

Spina Bifida Adult Resource Team (SBART)

Spina bifida is a complex congenital condition affecting the spinal cord and brain. Health needs of those affected are complex and lifelong.

In 2009, the NSW Ministry of Health funded the Spina Bifida Adult Resource Team (SBART). The team, which consists of a Clinical Nurse Consultant and a Senior Occupational Therapist, aims to provide clinical consultation, education, support and preventative health strategies to adults with spina bifida. The service is open to adults aged 18 and over who have spina bifida. SBART is a state-wide resource team and covers all areas of NSW.


Role of SBART

- Assisting any young person making the move from paediatric to adult services
- Orientating any young person to their new adult health service
- Assisting with any medical concerns as well as providing education and support to any adult with spina bifida
- Linking adults to appropriate health services as required
- Promoting healthy lifestyles for all clients with spina bifida
- Attending all adult spina bifida clinics across NSW
- Educating community services about spina bifida
- Supporting NDIS queries or concerns

Resources created by SBART

Shunt Card

Front

Contacts Northcott Spina Bifida Group Ph: 02 9890 0990 Email: sbgroup@northcott.com.au National Continence Hotline 1800 330 066 Useful Websites www.asbha.org.au www.ifglobal.org www.northcott.com.au www.health.nsw.gov.au	My information Name: _____ My email: _____ <hr/> Emergency contact name: _____ Ph: _____ Mobile: _____ <hr/> GP: _____ Ph: _____ Mobile: _____ <hr/> Spina Bifida Clinic Name: _____ Ph: _____ Mobile: _____ <hr/> Neurosurgeon: _____ Ph: _____ Mobile: _____ <hr/> Medicare No: _____ Pension No: _____ Private Health Fund/No.: _____ <hr/> Notes: _____	SPINA BIFIDA HEALTH CHECKLIST AND EMERGENCY CONTACT  Let's see what you can do. <small>Developed in partnership with Northcott Disability Services, the Greater Metropolitan, Tasforce and South East Sydney Illawarra Area Health Service.</small>
	PLEASE NOTE THAT THIS HEALTH CHECKLIST IS FOR INFORMATION ONLY NOT MEDICAL ADVICE. IF YOU NOTICE ANYTHING DIFFERENT OR ARE CONCERNED, DON'T HESITATE TO CALL YOUR GP OR SPECIALIST STRAIGHT AWAY.	

Back

Shunt/hydrocephalus	Chari Malformation	Bladder and bowel/skin	Cord tethering
Potential issues <ul style="list-style-type: none"> • Headaches • Vomiting • Vision problems (cross-eyed, double vision) • Tired - more than usual • Easily upset/moody • "Just don't feel right" • Pass out or collapse • Memory problems • Balance altered • Head and neck pain • Numbness in arms • Gagging/swallowing problems 	Potential issues <ul style="list-style-type: none"> • Difficulty swallowing/choking problems • things go down the wrong way • Wheezing • Arching of the head • Stiffness and spasms in neck, arms or hands • Head and neck pain • Turned eye • Loss of feeling in hands or arm • Loss of coordination or balance 	Urinary Tract Infection/Bladder <ul style="list-style-type: none"> • Chills and fever cloudy or dark/bloody urine • Nausea or vomiting • Back pain • Change in urinary continence Bowels <ul style="list-style-type: none"> • Increased difficulty at home • Unusual/unexplained changes • Bowel accidents Skin/Pressure Sores (remember to check skin daily) <ul style="list-style-type: none"> • Redness one hour after clothing or shoes removed • Sore, ulcerated or broken skin 	Potential issues <ul style="list-style-type: none"> • Altered walking ability • Pain • Progressive changes bowel/bladder • Foot deformities • Headaches • Muscle weakness/wasting • Curved spine • Altered sensation in genital regions and during sex • Impotence • Any motor or sensory deficits in legs

Some of these issues can be URGENT! Please discuss with your specialist.

The shunt card is a useful pocket-sized resource for adults to carry in their wallets and/or purses. It allows easy access to important health information.

SBART Facebook page

Although health advances have improved the lifespan of people with spina bifida, less emphasis has been placed on psychosocial functioning. Discrepancies in education, independent living, employment and social contacts are noted between those with spina bifida and their able-bodied peers.

Social isolation is common in people with spina bifida, particularly those with mobility issues who face particular barriers to accessing the community. SBART has utilised the success of Facebook to address issues of social isolation and to distribute health information to SBART clients. The Facebook page has 92 members and connects adults with spina bifida with their peers.



SYMPTOMS						
PERSISTENT HEADACHES Presents with: <ul style="list-style-type: none"> • Nausea and vomiting • Decreased level of consciousness • Blurred vision 	PERSISTENT HEADACHES Presents with: <ul style="list-style-type: none"> • Fever • Bloody urine • Increase incontinence 	ABDOMINAL PAIN Faecal loading UTI, renal calculi Shunt dysfunction Other including: oesophageal reflux, gall stones, appendicitis and bladder rupture (if bladder augmentation)	SKIN BREAKDOWN Pressure areas Lymphoedema Cellulitis Burns NOTE: Most pressure areas are a result of poor pressure care. Ensure that the adult is referred to an Occupational Therapist for follow up and review of their pressure care equipment.	LOWER LIMB SWELLING Fracture Lymphoedema Cellulitis Deep Vein Thrombosis (DVT) Other including: chilblains, eczema and poor circulation	OTHER CONSIDERATIONS When treating the acute medical problem other aspects of care need to be considered. DOES THE PATIENT NEED ASSISTANCE WITH MOBILITY? <ul style="list-style-type: none"> • walking frame / crutches / wheelchair • assistance with transfers • consider referring to rehabilitation team for further assessment DOES THE PATIENT NEED PRESSURE AREA CARE? <ul style="list-style-type: none"> • air mattress (ideal for inpatients as they help with protection against pressure areas on sacrum, legs and heels) • as an inpatient, consider all chairs that the client is sitting on (wheelchair cushions can be used as pressure relief on other chairs) DOES THE PATIENT NEED DVT PROPHYLAXIS? <ul style="list-style-type: none"> • clean intermittent catheterisation • enema/bowel washout NOTE: If an inpatient is confined to a hospital bed or has intravenous drip and/or fluids running, they may also need help with personal care. WHAT MEDICATION DOES THE PATIENT TAKE?	DISCHARGE PLANNING When considering discharge planning ensure that: <ul style="list-style-type: none"> • Adults are assessed to determine how they will cope once discharged from hospital. Attention should be given to their mobility and personal/domestic care needs. • All adults should have their discharge summary sent to their GP and any relevant specialist. • The Spina Bifida Adult Resource Team (SBART) is contacted to provide support to the adult in the community and ensure they are followed up to prevent further hospital admissions.

For any further information please contact the Spina Bifida Adult Resource Team (SBART) on 9472 5214 or 9472 5215

Hospital Management Plan

Another resource that has been developed by SBART is Hospital Management Guidelines for Adults with Spina Bifida. The manual was developed with comprehensive information on the medical management of adults with spina bifida. Additionally, a one-page guide was developed for clinicians to use as a quick guide to common medical presentations for people with spina bifida, as seen above. Both documents are available on request.

For more information contact SBART on:

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Email: SBART@northcott.com.au


Northcott
 Let's see what you can do

