SPINA BIFIDA
HYDROCEPHALUS QLD

SBH Queensland
WHO ARE WE?

• Began as a parent support group almost 40 yrs
• 15 staff in Brisbane + 1 in Townsville
• Therapists, social workers, education advisers, information officer plus fundraising and admin - most part-time
• 3 part timers work with 300 adults
SBH Queensland

- booklets such as
  - what is spina bifida and hydrocephalus
  - early childhood ideas
- information sheets
- newsletter - SPINET
- websites
  - www.spinabifida.org
  - www.asbha.org.au
SPINA BIFIDA
What is it?

• group of birth defects which interfere with the development of the CNS: brain, spinal cord and nerve tissues

• back part of the vertebrae have failed to join at some point along the spine, leaving a split/gap in the spine

• Fourth week after conception
Types of Spina Bifida

- Myelomeningocele
- Meningocele
- Occulta
SPINA BIFIDA

• Incidence  1 NTD every 800 pregnancies
  10 live births in Qld per year

• Prevalence  600 in Queensland

• Life expectancy  unknown

• Cause
PREVENTION

- Up to 70% preventable with folic acid
- Naturally occurring B vitamin
- Daily supplement of 0.5 mg *at least* 1 month before to 3 months after conception
- Fortification

SBH Queensland
HYDROCEPHALUS

Normal ventricles

Hydrocephalic ventricles
SHUNT SYSTEM TO DRAIN CSF INTO ABDOMEN

Catheter into ventricle

Shunt valve

Tubing to the abdomen

Brain

Cerebrospinal fluid
SYMPTOMS of SHUNT MALFUNCTION

- Headaches
- Vomiting
- Fever
- Functional loss - balance, gait, concentration
- Lethargy
- Dizziness
- Severe - Visual disturbances, seizures

SBH Queensland
DETERIORATION by COMPLICATIONS

- Tethering
- Shunt malfunctions
- Arnold Chiari Malformation
- Syrinx
- Seizures
- Hospitalisation
- Sleep aponea
- etc

SBH Queensland
ISSUES TO CONSIDER

• Physical:
  - Mobility - from walking, to mobility aids such as splints (AFO’s), walkers, walking frames, to wheelchairs.
  - Continence - neurogenic bowel and bladder
  - Skin care - sensory nerves, skin areas, and blood supply

SBH Queensland
SENSATION

• Burns
  - sunburn, hot objects in the lap, car seats, seat belt buckles, hot bath water

• Scrapes

• Pressure areas
  - prolonged sitting, ill fitting orthoses, wallets

• Prevention
  - Bottom lifts, Check daily, Pressure relief cushions

SBH Queensland
PRESSURE AREA
LATEX ALLERGY

• Natural Rubber Latex Only - Proteins
• Studies reflect up to 40% of people with spina bifida are affected.
• First symptoms tend to be rash, swelling and itch, running nose, sneezing.
• Now not as common in household items
IMPLICATIONS FOR SETTINGS

• Limited mobility & Access
  - Dependence on adults, ‘protection’

• Lack of Experiences
  - Play experience vs ‘therapy’

• Medical Intervention / Hospitalisation

SBH Queensland
• Adult Interactions
  - SEDU, Therapy, Medical, Special Needs Worker etc.

• Learning difficulties
  - Often difficulties present similar to other developmental hiccups: ‘all the children have these difficulties’
ISSUES FOR LEARNING

- Concentration and Attention - visual & auditory
- Memory and Comprehension
- Organisation
- Problem solving
- Decision Making
- Fine motor - visual motor, visual perceptual
OTHER ISSUES

- Fatigue
- Anxiety
- Self Esteem/Motivation
SOCIAL SKILLS

- Verbal and non-verbal skills are needed for positive social interaction
- Model the skill - break it down
- Imitation and rehearsal
- Feedback
- Encourage eye contact
- Social distance, and discourage over talking
WHAT DO YOU NEED TO TAKE AWAY FROM THIS BRIEF TALK?
TEN TIPS TO REMEMBER

1. Don’t panic - CALL US!
2. All children with spina bifida and hydrocephalus will present quite differently.
3. Early childhood is a time where children learn to work and play together and form friendships - it’s natural - but will often need you help or ‘coaching’.
4. Rules and structure are good!

SBH Queensland
5. Organise the classroom for maximum physical independence.

6. Allow time.

7. Goal setting

8. Call us

9. Call us

10. CALL US!

SBH Queensland