.justice.qld.gov.au/justice-services/guardianship/adult-guardian

NDIS – Changes. As from 2016 Qld will start to introduce the NDIS. If you are eligible, this means you might have more control over where and when you get services from. You will also get more control on how you spend the money you receive to help cover the costs of your disability.
www.communities.qld.gov.au/disability/key-projects/national-disability-insurance-scheme

EMPLOYMENT

Link up with an employment service

Many people find the best place to start in terms of finding a job is by joining an employment service. The commonwealth government funds disability specific employment agencies which should have greater capacity to help you in your job search. To access this help, you need to start by making an appointment with Centrelink – **www.humanservices.gov.au/customer/dhs/centrelink**

Your employment agency should be able to assist you in developing a list of potentially suitable jobs. To help you identify what kind of work might best suit you, consider some of the following:

- Make a list of things you enjoy doing. Consider tasks that you are good at, like fixing things or number problems
- Make a list of your personal attributes: Are you outgoing and sociable? Do you prefer doing things alone?
- Make a list of the things you find difficult, (this is not to be negative about yourself – it's all about considering your strengths and weaknesses to develop areas of work you may enjoy and be suited to)
- List any qualifications
- List any work experience
- Be realistic about the hours you are capable of and want to work

Your employment service will be able to assist you in this process of identifying suitable jobs to apply for, considering if you would benefit from getting extra training or qualifications, creating a CV and completing job applications.

Be pre-prepared in developing strategies to manage difficulties

Managing medical issues

- Be realistic about the number of hours you are able to work if you are likely to have ongoing frequent medical appointments or hospitalisations related to surgery.
- Ensure you have medical information, like lists of medications and allergies available for your employer.
- Ensure you have developed an effective continence routine

Managing physical and mobility issues – Many employers are probably apprehensive about their ability to accommodate a worker with mobility difficulties. You can re-assure them that many difficulties can be easily accommodated with quite minor adjustments, such as the re-arrangement of furniture to improve space for manoeuvring a wheelchair or the installation of grab rails in a toilet cubicle. If more major modifications to a workplace environment are required, the commonwealth government may be able to provide funding for this through the Job Access initiative – **www.jobaccess.gov.au**

Managing cognitive issues – such as memory and learning problems. Most people with Hydrocephalus experience some problems with tasks requiring concentration, memory, and organisational skills. It's probably best to explain these issues upfront with your employer, rather than waiting to deal with them once they have begun to cause difficulties with your work performance. These difficulties can usually be managed with a variety of strategies, such as using memory aids like diaries, requesting written instructions for tasks and using highlighters to clarify important information.

Prepare for interviews

Practise interview skills – try to anticipate some of the questions you may be asked in the interview. You could even get a friend or family member to do a "mock interview" with you.

Do some homework on the company or organisation – there is often a lot of information on websites. A background knowledge of the company shows that you are interested in them and the job and can give you a competitive edge.

Work out how you will get to the interview and make sure you have plenty of time for unexpected hold ups. Getting to the interview on time is imperative to the first impression your potential new employer has of you.

Consider in advance how you will respond to questions in relation to your disability. A potential new employer does not need to know a lot of detailed medical information, but they will want to know how your disability may affect your ability to do the job. Remember that these questions give you the opportunity to place a positive "spin" on your abilities. For example, you can explain that although your disability does cause some short term memory difficulties, that you manage this through the use of a diary. This demonstrates your initiative with dealing with difficulties.

Adjusting to a new work situation

Starting a new job is an exciting time, but it can require some adjustments too.

Support mechanisms – your Disability Employment Service should be able to offer some support during your "settling in" time in a new job. Also ask if it's possible to have a contact person or mentor in the organisation with whom you can discuss issues, e.g. telling if you are feeling unwell or anxious, and also ask questions. The impacts of Hydrocephalus may mean you struggle to learn new routines, so ask for written instructions whenever possible. People are usually very happy to answer questions related to the job, but they probably don't want to be asked the same thing multiple times, so why not write down your questions and then write the answer down alongside.

Disability specific issues – generally speaking, most people have very little (if any) understanding of Spina Bifida and Hydrocephalus, so it's fair to say that they will have very little understanding of how it may impact on your work. Therefore, it's really up to you to communicate that. If you think you may need assistance with certain tasks, ask politely for it, rather than expecting that people should know you need help. Communication is the key. ☺

Managing fatigue – entering into employment usually involves a very significant change to your routine and timetable. Long hours at work, as well as in travel time, can leave many people feeling exhausted. Even with jobs that don't involve a lot of physical activity, there is still a lot of energy required in maintaining your concentration over an extended period and in decision making. Managing fatigue is an important means by which to make your working life sustainable and enjoyable. This may require limiting other outside work activities until you get more used to the new routine and taking care of yourself physically by eating well and getting enough sleep.

Volunteering

Working on a voluntary basis is a great option for many people. For some, it is a means to gain skills, experience and confidence as a stepping stone to paid employment. For others, it is an avenue to give their time which provides its own sense of achievement and satisfaction.

If you are interested in finding opportunities for volunteer positions, contact Volunteering Qld. www.volunteeringqld.org.au

TRANSPORT

Being able to access the community is vital to fulfilling many people's goals. Transport is the key to getting out and about and accessing community activities.

There are a variety of schemes and services which are available to people with disabilities to increase their ability to access their community through transport. These schemes include:

Taxi Subsidy Scheme

The QLD Taxi Subsidy Scheme subsidises taxi journeys for people with severe disabilities. Visit the website to download an application form:

www.qld.gov.au/disability/out-and-about/taxi-subsidy

Council cabs

Contact your local council to enquire about the Council Cabs scheme. For eligible persons, shared taxis at scheduled times may be available to assist residents with disabilities to access their local shops.

Community transport services

Visit the Queensland Government's community transport page to find out more about what is available in your area:

www.qld.gov.au/disability/out-and-about/community-transport

Translink Access Pass

The TransLink Access Pass is a travel pass for people with a significant permanent disability who can **a**) travel independently on TransLink services, and **b**) demonstrate that due to their significant permanent disability they are unable to independently use a "**go card**". See the Translink website for more information:

www.translink.com.au/resources/tickets-and-fares/other-tickets/access-pass-application.pdf

Disability Parking Permit

An Australian Disability Parking Permit is granted to applicants when their ability to walk is severely restricted by a medical condition or disability.

An application form is available on the Department of Transport and Main Roads website:

www.tmr.qld.gov.au/disabilityparking

A non-refundable fee is required. The application form will need to be supported by your doctor or occupational therapist.

Transport for Medical appointments

Queensland Ambulance Service

Provides non-emergency patient transport for:

- Pre-arranged visits to a medical facility for ongoing treatment
- Transfer between medical facilities for specialist treatment

The Queensland Ambulance Service must have at least 24 hours notice for bookings.
An authorisation certificate from a doctor is required for non-emergency patient transport.

Contact the Queensland Ambulance Service on 13 12 33 for details or bookings:

www.qld.gov.au/emergency/emergencies-services/ambulance.html

The Patient Travel Subsidy Scheme

Contributes to the cost of transport and accommodation when specialist services are more than 50 kilometres from the referring hospital. A doctor's referral to the specialist service is required.

www.qld.gov.au/health/services/travel/subsidies

Public Transport

South East Queenslanders have access to public transport in the forms of bus, train and ferry services. The Translink website www.translink.com.au has information, timetables and a journey planner. The journey planner provides information about public transport options between any given starting point and destination. The cheapest option for using public transport in South East Qld is by getting a "**go card**". The go card provides cheaper fares than buying a paper ticket and concession cards are available. Information is also available on the Translink website about wheelchair accessibility of services and stations.

Personalised public transport (PPT) operates in areas where TransLink services are restricted. Black and White Cabs provide wheelchair accessible and air conditioned maxi-cabs.

PPT services:

- Carry up to 10 people
- Pick up passengers where safe to do so on a fixed route

DRIVING

Driving can by a key way of increasing your level of independence and community access. However, the physical and cognitive affects of Spina Bifida and Hydrocephalus may have an impact on your ability to drive or influence how you drive.

If you are interested in pursuing the option of driving independently, the following steps are suggested:

- **Get a medical certificate**

  It is a requirement by law to disclose any medical condition that may impact on your ability to drive, to the Department of Transport and Main Roads. Information is available about this at the Department's website:

  www.tmr.qld.gov.au/Licensing/Medical-condition-reporting/Medical-requirements.aspx

- **Get your learner's permit**

  Getting your learner's permit involves completing an application form, paying a fee and a written test at transport customer service centre. The written test involves 30 questions and you can prepare for this by reading the "Your keys to driving in Queensland" booklet. Online practice tests are available.

- **It is recommended that you have an Occupational Therapy driving assessment**

  The Occupational Therapy assessment will involve an off-road assessment of your physical and cognitive capabilities and then an on-road assessment. Through this assessment the Occupational Therapist can assess your fitness to drive, and make recommendations about any car modifications that may be required to allow you to drive independently and safely.

- **Practice driving**

  Learner drivers are required to keep a log book to record their driving practise. If you require a modified vehicle with hand controls in which to do your driver training, please contact SBH Qld for contacts.

- **Take the practical driving test**

Vehicle Options Subsidy Scheme

The Queensland Government offers a subsidy scheme to enable people with disability to have improve access to driving and private car transport.

For those eligible for the program, VOSS contributions are available to subsidise the costs of:

- Having an Occupational Therapy assessment
- Some driving lessons
- The purchase cost of a vehicle
- The cost of modifying a vehicle

The Department of Communities, Child Safety and Disability Services (DCCSDS) determines if you are eligible for VOSS. Contact your local DCCSDS service centre for assessment and referral:

www.communities.qld.gov.au/disability/contact-us/disability-services-regional-offices

Did you know??

SBH Qld's Occupational Therapist is able to complete your OT driving assessment with you and can also assist with VOSS applications for people in SE Qld.

Spina Bifida Hydrocephalus Queensland

medicare local
METRO NORTH BRISBANE
Connecting health to meet local needs

COMMUNICATION

Having Hydrocephalus has affected the frontal lobe of the brain. Among other things, this is the area of the brain that helps us manage language and communication.

We often hear people say that general communication is up to 93% non verbal. The non-verbal language within communication is the very thing that has been affected by Hydrocephalus. Picking up non verbals and understanding the subtle flow of conversation is very difficult for someone with Hydrocephalus.

It is important to recognise that these difficulties are part of the condition. There are strategies that might work.

Some of the common difficulties are around

Comprehension difficulties

- Problems understanding what people mean
- Reading difficulties
- Difficulties picking up on non-verbal cues i.e. body language
- Problems recalling the meanings of some words
- Problems maintaining your attention when listening
- Difficulties understanding complex language e.g. jokes, puns, sarcasm and metaphors

Expression difficulties

- Difficulties finding the correct words when speaking e.g. mixing words up, using filler words such as “um” or “err”
- Problems getting your ideas across to others
- Problems with writing tasks
- Disorganised conversation
- Conversation which goes off track
- Conversation where the point and sequence are not clear

What can you do about problems with language?

Comprehension

- Minimise distractions when listening is important
- Ask the speaker to slow down, repeat what they have said, say something in a different way, or to make it more simple
- Ask the person to write the information down for you
- Highlight the key information in written material
- Let people know that it may be difficult for you to grasp the more subtle aspects of communication e.g. that it is better for them to ‘call a spade a spade’

Expression

- Allow yourself time to think of the words, try to avoid becoming frustrated. Sometimes silence is OK in a conversation
- Try to think of another word with a similar meaning to the one that you want
- Try to talk around the word e.g. describe it, rather than name it
- Try to picture the object in your mind
- Use other modes of communication e.g. hand gestures, writing
- Rehearse what needs to be said with a family member
- Have safe topics prepared – if you know you struggle thinking of topics to talk about have some safe topics ready. NOT politics, religion or controversial subjects

BUILDING PERSONAL AND SOCIAL NETWORKS

Building personal and social networks is different and often more challenging as an adult than when you were younger. Without the structure of school and family to encourage you, it can become increasingly difficult. Having Spina Bifida and Hydrocephalus could also cause barriers both physically and emotionally – all these could result in you feeling isolated and alone.

Lack of transport, lack of finances and low motivation play a big part in the reasons why we say to ourselves it is all too hard BUT regardless of this, if you want to meet more people and do more, you must 'just do it'... Because... as an adult, it is up to you! You must be the person to take responsibility. So how can you make this happen with limited resources?

Where to build your network

- Find your passion. What are your interests and skills? What are the things you like to do?
- Look at your local community – Read your local newspapers to find out about local events
- Local councils often have free community activities or groups to join such as neighbourhood centres and local craft groups
- Attend sporting groups, gyms and swimming centres. Sporting Wheelies offers both a gym and recreational activities
- Consider internet dating, friendship groups or book clubs

How to build your network

- List the names of people who can help you. These will be people who you like and trust, and whom you feel also like you.
- Surround yourself with people who give you give support, encouragement and advice then you are more likely to enjoy some kind of success
- Ask someone to go with you on the first occasion to a new outing
- Get out of your comfort zone – Make new discoveries, new friends, do new ideas often and without fear. If you don't try you'll never know
- Embrace challenges and make mistakes – they can be our greatest teachers. Be confident!
- Define your goals – make it concrete –and break it into steps. If the steps are not clear actions you haven't gone far enough
- Let go of the negative – it doesn't help you in any way

Have a positive attitude – this opens up possibilities, alternatives and therefore influences your actions and outlook. Having a positive outlook leads to more positive outcomes – or at the very least the possibility to learn from any mistakes/failures. Studies are proving that if you're a happy and positive person you will be drawn to other positive and happy people. And likewise – unhappy people will find themselves in the company of unhappy people

Wheelchair accessibility and Physical Assistance

- You can't assume others SHOULD know what your needs are... you need to do the checking, and if something isn't accessible, YOU need to negotiate a new venue etc.
- Check access to toilets too. If there isn't one in the venue, check where the nearest may be. There are apps on mobile devices that can assist with this.
- You need to be clear on the level of assistance you require (helping up ramps, balance) – again don't assume that others should know.
- Know your own condition – By understanding the areas of SBH that might affect you, you can start to work on strategies to help, particularly when faced with new social situations.

Staying safe in new friendships or relationships

Its important to remember a few tips when you are heading out in new situations. Some of these sound basic, but they can mean the difference between having a good time or being caught out in unfamiliar territory. These tips can be used for any social situation or for negotiating a new friendship or relationship.

- Meet and stay with a group of friends
- Meet each other in a public place
- Have the person meet your friends and family
- Leave names and phone numbers of where you are going
- Use a mobile phone
- Drive yourself or use a cab to meet someone new
- Don't hang around with someone who is abusive (verbally or physically)
- Maintain your individualism
- Maintain your own interests and accept that they have their own
- Maintain your other friendships
- Do your own thing as well as things together
- Never allow the person to use your disability in a negative way

MENTAL HEALTH

Mental health refers to our psychological wellbeing and is about how we see and feel about ourselves, how we deal with the ups and downs of life and how we manage our emotions.

Our mental health and physical health is closely linked and when one falters, the other risks being weakened.

Looking after our physical self is important. Having Spina Bifida and Hydrocephalus means there has always been since you were born a focus on your physical health and that needs to remain the case. There also needs to be an ongoing focus on your emotional and mental health. As you age and you have different experiences throughout your life your mental wellbeing may fluctuate.

In the past there has been stigma surrounding mental health issues which resulted in many people feeling scared or ashamed to speak up when they knew that something was not right. When our heart has problems we go see a cardiologist. When our kidneys run into trouble we go see the urologist. When our emotional health or mental wellbeing are feeling damaged or weakened then it is time to talk to someone who can help.

There are many strategies to assist manage mental health issues. This might be through counselling, therapy, or medication. There are many community services equipped to help and chances are you have people in your life that would be willing to support you as well.

We know that people with SBH are more likely to experience anxiety, depression, low self worth and suicidal thoughts than the general population. Having SBH brings with it difficult life experiences that may contribute to mental health issues for some people. Not everyone with SBH will have mental health issues but at some point in their lives many will. How well we cope with the ups and downs of life varies from person to person. How well we cope also varies at different times in each person's life.

Having good mental health is not just about the absence of mental health issues or illnesses. It is also about building strengths and strategies and positive characteristics. We will all go through hard times, face change and experience stress and disappointment. There are things we can do to help protect ourselves.

Tips for better Mental Health

- Learn to recognise and understand your emotions. Patterns, triggers, behaviours might become apparent.
- Build confidence – understanding your strengths and weakness gives you tools and strategies to manage in different situations.
- Build resilience – This is about how you recover from negative or difficult experiences. How you 'bounce back' from life's knocks.
- Have people who you trust and who support you. Look after and find comfort and enjoyment in friendships.
- Manage your physical health.
- Nurture yourself with good sleep, nutrition and exercise. These are all important for both mind and body.

- Develop a number of relaxation strategies to help you unwind and manage stress and anxiety.
- Maintain an awareness of activities that can become negative – e.g. alcohol may seem like it helps in the short term but a reliance on it can impact on mental and physical health. Other examples might be avoiding or denial of problems, self harm and using drugs.
- Make time for things you enjoy.

Types of Mental Health Illnesses

There are many different mental health conditions. Some of the more common are:

- Depression – see information sheet
- Anxiety – see information sheet
- OCD
- Phobias
- Post Traumatic Stress Disorder
- Panic Attacks
- Bi-Polar
- Schizophrenia

Who can help?

There are options included here for information and counselling, for talking face to face, on the telephone or online. If you are concerned about yourself or someone you know please reach out and contact one of them.

- **000** – if there is immediate concern for safety call emergency assistance
- **Your GP**
- **Psychologist, Social Worker, Counsellor**
- **Local hospital / community mental health centre**
- **Mental Health Association QLD** – Support and information about mental illness www.mentalhealth.org.au
- **Lifeline** www.lifeline.org.au – 13 11 14 – phone support 24/7. Free from mobile phones, local call cost from landline + Crisis Support online chat 8pm-4am + Online information and resources + Referral to local services lifeline.serviceseeker.com.au find a range of services in your local area

- **Beyond Blue** www.beyondblue.org.au – 1300 224 636 – phone support 24/7 + online chat option + Online information and resources + Referral to local services
- **13 HEALTH** – 13 43 25 84 (Qld) – 24 hour assessment, referral, advice and hospital and community health centre contact details
- **Salvo Care Line** – 1300 36 36 22 – 24 hour / 365 days a year phone counselling, referral to local services
- **Suicide call back line –** 1300 659 467
- **SBH Qld**

Depression Facts

* On average, 1 in 7 in Australia people will experience depression in their lives[6] Most will not seek assistance.
* Depression is the number one cause of non-fatal disability in Australia (24%).[7]
* People with SBH are more likely to to experience anxiety, depression, low self worth and suicidal ideation than the general population. [2/3/4]
* Stress, especially chronic stress, plays a role in depression.[11]
* Alcohol abuse positively associated with major depression in adults with SBH.[3]

Suicide in Australia Facts

- * At least 6 Australians die from suicide and a further 30 people will attempt to take their own life every day.[8]
- * Suicide is the leading cause of death for young people aged 15-24.[9]
- * Australians are more likely to die by suicide than skin cancer.[5]
- * More women attempt to take their own lives (and survive).[5]
- * Males are at greatest risk suicide but least likely to seek help.[5]
- * Suicide and attempted suicide figures are likely to be underreported due to difficulty determining intention and stigma around self harm.[5]

References

(1) Mental Health Council of Australia.

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Journal of Pediatric Psychology, 1997.

(5) Black Dog Institute factsheet.

(8) *The Hidden Toll: Suicide in Australia* Report of the Senate Community Affairs References Committee. The Australian Senate (2010). Commonwealth of Australia, Canberra.

(9) *Causes of Death, Australia.* ABS: Canberra. Australian Bureau of Statistics (2012).
ABS 3303.0 2010.

DEPRESSION

What is Depression?

Depression is more than feeling sad or down. We can all experience down days but some people experience sadness, feeling down or miserable intensely for long periods – weeks, months, even years. Sometimes you might know what is causing you to feel this way, other times you might not.

If these feelings continue for a long time it can be confusing for you, and for other people who have noticed changes in you and know that something is wrong.

Depression is a serious medical condition and has an impact on both your mental health and physical health. It can interfere with many aspects of daily living including your independence, your mobility, and your ability to manage personal care. It can change how much and how well you sleep, alter your appetite, and your interaction with other people. If you are studying or working having depression can make it difficult for you to perform well.

Depression will impact how you see and feel about yourself. Your self confidence and self esteem might be low and you may have difficulty finding the motivation to do even the things that once gave you enjoyment.

For some people it might feel like all the very basic things that make life worth living are gone and they may feel so overwhelmed they have suicidal thoughts or consider suicidal behaviours.

When is it depression?

- The mood state is severe
- It lasts for 2 weeks or more
- It interferes with your ability to function in your daily relationships and activities

Signs of a depressed mood include:

- Lowered self-esteem (or self-worth)
- Change in sleep patterns – unable to sleep or wanting to sleep much of the day
- Changes in appetite
- Significant weight loss or gain
- Decreased ability to control emotions such as pessimism, anger, guilt, irritability and anxiety
- Unable to enjoy what’s happening now, or look forward to anything with pleasure
- Hobbies and interests drop off
- Withdrawal from family and friends
- Reduced pain tolerance
- Poor concentration and memory

- Reduced motivation – it doesn't seem worth the effort to do anything, things seem meaningless
- Lowered energy levels
- Feeling overwhelmed all the time
- Thoughts like: "I'm a failure", "Nothing good ever happens to me", "I'm worthless"

Depression and SBH

People with SBH **are more likely** to experience depression and anxiety than the general population.

Diagnosing depression in people with disabilities is somewhat complicated as some depression indicators could be attributed to the physical condition itself (e.g. pain, infection, shunt problems) or to treatment and medications so it is important to rule out other causes of symptoms.

There are a number of things about having a disability that may impact on a person's mental health and contribute to depression:

- Cognitive effects of SBH
- Mobility issues associated with SBH may mean less exercise and more sedentary lifestyles
- Lowered energy levels
- Feeling isolated and/or 'different' from peers
- Managing periodic and/or chronic pain
- Cumulative effect of coping with surgeries, hospitals, tests, doctors and disability
- Worry about the future – SBH brings with it an unknown future medically. SBH is a complex condition where the effects of ageing are only now being unveiled as the first wave of people with SBH are living into their 50s and beyond thanks to the invention of the shunt to manage Hydrocephalus
- Negative experiences at school/employment
- Discrimination
- Lack of understanding of disability in the community – stares, comments, judgements

People with SBH are just like anybody else. Having a disability may contribute to having depression but it is important to not assume that it is the only reason. Not everyone with SBH will experience depression. How well a person copes with the ups and downs of life depend on many factors. Sometimes so much focus is given to the disability that other factors get missed.

Understanding depression will help you and the people supporting you to develop a plan to help manage it.

Tips to help manage Depression

Seek help and talk about it – Talk to family/friends you trust. Talking to a trained professional can help – a counselor, social worker, psychologist or your GP.

Take baby steps – There is no quick fix and no definite timeframe for depression. It is different for each person. It might seem like progress is slow but every step forward is progress.

Have a routine – Routines can really help when motivation is low. Try getting up at the same time each morning, exercising, even if it is for only 10 minutes. Routines encourage movement while depression feeds on and encourages inactivity.

Get the 'Thought Police' working – Allowing negative thoughts and worries to build up leads to feeling down. Shut down the negative thoughts quickly.

Trust – Trust in those who love and support you. Learn who is there to help and who is being unhelpful. Trust in yourself.

Take care of yourself – Your mood affects your physical health and vice versa so try to get enough sleep; good nutrition; manage and maintain your general health.

Keep active – exercise is a proven mood enhancer.

Stay engaged with activities and social networks –It might feel hard at times to do but you might just feel better afterwards.

Follow all medication directions if you are prescribed some by your doctor. This is very important.

Give yourself a break – On the days when it seems too hard try not to beat yourself up. It's a good idea not to make big decisions on these days either. Tomorrow is a new day.

Give yourself some time – You may have difficulty expressing negative emotions to others not wanting to worry other people or be judged. Many people find it hard to talk about things that are really bothering them and some of the cognitive effects of SBH make it that bit harder. It might be hard to process your thoughts and feelings into words or sometimes you might feel you have not been given enough time by others to express yourself. Let the person know that you might need that bit of extra time (e.g. book a longer appointment at the GP) so you don't need to feel rushed.

Treatment of Depression

Counselling and/or Therapy – to help explore the causes/ triggers of emotions and find healthy ways of managing depression. Some of the people who can help are GPs, Counsellors, Social Workers and Psychologists.

The Better Access initiative provides access to mental health professionals through Medicare. Talk to your GP for a referral.

Medication – some forms of depression respond to medication, others do not. A doctor can diagnose the type of depression and whether medication is appropriate for the individual.

Physical Activity – exercise is proven to have a positive influence on mood so whilst feeling the least like doing any physical activity, it is the most important time to get active.

If you find the person/professional you try to talk to about feeling depressed or anxious doesn't react the way you think they should – go to another. Feeling comfortable and being listened to is important.

How can SBH Qld help?

- We run intensive programs – Island Retreat GOALS Program, REACH Wellbeing Group (Black Dog Institute)
- Fortnightly Download and Reboot Support Group for people with SBH dealing with depression, anxiety, grief and loss, loneliness
- Counselling and support from Social Workers
- Information and Resources

Resources for Depression (and Anxiety)

- **Lifeline** www.lifeline.org.au – 13 11 14 – phone support 24/7. Free from mobile phones, local call cost from landline + Crisis Support online chat 8pm-4am + Online information and resources + Referral to local services lifeline.serviceseeker.com.au find a range of services in your local area
- **Beyond Blue** www.beyondblue.org.au – 1300 224 636 – phone support 24/7 + online chat option + Online information and resources + Referral to local services
- **13 HEALTH** – 13 43 25 84 (Qld) – 24 hour assessment, referral, advice and hospital and community health centre contact details
- **Black Dog Institute** www.blackdog.org.au
- An excellent book – "**I Had A Black Dog**" Matthew Johnstone. Pan Macmillan Australia 2005
- **SBH Qld**

Being depressed is not a sign of weakness.

You do not have to deal with depression on your own.

There are people who can help.

Depression Facts

- On average, 1 in 7 in Australia people will experience depression in their lives[6] Most will not seek assistance.
- Depression is the number one cause of non-fatal disability in Australia (24%).[7]
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References

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(5) Black Dog Institute factsheet.

(6) *National Survey of Mental Health and Wellbeing: Summary of Results*. ABS: Canberra
Australian Bureau of Statistics (2009). ABS 4326.0,2007.

(7) *The Burden of Disease and Injury in Australia*, AIHW: Canberra.
Australian Institute of Health and Welfare (2007).

(10) *The global burden of disease: 2004 update*. World Health Organisation (2008).

(11) *Depression and Anxiety fact sheet*. Spina Bifida Assoc. www.spinabifidaassociation.org

ANXIETY

What is Anxiety?

Everyone experiences anxiety from time to time. Anxiety might be anything from an uneasy feeling in the mildest form to a panic attack at its most severe. It is a feeling of worry or dread and is accompanied by a range of physical symptoms.

Anxiety itself is part of life. Most people will be able to identify something that causes them to feel anxious. It is different from stress in that stress usually fades once the trigger is over or removed (e.g. stress about a job interview will ease once it's over). Anxiety persists after the event or trigger has passed and can affect daily activities and life (e.g. anxiety about meeting new people might lead to you avoiding social situations resulting in limited friendships and social life).

Anxiety can be about a real threat (e.g. failing a test you haven't studied for) or a perceived one (e.g. 'if I go in a lift it will fall and I'll die').

One of the biggest causes for anxiety is fear of change, which is about us wanting to know exactly how things will turn out. Not knowing means we are not in control. Things might go as we want, or they might not. Anxiety pushes us to fear the outcome and hesitate. The experience of anxiety is often far worse than facing or doing what we're anxious about. Procrastination fuels anxiety and keeps us stuck in one place.

If we don't push past it, anxiety can stop us reaching for goals, achieving things that are really important to us and living the life we want to lead.

Anxiety can be debilitating and exhausting. If anxiety is affecting your daily activities and quality of life it's important to get some help.

Anxiety and Spina Bifida and Hydrocephalus (SBH)

People with SBH are more likely to experience anxiety (and depression) than the general population.

Cognitive effects of SBH contribute to anxiety and can make managing anxiety a little more complex.

These difficulties can impact on the ability to problem solve, see alternatives and foresee consequences of actions. These cognitive issues may also mean difficulty processing emotions, organising thoughts and being able to express those thoughts to another person. A person with SBH may feel it is not OK for them to express negative emotions; they do not want to be seen as a burden or to be judged.

Having a disability adds more stress to a person and can trigger anxiety.

SBH brings with it an unknown future medically. SBH is a complex condition where the effects of ageing are only now being unveiled as the first wave of people with SBH are living into their 50's and beyond due to the invention of the shunt to manage Hydrocephalus.

What does Anxiety look/feel like?

- In your feelings – tense, apprehensive, nervous, fearful, embarrassed, overwhelmed
- In your thinking – expecting that things will go wrong, taking things personally, catastrophising about problems or thinking things are only either good or bad (or failure or success), difficulty making decisions
- In your behaviour – Restlessness, being easily startled, speaking rapidly, being irritable, avoiding situations, being overly dependent on others, easily tearful
- Physical sensations – racing heart, muscle tension, trembling, dizziness, feeling faint, difficult breathing, sweating

Tips to deal with Anxiety

- **Breathe** – long deep breaths
- **Relax muscles** – clench then relax. Repeat.
- **Allocate worry time** – 10 mins to worry about it, then stop and move on
- **Externalise it** – get it out of your head and might give new perspective
  - Write it down –Try a pro/con list
  - Talk about it – with someone you feel is rational
- **Put it in perspective** –
  - Will it matter in a weeks time... 6 months?
  - On a scale of 1 – 100 of life events... Where does this really sit?
- **Master Self Talk** – What that voice in your head is saying to you is important. Make sure you listen to the positive voice “I will get through this” “Keep going, you can do it”
- **Distract yourself** – it’s hard to focus on multiple things
- **Know that this feeling WILL pass**
- Trust yourself – trust your judgement and your ability to learn from the outcome.
- **Exercise** – as with depression exercise has shown to be useful in helping reduce symptoms of anxiety
- **Getting enough sleep, good nutrition and managing general health** – are all important
- **Be as organised as you can** – good planning and time management really help

Anxiety is a legitimate health issue and as we would seek help for other health issues, it is important to reach out if you feel you are struggling with anxiety. You do not have to deal with it on your own and you might be surprised how much it helps just to talk about it with someone else.

Who can help with Anxiety?

- **Your GP –** The Better Access initiative provides access to mental health professionals (up to 10 individual and 10 group consultation sessions) through Medicare
- **Psychologist** – private or through community health service
- **Social Workers or Counsellors**
- **Lifeline** www.lifeline.org.au – 13 11 14 – phone support 24/7. Free from mobile phones, local call cost from landline + Crisis Support online chat 8pm-4am + Online information and resources + Referral to local services lifeline.serviceseeker.com.au find a range of services in your local area
- **Beyond Blue** www.beyondblue.org.au – 1300 224 636 – phone support 24/7 + online chat option + Online information and resources + Referral to local services
- **13 HEALTH** – 13 43 25 84 (Qld) – 24 hour assessment, referral, advice and hospital and community health centre contact details
- **SBH Qld**

What can SBH QLD do to assist someone with Anxiety?

- GOALS programs
- Download and Reboot support group fortnightly for people with SBH dealing with depression, anxiety, grief and loss, loneliness
- Counselling and support from ASSIST Social Workers and Occupational Therapist

What can you do if someone with SBH is experiencing Anxiety?

- Remind the person to breathe – long slow breathes will calm many of the physical symptoms
- Talk about the anxiety – a way around it might be able to be identified
- Listen without judgement
- Break down tasks into small manageable steps
- Check the person understands the task/ what is expected of them. Get them to repeat/explain it back to you in detail
- Write things down for the person or get them to write it down so they don't have to worry about remembering
- Checklists work well
- Identify a backup plan
- Encourage the person to trust their abilities
- Encourage the person to seek help for the anxiety if it affecting their daily activities or causing distress

Spina Bifida Hydrocephalus Queensland

medicare local
METRO NORTH BRISBANE
Connecting health to meet local needs

GRIEF AND LOSS

When we hear the word grief, we tend to think of death and the loss of a loved one. Grief and loss can be about much more than death and this is the grief and loss we are talking about here.

We can experience grief with the pain and loss of just about anything – an object, a goal, a hope, a friendship.

Grief is a normal response to a loss. A loss might be a real or actual loss e.g. loss of health; a job; a relationship; having your car or possessions stolen. A loss can also be a perceived loss which is something that was hoped for but had not yet happened e.g. loss of the 'white picket fence' marriage, kids and a dog ideal; loss of a career not yet embarked upon; loss of a much loved dream.

They are a loss because they meant something to us and when facing up to them being gone we experience an emotional reaction.

Understanding that loss and the feelings it evokes sit on a spectrum can be helpful. Some losses may be experienced as much greater than others and two people who experience the same or similar loss might react very differently because the loss means something different to each of them.

There is no right way to grieve. Some people get angry, others cry. Some want to talk about it, others may withdraw. Similarly there is no right amount of time for grief to pass.

Grief is an emotion universal to all human beings. We all experience grief but our emotional reactions are unique to each individual. This can help explain why we do not always understand why someone we know seems so upset about something when to us it does not seem like a big deal.

Elisabeth Kubler-Ross[15] outlined the 'Five Stages of Grief' to help describe the journey through grief and loss.

- **Denial** – Shock and disbelief. Try to deny what has happened to avoid/lessen the pain.
- **Anger** – You might lash out or want to blame yourself or others. Bottled up or explosive emotions.
- **Bargaining** – The if only phase…if only you could go back in time and change things.
- **Depression** – Emptiness on a deep level. This is not the same as clinical depression and is not a sign of mental illness but an appropriate response to significant loss. Withdrawal from others and regular activities.
- **Acceptance** – Accepting the reality, learning to live with what is. Finding a way forward and to engage, grow and move on.

The stages can last minutes, hours, days, weeks or months. Grief does not progress through the stages in order but may bounce back and forth in all directions.

Grief and SBH

People with SBH experience grief like anybody else does. Having a disability and ongoing health issues can create many examples of loss and each person will experience that loss and work through their grief differently. Seeking support if you are struggling with grief, or offering support if you know someone struggling with grief is helpful.

Tips to help you through grief

- Give yourself time to grieve the loss you have experienced
- Acknowledge what the loss meant to you and what it feels like now it is gone
- Talk to someone you trust about your feelings
- Identify strategies to work through your grief and loss (these might be different depending on the type of grief or loss you have experienced)
- If you are concerned that you may be experiencing something more than grief, possibly clinical depression seek support and diagnosis
- Use healthy outlet for emotions rather than bottling them up – e.g. some people like to write journals, do creative/artistic activities
- Exercise – be it activity to give you quite time to process the loss e.g. walks or swimming or high energy activities e.g. boxing or Zumba™ that help release anger and frustrations
- Setting new goals – these may be small, to have something to work towards/ look forward to

How can SBH Qld help?

- Fortnightly Download and Reboot Support Group for people with SBH dealing with depression, anxiety, grief and loss, loneliness
- Counselling and support from Social Workers
- Information and Resources

References

(15) "*On Death and Dying*" Elisabeth Kubler-Ross. Macmillan [New York]. 1969.

SUICIDE

When a person’s mental health deteriorates or they experience an intense or emotional situation they may have thoughts of suicide or self harm.

Depression is closely linked to suicidal thoughts and behaviours. However it must be noted not everyone with depression will consider suicide and not everyone who considers suicide will have depression.

Whether it is from an inherited mental health condition, the reaction to a specific critical situation or the building up over time of experiences, emotions and the inability to deal with them, the person may feel such profound feelings of hopelessness, sadness and isolation that they are unable to see a way through the situation. Harming themselves might be seen as a coping mechanism to help deal with pain, or as a way to communicate to others about how they are feeling.

What might contribute to a person having suicidal thoughts?

- Feeling they don’t belong
- Loss of a loved one
- Relationship breakdown
- Experience of trauma
- Violence or bullying
- Drugs/ alcohol abuse
- Financial difficulties
- Fear of future
- Feeling a burden to others
- Loneliness and social isolation
- Failure in study or employment

Sometimes a person might be open with their feelings or thoughts of suicide but more often the clues are far more subtle.

It is imperative to address the issue of suicide if expressions of hopelessness; revelations the person feels it would be better if they were not here; or indications of them finalising their affairs/ saying goodbye is picked up on.

Mental health and people with SBH

Having a disability is known to increase a person's risk of experiencing depression and anxiety, both of which if not managed well could lead to suicidal thoughts and behaviours. Added to the above list of things that may contribute is:

- Higher prevalence of depression and anxiety for people with SBH compared to the general population
- Discrimination or judgements based on disability
- Chronic pain
- Uncertainty of the future – ageing with SBH is largely an unknown path
- Health/ medical situations and complications
- Cognitive issues associated with SBH (see below)

People with SBH experience cognitive difficulties which can impact on their ability to problem solve, see alternatives and foresee consequences of actions. These cognitive issues may also mean difficulty processing emotions, organising thoughts and being able to express those thoughts to another person. A person with SBH may feel it is not OK for them to express negative emotions, they do not want to be seen as a burden or to feel further judged.

What should you do if you think someone with SBH might be suicidal?

- Ask the person if they have/ are having suicidal thoughts. It might seem difficult to broach but it is important
- If you believe a person to be in immediate danger call 000 (This can include a police welfare check if you are not with the person but believe them to be in danger)
- Make sure the person has direct and online contacts to support services
- Encourage them to talk about their feelings
- Find out who the person sees as helpful and trustworthy
- Ask open ended questions to encourage the person to talk (rather than yes/no questions)
- Remain calm and listen without judgment
- Encourage and assist them make an appointment with an appropriate professional
- Be clear with the person if you have exceptions to confidentiality

While you may not feel comfortable or skilled to deal in any depth with a person who may be considering suicide you can be the person who assists them link with people and resources that can help. You can be the person who makes a difference in someone's life.

What is NOT helpful to do/say to a person who is/may be suicidal?

- Stay away or avoid them or the issue
- Tell them to “snap out of it” or “get it together”
- Tell them to “stay busy” or to “get out more”

Who can help?

- **000** – if there is immediate concern for safety call emergency assistance
- **Local hospital / community mental health centre**
- **Mental Health Association QLD** – Support and information about mental illness **www.mentalhealth.org.au**
- **Lifeline** **www.lifeline.org.au** – 13 11 14 – phone support 24/7. Free from mobile phones, local call cost from landline + Crisis Support online chat 8pm-4am + Online information and resources + Referral to local services **lifeline.serviceseeker.com.au** find a range of services in your local area
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- **13 HEALTH** – 13 43 25 84 (Qld) – 24 hour assessment, referral, advice and hospital and community health centre contact details
- **Salvo Care Line** – 1300 36 36 22 – 24 hour / 365 days a year phone counselling, referral to local services
- **Suicide call back line** 1300 659 467

What can SBH Qld offer to someone who is suicidal?

- Support and counselling from ASSIST Social Workers
- Fortnightly Download and Reboot Support Group for people with SBH dealing with depression, anxiety, grief and loss, loneliness
- Information resources and referral

Suicide in Australia Facts

- At least 6 Australians die from suicide and a further 30 people will attempt to take their own life every day.[8]
- Suicide is the leading cause of death for young people aged 15-24.[9]
- Australians are more likely to die by suicide than skin cancer.[5]
- More women attempt to take their own lives (and survive).[5]
- Males are at greatest risk suicide but least likely to seek help.[5]
- Suicide and attempted suicide figures are likely to be underreported due to difficulty determining intention and stigma around self harm.[5]

What can you do to strengthen your mental health?

- Seek help by talking to a professional for support and information (GP, psychologist, social worker, counsellor)
- Identify trusted and supportive people in your life
- Learn new ways to reduce and manage stress
- Maintain a healthy lifestyle (eat well, stay active/exercise, get quality sleep)
- Recognise triggers or warning signs
- Develop strategies to manage setbacks/ letting go
- Build resilience

Mental health issues are not a sign of weakness.

You do not have to deal with the situation on your own.

There are people who can help.

References

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JOINT CARE

Long term use of a wheelchair or other mobility aids can have a significant impact on the health of your joints. Arthritic joint changes, such as in the shoulders due to the ongoing strain of propelling a wheelchair and transferring, are increasingly prevalent and can impact on your level of independence.

How to prevent joint deterioration

Equipment

Ensure your equipment is well fitted and suited to your mobility needs.

- **For wheelchair users** – good positioning and equipment fit will allow for greater efficiency in wheelchair propulsion and therefore less strain on your joints. Postural support from your cushion and back rest can also assist in the prevention of spinal deformities such as scoliosis and kyphosis. An increasing range of power assist devices are now becoming available which give extra power to traverse rough terrain or manage hills or ramps whilst still maintaining your active mobility.
- **For people using walking aids** – such as crutches, sticks or orthotics, good equipment fit is essential to the prevention of joint strain. Correctly measured and fitted crutches or sticks will enable you to maintain a good walking gait pattern. If you have been recommended to use orthotics or splints, regular use of these will help to avoid extra joint strain.

If you have any concerns or queries about your mobility equipment, seek advice from a Physiotherapist or Occupational Therapist.

Activity

Ensure you remain as active as possible – there is a lot of truth to the old adage "Use it or lose it". Of course, activity levels need to be balanced within physical limitations. Be careful not to try to lift weights that are too heavy or overdo your exercise program. When completing regular home or work related tasks, make sure the work environment is set up to suit your needs. As an example, when cooking, bench heights should be in easy reach.

Nutrition

A healthy balanced diet helps to maintain the health of your joints. A good diet helps us to maintain a healthy body weight – this is important as there is a clear link between being overweight and developing arthritic joint changes. Foods which are rich in Omega 3 fats have been shown to help reduce inflammation, which can help our joints. Omega 3 fat rich foods include fish, fish oil supplements, linseed oil and walnuts. Please refer to the fact sheet on weight for further information.

Osteoporosis

Osteoporosis is a condition in which bones become fragile and brittle leading to a higher risk of breaks or fractures, than in normal bone. Osteoporosis occurs when bones lose minerals, such as calcium, more quickly than the body can replace them, leading to a loss of bone thickness (bone density or mass).

Early onset Osteoporosis (developing the disease in your 20s or 30s) occurs in almost 50% of adults with Spina Bifida. This increased incidence is the result of a number of factors, most particularly the lack of weight bearing exercise, such as walking, as weight bearing facilitates bone density. Other risk factors for Osteoporosis are being female, renal failure and some medications.

How can you help prevent Osteoporosis?

- Exercise
- Healthy eating – particularly foods rich in calcium and other vitamins and minerals
- Vitamin D intake – healthy diet in conjunction with exposure to sunshine
- Monitor caffeine and alcohol intake
- Avoid smoking

Ask your GP to consider a bone density check.

KIDNEY HEALTH

People with Spina Bifida often experience a higher incidence of urinary tract infections and the risk of chronic kidney disease is higher, however these problems can be prevented.

How to look after your kidneys

Drink Water!

It is recommended that everyone drink at least 2 litres of water per day. Drinking water allows the kidneys to better flush wastes out of your system and thus prevent infections.

Keep your blood pressure in the target range

Blood pressure puts a lot of stress on the kidneys. Keeping your blood pressure in the target range will help protect your kidneys.

Get treated for urinary tract infection (UTI) early

Get to know the symptoms of UTIs and see your GP straight away if you have an infection. Common symptoms of UTI include:

- Confusion
- High temperature
- Headache
- Cloudy urine
- Strong smelling urine
- General feeling of being unwell
- Back pain

Have regular medical checks of your kidney health

Remind your GP to do a full blood count every year. Also ask for a check of your blood pressure (see above) and ask whether a diabetes test is relevant to you (Diabetes can impact on kidney function).

Regular check ups with a Urologist are also recommended.

SKIN CARE

People with Spina Bifida generally have limitations to the sensation from below the mid trunk level. This means there is limited feeling in the lower body, which places people at risk from injuries to their skin, particularly due to pressure, friction or heat.

Common causes of skin problems

Burns

- When cooking or handling hot food
- From contact with hot seating or equipment such as seat belts in cars
- Sunburn on the legs or feet

Friction

- Transferring from a chair to wheelchair can result in scraping of buttocks over wheel
- Scraping on flooring

Pressure – remaining in one postural position for any extended period of time can result in a pressure area where bony prominences are pressed against any firm surface:

- On buttocks or sacrum from prolonged sitting in a wheelchair
- On heels from ill fitting splints

Prevention of skin problems:

- Always check for hot surfaces
- Use additional precautions when cooking e.g. use a thick towel when carrying hot foods on lap
- Use pressure re-distribution equipment e.g. wheelchair cushions at all times
- Check regularly that your pressure re-distribution equipment is in good condition and functioning correctly
- Check your skin on a daily basis – look at your skin by using a mirror or taking a digital photo; feel for any changes to your skin (lumps, pimples, warmth); ask someone to check it if you have any concerns
- Wear protective clothing when practical e.g. long pants and shoes
- Use good transferring techniques e.g. when getting on and off a wheelchair
- Regular forward and side leans for wheelchair users
- Don’t keep things in your pockets if this is going to cause pressure e.g. don’t sit onto a wallet in your back pocket

- Keep a very careful continence routine – wet skin is much more likely to break down quickly
- Maintain a good diet – protein, calories, vitamins A and C, zinc and iron are all important to maintaining the health of your skin

What to do if you get a pressure sore:

Keep pressure off the area!

Pressure, such as from sitting in the same position for extended periods, restricts blood being supplied to the area, so that tissues become deprived of oxygen, and toxins build up which cause the skin and tissue cells to die. This may mean having to spend some time not sitting up – it may well be worth spending some period of inconvenience early on rather than having prolonged hospitalisations and even surgery.

Seek medical assistance as soon as possible

- Check the area regularly – digital photographs are a great way to monitor any changes to the area and to show medical or nursing staff the development of the sore
- Do not massage the area with creams etc. if the skin is broken – this can make tissue damage worse
- Be extra careful about your skin hygiene, particularly your continence routine
- Seek advice about the appropriateness of your pressure redistribution equipment

Stages of a pressure area:

	DESCRIPTION	WHAT TO DO
Stage 1	Skin is not broken but is red or discoloured The redness or change in colour does not fade within 30 minutes of pressure being removed	Keep pressure off the area Maintain good hygiene (wash gently) Review your equipment, bed etc. If the sore does not heal in a few days or recurs, see a health professional
Stage 2	The topmost layer of the skin is broken Shallow open sore	As above Plus see a health professional to determine a course of treatment. This may involve cleansing the area with saline and applying a dressing.

Stage 3	Open and deep sore (extends down to the second layer of skin)	As above Plus see a health professional. Wounds at this stage will need frequent additional wound care such as special cleaning agents, debriding agents, irrigations or antibiotics
Stage 4	The wound breakdown extends into the muscle and can extend as far down as the bone. Usually lots of dead tissue and drainage are present	Consult a health professional immediately – this is very serious. Surgery is frequently required for this stage of wound.

Lymphoedema

Lymphoedema is a swelling in certain parts of the body due to fluid collection in the tissues under the skin. People with Spina Bifida are more prone to Lymphoedema due to poor circulation, particularly in their lower legs. Lymphoedema can result in skin breakdown, increased risk of cellulitis and can make mobility and transfers more difficult by increasing the weight of your limbs. Treatment of lymphoedema is possible with the use of pressure stockings or particular types of massage. Seek advise from your GP about this.

Cellulitis

Cellulitis is a bacterial infection of the skin that tends to occur in areas that have been damaged or inflamed, such as areas of lymphoedema. The affected area of the skin is red, hot, swollen and tender. There may also be discharge of fluid or pus. You may have a fever and feel unwell. Cellulitis can spread rapidly and should be treated as soon as possible. Seek help from your GP as antibiotics are often effective in the treatment of cellulitis.

Foot care

Poor circulation, loss of sensation and difficulties with seeing or reaching the feet mean that people with Spina Bifida are prone to problems with their feet. Regular check ups with a podiatrist are recommended for foot care. Regular use of moisturising creams can assist in prevention of skin cracking, which is important in the prevention of bacterial infections. It is also important to ensure your feet are kept dry to prevent infection – you may need to consider long handled showering and drying devices to facilitate this. Wearing supportive and protective footwear is important for both wheelchair users and walkers with impaired sensation in their feet in order to avoid cuts and scrapes that may not be felt or noticed.

WEIGHT

Maintaining a healthy weight can be a challenge to everyone, but more particularly to people who have restricted mobility. Healthy weight is vitally important, however, to long term health and independence. A healthy diet and regular exercise are key to maintaining a healthy body weight.

Nutrition

If you have reduced muscle bulk because of your Spina Bifida or if your mobility is restricted, you will need substantially fewer calories on a daily basis.

Some basic principles for good nutrition:

- Control your portion sizes – it may be useful to use smaller plate sizes to reduce the temptation to fill up the plate.
- Limit high fat and sugar content foods – easiest just not to keep them in the house.
- Check food labels for lists of ingredients and nutritional information – there is often a lot more "hidden" sugar and fats than you may at first think.
- Eat at regular meal times – this helps to reduce the urge for snacking
- Limit alcohol intake – calories from alcohol can only be stored as fat

If you are really struggling to maintain a good weight, seek help from your GP or a qualified Dietician.

The Australian Dietary Guidelines encourage us all to enjoy a wide variety of nutritious foods from these five groups each day:

1. Plenty of vegetables, including different types and colours, and legumes/beans
2. Fruit
3. Grain (cereal) foods, mostly wholegrain and/or high cereal fibre varieties, such as breads, cereals, rice, pasta, noodles, polenta, couscous, oats, quinoa and barley
4. Lean meats and poultry, fish, eggs, tofu, nuts and seeds, and legumes/beans
5. Milk, yoghurt, cheese and/or their alternatives, mostly reduced fat

Exercise

- Helps burn calories from food, thus helping us maintain a healthy weight
- Exercise builds muscle strength which in turn protects your bones and joints
- Exercise helps us deal with stress and maintain good mental health

Finding a suitable exercise can be tricky for people with mobility limitations. Don't give up though – there are a surprisingly large number of options, like:

- Wheelchair basketball
- Hand cycling
- Gym sessions
- DVDs with seated workouts you can do from the comfort of your home
- Canoeing

Contact Sporting Wheelies Association for more great ideas for sports, recreation and exercise options.

www.sportingwheelies.org.au

SEXUAL HEALTH

People with Spina Bifida have normal sex drive and sexual needs. People with Spina Bifida experience normal sexual expression and sexual pleasure. The experience of sexuality however may be somewhat altered due to the effects of Spina Bifida on the body.

Impacts of Spina Bifida upon sexual function

The effects of Spina Bifida on sexual function will be different for every individual depending upon the level of lesion, that is, depending on where on the spine your lesion was. Aspects of sexual function which may be impacted by Spina Bifida are:

- Muscle strength and movement
- Sensation
- Continence
- Sexual function

Frequently asked questions

How can I do it? What position for sex will work?

The impact of Spina Bifida on pelvic and lower limb muscle strength and movement, usually means that people need to be a little more creative with sexual techniques and positions. You will need to experiment to find positions that are comfortable and possible for you. Lying face to face, spooning, using pillows to prop up hips, sitting on your partner's lap are all possibilities to try. Many couples consider oral-genital intercourse options also. Whatever seems satisfying and pleasurable is acceptable as long as both partners agree. There is also a range of adaptive equipment which can assist with positioning for sex. One example is the "IntimateRider", which is a swing chair that offers a natural gliding motion to improve "sexual mobility". The chair moves with very little pushing effort, allowing the pelvis to thrust during sex.

Is orgasm possible?

Orgasm (an intense release of sexual energy) may or may not occur in people with Spina Bifida, however it's important to remember that sexual pleasure is not only linked to the short period of orgasm. Spina Bifida may affect your sensory experience from the genital area, but remember, sexual pleasure can be experienced throughout the body and is not solely linked to the genital area. Learning to feel and appreciate pleasures in a variety of ways e.g. through sight, hearing and taste can increase sexual arousal.

How can I manage continence issues during sex?

People with Spina Bifida often fear bowel or bladder "accidents" during times of intimacy. Issues of incontinence may require a little bit of preparation before sex. In order to minimise any risks of an "accident" during sex, it is a good idea to empty your bladder and your bowel prior to sex. Leakage of small amounts of urine is harmless to both partners. Bowel leakage should be quickly cleaned away with a moist towel so it does not get into the vagina due to the risk of urinary tract infection.

If you have an indwelling catheter, you can still have penetrative sex. If you are male, a condom can go over the catheter. Make sure you empty your bag first and use a spigot or bung in the end of the catheter tube where the bag is usually attached. If you are female, again empty the bag and place the spigot or bung where the bag usually goes. Then tape the catheter to the inside part of your thigh – this will keep it out of the way. If you are able to catheterise yourself you can just remove the catheter and then replace it with a new one when you are finished.

Can I achieve an erection?

An erection is the ability of the penis to get hard and erect so that sexual penetration can occur. There are two types of erections:

- Psychogenic erection (psychological) – occurs when a male thinks of something sexual. This causes blood to rush to the penis to make it hard and erect.
- Reflex erection – this is not controlled by the brain. This is usually present when the bladder is full or when doing CIC.

Males with Spina Bifida who have a lesion at or above L2 will not usually have psychogenic erections. Males with a lesion between T11-L2 will not usually have either type of erection.

Erection aids are available which will help males to get and keep an erection. Erection aids include vacuum devices, oral medications, injections and internal prostheses. Ask your GP for more information about these options.

Can I achieve ejaculation?

Ejaculation –this is the ejection of semen (usually carrying sperm) from the male reproductory organs and is usually accompanied by orgasm.

The achievement of ejaculation is often more difficult for men with Spina Bifida as it is a function of the spinal cord.

Sometimes in males with Spina Bifida, ejaculation goes backwards into the bladder, which is Retrograde Ejaculation. This is not a health risk, but can make a male infertile.

Can I get pregnant when I have Spina Bifida?

Pregnancy is possible for almost all women with Spina Bifida, so appropriate contraception is strongly recommended if pregnancy is not currently desired. More information is available on the Pregnancy Fact Sheet.

What kind of contraception should I use?

People with Spina Bifida have most of the same options for birth control as the general population. Your GP or another health care professional, such as Family Planning Qld, can provide additional information about contraception. Some options you may consider include the oral contraceptive pill and condoms. Remember to choose latex free condoms.

How does Spina Bifida affect your chances of falling pregnant?

For women – having Spina Bifida has no impact on your fertility, so you can fall pregnant.

For men – Spina Bifida can affect your level of fertility, so it is a good idea to speak to your doctor or specialist if you are considering fatherhood.

Can I reduce the risks of my child having Spina Bifida?

In the Queensland population approximately 1 in 1,000 babies are born with Spina Bifida. That is a 0.1% chance. However, if you also have Spina Bifida, there is an increased risk that you will have a baby with Spina Bifida too. The chance rises to around 1 out of 33 children – that's a 3% chance. If you would like more information about your specific risk of having a child with Spina Bifida, it is recommended that you speak with a genetic counsellor. Ask your GP for a referral.

Taking **folic acid** does reduce this risk. Folic acid, or folate, is a B group vitamin that can decrease the chances of having a baby with Spina Bifida by up to 70%. Folate is found naturally in many foods, however it is recommended that all women who are planning to have a baby take a folic acid supplement. You should take the supplement at least 3 months before you fall pregnant and during the first 3 months of pregnancy. For people with Spina Bifida a mega dose of folate is required. That is 5mg of folate per day – you will need to make a specific request for this dose from your pharmacist.

What should I be thinking about when considering having a baby?

Having a child is an amazing and wonderful experience, but like for all prospective parents, it can present significant challenges. Things to consider:

- Do you feel emotionally ready to be a parent?
- Do you have family and social supports to help you out with your parenting role?
- Is your relationship with your partner ready to handle the challenges of parenting?
- Are your finances able to stretch to cover the costs of raising a child?
- Is your home suitable for the needs of a child?
- Are you physically ready for parenting?
- It may be worth considering dealing with niggling health issues now rather than after there is also a child to consider
- How will any mobility limitations you have impact on your ability to care for a child?

SBH Qld's ASSIST team can help you consider all of these things and can help you plan home or equipment modifications you may need to look after a child.

AGEING

To live well with SBH

What happens as a person with Spina Bifida and Hydrocephalus ages is not very well known. Most people with Spina Bifida also have Hydrocephalus. People with Hydrocephalus did not survive into adulthood before the invention of the shunt in the 1960s and this means we are only now seeing people living into their 50s and beyond.

Ageing means change and change can be a scary thing. Some people want to avoid or run from change. Perhaps they dislike the uncertainty, or find getting out of their comfort zone too confronting. Other people embrace the challenge and run toward change, ready to give it their best shot. Whatever your thoughts are on change when it comes to ageing it's going to happen anyway so why not do what you can to lead a long, healthy and happy life?

We have many choices in life. Doing nothing is making a choice and with it comes consequences. Choosing to do what you can, to make your life the best it can be is smart and that choice can start right now. Every choice you make each and every day is a building block to achieving the goal to age well with SBH.

What can you do to age well with SBH?

Ageing well means looking at all aspects of your life. It's not just about the medical stuff. It takes energy and a good bit of effort to age well and it is not something that you do once and the job is done. It's building a whole lot of strategies into your daily life and knowing that each one contributes to a healthier you. There is no right time to start other than right NOW! So whether you're reading this and are 21, heading toward your 30s or well beyond the big 40 if you haven't begun already it's time to get thinking.

Here are some tips that might help:

- **Be proactive with health checks** – a quick visit with a doctor now might save you a whole lot of time in hospital or pain dealing with a problem that has progressed.
- **Seek medical advice early** for any concerns or changes.
- **Follow medical advice** – it's designed to help your health improve.
- **Arm yourself with information and think ahead** It might be able to save you pain (literally) and frustration down the road.
- **Know your health history** – Get it written down. Consider options like My eHealth Record www.myehealthrecord.com.au so you don't have to remember everything when seeing a new health professional.
- **Keep important information together in a known place.** SBH has a 'All In One Info Kit' folder that might help you make sure you have thought about what information is good to have handy. Have an all in one info kit completed and kept where you and those closest to you know where it is. It includes medical, financial, employment and services information and more.
- **Be confident in explaining your disability** – what is it and what does it mean for you?

- **Plan for the future** – talk with fmaily/partners about getting things set up ahead of time to minimise stress should a family crisis occur.
- **Get confident in setting goals** – understanding the goal setting process can help you achieve… well almost anything you set your mind to!
- **Know what motivates you** – Motivation is often hard for people with SBH. It gets harder as we get older and the body doesn't feel youthful.
- **Look after your mental health.** It is as important as your physical health.
- **Ask for help when you need it** – letting problems go may mean they only get worse, or at the very least you worry about something longer than is needed.
- **Maximise your abilities** – learn as many skills in independence as you can as early as possible. Practice creates skills, and skills bring confidence.
- **Think about and build your support network** – surround yourself with supportive people
- **Nurture your social life** – it is important (and fun) to have friends.
- **Enjoy life.** It sounds obvious but how often do we tend to forget and wish the days away or wait for things to get better or for life to 'begin'. We only get one so dance, explore, create, laugh, love! Do the things that make you feel good NOW!

What does getting older mean?

- Many 'normal effects' of ageing still apply
- Your body is also changing thanks to the wear and tear of life with SBH

Physical health

As a child and young adult with SBH there would have been a lot of medical monitoring and input. This is because as the body develops the effects of SBH become known and interventions (be that surgery, equipment, physio etc.) early can help greatly.

This medical monitoring tends to lessen as a child with SBH becomes an adult with SBH. What has been seen is that some health issues arise or worsen that if discovered and treated early could have minimised the impact on the individual.

- Deteriorating mobility
- Joint issues
- Continence issues
- Pressures areas / skin issues
- Managing pain
- High blood pressure
- Kidney problems

Regular health monitoring is important not just for SBH specifically, but also ensuring your general health needs are being addressed also. Sometimes this can get overlooked due to the complexities of SBH so you might have to be proactive and ask the questions to your GP.

This means checking things like heart, bone density, diabetes, eyesight, dental and mole/ skin changes. There are also things like checking periods, pap smears and breast exams for women and testicle checks for men.

Any health issue can impact on your overall quality of life and independence. By staying on top of your health it should actually mean LESS time in the presence of doctors and visits to hospitals – so it's worth getting it sorted.

Cognitive function

Cognitive function is affected with SBH in a number of areas such as memory, learning, organising, motivation and information processing. These are the same areas of function that can be affected by ageing. Any deterioration in cognitive functioning should be checked medically to determine if it is SBH related (e.g. shunt malfunction) or whether it is the effects of ageing and have strategies put in place to help manage the issues.

Health professionals you may need at some point living with SBH

- GP – general health, monitoring blood pressure, UTIs, mental health, etc.
- Urologist – Kidneys are often affected with SBH and need regular monitoring
- Neurosurgeon – for shunts and any nerve changes that might be related to SBH e.g. tethering
- Orthopaedic Specialist
- Physiotherapist
- Occupational Therapist

Dealing with doctors

For some people, talking with doctors and health professionals seems easy, for others it can be pretty daunting. Like most things confidence comes with practice. Firstly remember doctors are people too and they are there to help.

If you have difficulty remembering information you could write questions down so you don't forget, ask the doctor to write down the answers/instructions or take someone along with you that you trust. It's OK to let them know if you're not understanding 'medical speak' or asking them to repeat something. And there is no such thing as a silly question. Ask them all!

Not everyone you come across is going to know everything about SBH e.g. if you go to a new doctor for say a skin rash. Become confident at being able to describe the condition and what it means for you. You have a lot of important information that just might be relevant (and even if it's not, you're educating someone else about SBH!)

Building confidence means you are taking responsibility for your own health and well being. You and your doctors will be able to work together as a team for the best outcome.

Mental health and wellbeing

Mental health issues can arise at any age. We see significant numbers of adults with mental health issues. Should you have any concerns about depression, anxiety, grief, OCD or any other mental health concerns there are people who can assist. Physical and mental health are closely linked. A decline in one can affect the other. You don't have to figure it out alone.

Social contact

Maintaining social contact with other people is important for a person of any age. Human beings are social beings by nature. We find comfort, meaning and validation in our relationships. Relationships can change over time and while some friendships last for long periods, others might not. Maintaining friendships takes time and effort but gives great rewards.

It is worth the effort to stay connected to people as social isolation can contribute to mental health issues. Social media helps people stay in contact but should not be the sole means of social interaction. Sometimes barriers such as increases in the costs of living can impact on social activities, getting older might mean getting out and about is not quite as easy or you may need to branch out and find new friends and not know where to start. Solutions might require looking at budgets, thinking creatively about what activities you choose and putting yourself out there into new situations with new people. Take the leap, give it a go. You can never have too many friends.

Family changes

Getting older happens to everyone. In families roles change over time. Parents will age and if they provide supports to you on a regular basis some conversation and planning around what happens if they can no longer assist you is recommended. You have a right and a need to make sure your wishes as part of the family are heard. Be a part of the conversation and planning.

Hopefully you now have some ideas on what you can do to take responsibility for ageing well and for living the best life you can. These are just a handful of ideas. If you would like more information or support talk to SBH ASSIST. We're happy to help.

FUTURE PLANNING FOR FAMILIES

"Age is an issue of mind over matter.
If you don't mind, it doesn't matter."

Mark Twain famously said. And we have all heard:

"You're only as old as you feel."

It serves a lot of good to follow these messages for the most part. There are a number of realities about ageing though that cannot, or perhaps more importantly should not, be ignored. Ageing affects us all. Even the healthy and active must confront the effects of ageing eventually.

Parents of people with SBH often remain quite involved with supporting their son/ daughter in their adult years – whether it is support in day to day activities, decision making, financial support or managing financial, household or health matters. Similarly partners or other family members may be in support roles.

The circle of life is well known. What happens as parents age and become less able to do what they used to? What happens if the parent/s die? These are difficult topics, but ones which it does not benefit family's to ignore.

Every family is different and each family's path through these issues might be quite different.

There is value in families talking while there is no immediate crisis with impending consequences and while plans about the future can be negotiated amongst all involved. Plans can change over time as circumstances change. Having no plans can leave a family dealing with potential resentment, guilt or friction that adds extra stress at an already very difficult time.

As Parents Age

The reality is that ageing brings changes and at some point parents will start to slow down, or experience difficulty doing the things they may have always done. They may need to focus on their own health issues and energy levels/ability to assist with person with SBH might be diminished in the short or long term. This will be a concern for both them and the person with SBH.

Is it possible to plan ahead a little to minimise stress and uncertainty when change occurs within your family?

One of the keys to successful planning is the importance given to hearing the opinions and preferences of **everyone** involved. The person with SBH needs to have their wishes for their life front and centre.

Useful conversations to have might include:

- **Maximising Independence** – What skills and information would benefit the person with SBH and can development of these skills begin now?
- **Physical Support** – As physical support becomes more difficult, e.g. lifting, driving, household maintenance – who else (personal connection or outside service) might be helpful?
- **Memory Loss / Dementia** – If parent/s experience memory loss / dementia – what supports can be put in place?
- **Emergency Plans** – What happens in an emergency? e.g. if adult with SBH and mum live together and mum suddenly is in hospital for extended period? What supports would need to be sourced? How long would this take to enact? What happens if the parent needs ongoing care?
- **Health and Legal Information** – Importance of having health background written down, and legal wishes/plans somewhere accessible and up to date. This is relevant for each family member.
- **Siblings / Extended Family Roles** – In supporting a person with SBH what role might siblings or other family members have? Avoid family friction by openly discussing issues of decision making (e.g. legal/financial/coordinating supports) or primary support (if day to day support required) or any other role relevant within your family.
- **If Limited Family Support** – Who else is close to the family and how reliable are the connections in the long term? There are organisations that can assist or act as back up.
- **Financial** – If parent/s are central to financial concerns and they are incapacitated for short or long term have provisions been made? E.g. Is there enough funds for day to day expenses accessible should parent be suddenly incapacitated? Who will, and is legally able, to assist? Estate planning – exploring the best options and legal ramifications for the family for the long term.
- **Transport** – Cost, accessibility and reliability are all important. There will always be health appointments, possibly work travel and importantly travel to maintain social connections to consider. Is gaining experience on public transport now something that will help the person with SBH in the future maintain independence and be financially viable?
- **Technology** – Keeping up with technology – we rely on it so much these days and we encourage use of technology to assist people with SBH – who can be called upon to help? It's more than setting up the dvd player. Keeping abreast of 'apps', the increasing reliance on internet (from updating Centrelink, grocery shopping, lodging tax returns) and opportunities to utilise technology to make daily life easier and/or more enjoyable.
- **Social and Emotional Support** – Ageing means change and change is often difficult to face. Having outlets to discuss worries and experiences is important for both people with SBH and their partners/families.

What happens if my parents were to die?

It is not an easy topic to think about, and certainly not easy to talk about.

For so many years parents are there to support, to guide, to help and just BE there. It feels like there couldn't be a time where parent wouldn't be around.

Unfortunately accidents and illness can affect any individual and age happens to us all eventually.

In what is a devastating time for anyone and a time when great and sudden changes happen some stress can be avoided by having some conversations ahead of time and putting some plans in place.

Useful conversations to have might include

- **Financial** – What financial assets will the person with SBH have? Would they need assistance to manage financial matters and who would assist manage this? Legal documents completed to allow an appropriate person to assist in financial decisions. What impacts will financial/asset arrangements have on the person with SBH benefits (e.g. will their Disability Support Pension be cancelled?) Are wills in order and up to date?
- **Living Arrangements** – If the person with SBH lives in a parental home – will this still be the case or will property be sold? Where will the person with SBH live? (there are different housing options available e.g. public housing)
- **Health and Legal** – Make your health/legal wishes known (person with SBH AND parents/family), have them written down and in a place that is known/accessible to family.
- **Seek Legal Advice** – The law is intricate and many things could land a well intentioned person in a legal quagmire simply by being unaware. There is also the issue of protection from being taken advantage of. If you have what you think is a workable plan for your family's affairs it would be worth getting it checked over by someone with an appropriate legal background in case there is a catch or something you haven't covered. As we keep saying – it's better to plan ahead than to have the family in difficulty at an already difficult time.
- **Social and Emotional Support** – Aside from the many practical issues to be taken care of who and what can be in place to ensure the emotional needs are not overlooked?

What if things do not go to plan?

There is always the fear of “what if..?”. What happens if something goes wrong. How will the person manage? Who will help them? There are a number of agencies that are useful for assistance and information in both planning for the future and as supports if other supports breakdown or are no longer available.

- Office of the Adult guardian – A statutory body protecting the rights of vulnerable adults who have impaired capacity to make their own decisions (as of July 1st 2014 this becomes the Office of the Public Guardian)
  www.justice.qld.gov.au/justice-services/guardianship/adult-guardian
- Public Trustee – Provides Enduring Powers of Attorney, free Wills, investment, executor and financial administration services
  www.pt.qld.gov.au
- Pave The Way – Information and assistance in planning for the future. See their online resources especially the Planning for Now, Tomorrow and the Future booklet
  www.pavetheway.org.au
- Advocacy Qld Advocacy Incorporated (QAI) – 1300 130 582
  www.qai.org.au
- Qld Aged and Disability Advocacy (QADA) – 1800 818 338
  www.qada.org.au
- Centrelink – Government assistance, some financial and emergency assistance
  www.humanservices.gov.au
- Legal Aid – 1300 64 11 88
  www.legalaid.qld.gov.au

Community Supports – There are many and depend on where you live and what your needs are so we will only give a couple of examples such as Meals on Wheels, St Luke’s, Home Help. These community agencies can assist in day to day supports.

Bottom line what are we saying here?

To parents/family of a person with SBH:

- Ageing is going to happen and illness and death can happen suddenly. If you are involved in supporting someone with SBH they will feel the consequences if some thought and conversation has not happened about future planning.
- Future planning enables the entire family to feel heard, ‘on the same page’ and at least somewhat prepared should something occur. This can bring calmness and comfort for all.
- As a parent you want to make sure you have done what you can to ensure your son/daughter with SBH has the best life and support possible. Seek legal advice while YOUR capacity is intact and have the conversations with your family before a crisis happens.
- Support your family member with SBH now to learn skills (whether that is about ordering their continence supplies, confidence dealing with doctors, navigating transport or being able to prepare a basic meal). Build a support and information system early. Support the person to gain experience and take on responsibility.

To a person with SBH:

- If you are a person with SBH you are going to want to have your thoughts, opinions and preferences about your future heard. Whether that’s about where you want to live, what your thoughts are on organ donation, medical care or who will have access to your bank account and help you make decisions.
    - You have legal rights that must be upheld so have your say in your future.
    - Develop as much experience and skills as you can now so that you build confidence in things like daily living skills (cooking, household management, budgeting), managing your health and medical (dealing with doctors, remembering appointments, talking about your condition), getting around in the community (be that public transport or driving).

Being prepared for some of life’s biggest changes cannot prevent them from happening but it can make a difficult time that much easier and comfort can be drawn from knowing the wishes of all involved were taken into account from the outset.

This information sheet is to get families thinking, and talking. It asks questions of which there are endless potential answers and that each family needs to at least begin to answer for themselves. When it comes to exactly what community supports might be suitable for an individual SBH Qld can help you narrow down what is available and relevant in your situation.

The NDIS

The NDIS is going to change the entire system of supporting people with a disability. As it becomes clearer what this will mean for people with SBH in QLD, we will update our information.