

Chapter 9: Organisations and further resources

Local organisations can put you into contact with specialist centres and other resources in your area.

State based spina bifida associations

The spina bifida association in each state is a good first contact point when seeking information about support and services. The associations can assist those affected by spina bifida, their carers and those working with people with spina bifida. Membership is encouraged for all those with and affected by spina bifida.

Spina Bifida Association of NSW
c/o Northcott Society
Contact: Mike Sheargold
PO Box 4055
Parramatta NSW 2124
Telephone: 02 9890 0172
Website: www.northcott.org.au
Email: mikes@northcott.org.au

Spina Bifida and Hydrocephalus Association of SA Inc.
PO Box 272
Torrensville Plaza SA 5031
Telephone: 08 8443 5200
Fax: 08 8443 5100
Email: info@spinabifida.asn.au
Website: www.spinabifida.asn.au/

SBH Queensland
21 Tillot St (PO Box 8022)
Dutton Park QLD 4102
Telephone: 07 3844 4600
Fax: 07 3844 4601
Email: bshead@spinabifida.org
Website: www.spinabifida.org

Spina Bifida Association of Tasmania
Contact: William Brown
PO Box 450
Sandy Bay TAS 7006
Telephone: 03 6275 0987

Spina Bifida Association of Victoria
c/o Yooralla Society of Victoria
705 Geelong Rd
Brooklyn VIC 3025
(PO Box 1101, Altona Gate VIC 3025)
Telephone: 03 9362 6111 or Freecall 1800 686 533
Fax: 03 9314 9825
Email library@yooralla.com.au
Website: www.sbav.org.au

Spina Bifida Association of WA Inc.

37 Hampden Rd
Nedlands WA 6009
Telephone: 08 9389 8311
Fax: 08 9389 8331
Email: sbawa@swannet.com.au
Website: www.sbawa.asn.au

Key Australian spina bifida contact points

Australian Spina Bifida and Hydrocephalus Association Inc.
The Australian Spina Bifida and Hydrocephalus Association Inc. is an incorporated body servicing the interests of state bodies. The state based associations are the best contact point for clients, their families, carers and health workers, but the website contains useful information and links to Australian websites.

Website: www.asbha.org.au

Spina Bifida Foundation of Victoria

The Spina Bifida Foundation of Victoria was established to improve the quality of life of the spina bifida community by raising money for and developing a range of activities and services. Activities have a strong focus on promoting independence for people with spina bifida.

Spina Bifida Foundation of Victoria
PO Box 166
Parkville VIC 3052
Telephone: 03 8344 7924
Website: www.sbav.org.au/foundation.htm

Assistance for continence aids and funding

Many organisations are available to assist with obtaining continence supplies and aids.

The provision of equipment, disposables and aids for successful continence management can be expensive and many programs are available to assist affected individuals

When applying for assistance for incontinence aids, the number of organisations providing assistance and their roles can be confusing. Social workers, continence nurses and doctors all have experience in applying for the various schemes, and may be asked to help when completing application forms to ensure that no errors are made that may delay payments or applications.

Continence Aids Assistance Scheme

The Continence Aids Assistance Scheme (CAAS) is a Commonwealth Government program offering assistance to people who have permanent incontinence due to permanent disability.

The program offers an annual subsidy to approved clients to order approved continence aids listed on a schedule.

People aged 16–64 years of age with permanent incontinence from a permanent disability can apply for CAAS if they are eligible to receive a disability support pension through Centrelink, or a pension from the Department of Veterans' Affairs. CAAS also has other restrictions and eligibility criteria.

For further information, CAAS can be contacted through the company PQ Lifestyles at:

PQ Lifestyles
PO Box 2082
Milton QLD 4064
Telephone: 1300 134 260

or contact:

The Department of Health and Aged Care
Telephone: 1800 807 487

or write to:

CAAS
Department of Health and Aged Care
GPO Box 9848
Canberra ACT 2601

State based organisations

Each state has aids and equipment programs, and some have additional services available to assist with incontinence management.

Health care providers will be able to identify and refer patients to these services, especially specialist continence clinics. In addition, local spina bifida associations will also be able to identify appropriate services and agencies.

Useful websites

The following international sites contain useful information on spina bifida and hydrocephalus.

Spina Bifida Association of America
www.sbaa.org

International Federation for Hydrocephalus and Spina Bifida
www.ifglobal.org

Spina Bifida & Hydrocephalus Association of Ontario
http://www.sbhao.on.ca/

Other sites of interest include:

Continence Foundation of Australia
www.contfound.org.au

Australian Council of Stoma Associations
www.australianstoma.org.au

Specialist spina bifida clinics

As well as adult spina bifida clinics, paediatric hospitals are listed as they can refer adult patients to suitable facilities in their local area. If there is no specific clinic listed in your area, contact your state spina bifida association for information on local specialist health care providers.

New South Wales

Adult Spina Bifida Clinic
Westmead Hospital
Department for Rehabilitative Medicine
Cnr Hawkesbury and Darcey Roads
Westmead NSW 2145
Telephone: 02 9845 7800

Spina Bifida Clinic (children)
Sydney Children's Hospital
High Street
Randwick NSW 2031
Telephone: 02 9382 1589

Spina Bifida Unit (children)
The New Children's Hospital at Westmead
Locked Bag 4001
Westmead NSW 2145
Telephone: 02 9845 2769

Northern Territory

Alice Springs — contact Spina Bifida Association of South Australia

Other places — contact SBH, Queensland

Queensland

Princess Alexandra Hospital
Spina Bifida Clinic for Adults
Cornwall St
Woolloongabba QLD 4102
Telephone: 07 3240 2641

Mater Children's Hospital (children)
Spina Bifida Clinic
Raymond Terrace
South Brisbane QLD 4101
Telephone: 07 3840 1812

Royal Children's Hospital (children)
Spina Bifida Clinic
Herston Road
Herston 4029
Telephone: 07 3636 7818

Spina Bifida Clinic Paediatrics Outpatients (children)
Gold Coast Hospital
Telephone: 07 5571 8345
Nerang Street
Southport QLD 4215

Townsville Children's Community Therapy Services (children)
Spina Bifida Clinic
Telephone: 07 4728 2681

South Australia

Spinal clinic (adult)
Royal Adelaide Hospital
North Terrace
Adelaide SA 5000
Telephone: 08 8222 4000

Spinal clinic (adult)
Queen Elizabeth Hospital
28 Woodville Road
Woodville South SA 5011
Telephone: 08 8222 6000

Continence Clinic (adult)
Repatriation General Hospital
Daws Road
Daw Park SA 5041
Telephone: 08 8275 1927

Spinal and continence (children)
Adelaide Women's and Children's Hospital
King William Road
North Adelaide SA 5006
Telephone: 08 8161 7000

Tasmania

Contact State Spina Bifida Association

Victoria

Adult Spina Bifida Service
 C/- Monash Institute for Neurological Disease
 Monash Medical Centre
 Clayton Road
 Clayton VIC 3168
 Telephone: 03 9594 2240

Spina Bifida Clinic (children)
 Royal Children's Hospital
 Flemington Road
 Parkville VIC 3052
 Telephone: 03 9345 5522

Western Australia

Spinal Rehabilitation Clinic (children)
 Princess Margaret Hospital for Children
 Thomas Street
 Subiaco WA 6008
 Telephone: 08 9340 8886

Continence organisations

National Continence Helpline

The National Continence Helpline is a joint project of the Commonwealth Government and the Continence Foundation of Australia. It aims to assist people with incontinence, their families and carers, as well as health professionals. The help line can refer patients to local services.

Telephone: 1800 330 066

More help can be gained by contacting the Continence Foundation of Australia at:

Continence Foundation of Australia Ltd
 AMA House
 293 Royal Parade
 Parkville VIC 3052
 Telephone: 61 3 9347 2522
 Fax: 61 3 9347 2533
 Website: www.confound.org.au

Ostomy associations

The following associations may be of use to patients for stoma care. Colostomy associations can also help with other stoma besides just colostomies. If no ostomy association is listed close to your area, please contact your state spina bifida association for local ostomy health care providers and services.

Australian Capital Territory

ACT & Districts Stoma Association Inc.
 2nd Floor, Department of Health Building
 Cnr Moore & Alinga Streets, Canberra City 2601
 PO Box 1260, Canberra City, ACT, 2601
 Telephone and fax: 02 6205 1055

New South Wales

Colostomy Association. of NSW Inc.
 Unit 5/7-29 Bridge Road
 Stanmore NSW 2048
 Telephone: 02 9565 4315

Ileostomy Association. of NSW Ltd
 Block E, Ozanam Village
 West St, Lewisham NSW 2049
 Telephone: 02 9568 2799

Queensland

Gold Coast Ostomy Association Inc.
 8 Dunkirk Close
 Arundel QLD 4214
 Telephone: 07 5594 7633
 Website: www.ostomy.org.au

North Queensland Ostomy Association Inc.
 Shop 4,
 52 French Street
 Pimlico QLD 2478
 Telephone: 07 4775 2303
 Website : www.ostomy.org.au
 All correspondence and orders to:
 PO Box 1017
 Hyde Park
 Castletown QLD 4812

Queensland Colostomy Association Inc.
 22 Beaudesert Road
 Moorooka QLD 4105
 Telephone: 07 3848 7178
 Email: colostomy@primus.com.au
 Website : www.ostomy.org.au

Queensland Stoma Association Inc.
Unit 4, 'Accent Place', 10 Valente Close, Chermside 4032
PO Box 370, Chermside South, QLD, 4032
Telephone: 07 3359 7570
Emergency Telephone: 07 3359 7570
Website : www.qldstoma.asn.au

Toowoomba & South West Ostomy Association Inc.
c/o Epworth Nursing Home
Stenner Street
Toowoomba QLD 4350
Mail address: P.O. Box 7314, Toowoomba M.C., 4352
Telephone: 07 4636 9701
Website : www.ostomy.org.au

Wide Bay Ostomy Association Inc.
c/o Bundaberg Base Hospital
Bourbong Street
Bundaberg QLD 4670
Telephone: 07 4150 2074
Website : www.ostomy.org.au

South Australia

Colostomy Association of SA (C.A.S.A.)
160 South Road
Torrensville SA 5031
Telephone: 08 8354 2618

Ileostomy Association SA Inc.
1 Shipster Street
Torrensville Adelaide SA 5031
Telephone: 08 8234 2678

Tasmania

Ileostomy & Colostomy Association (TAS) Inc.
Statton Bldg, Repatriation Centre
Hampden Road
Hobart TAS 7000
PO Box 415, Sandy Bay, Tas, 7006
Telephone: 03 6223 2974

Victoria

Ileostomy Association (VIC) Inc.
Suite 322, 3rd Floor, The Block
98-100 Elizabeth Street
Melbourne, VIC 3000
Telephone: 03 9650 9040

Ostomy Association of Melbourne Inc.
Cabrini Medical Centre
Isabella Street
Malvern VIC 3144
Telephone: 03 9508 1879

Western Australia

WA Ostomy Association Inc.
15 Guildford Road
Mount Lawley WA 6050
Telephone: 08 9272 1833

Further reading for patients

Information on the following publications is available from either the Spina Bifida Association in your state, or by contacting:

Library and Information Service
Yooralla Society of Victoria
705 Geelong Road Brooklyn VIC 3025
Telephone: 03 9362 6143
Email: library@yooralla.com.au
Website: www.yooralla.com.au/library

Spina bifida and hydrocephalus explained. Spina Bifida Association of Victoria.

A booklet explaining the basics of spina bifida and hydrocephalus in plain language.

Downloadable from the website www.sbav.org.au

Spinabilities. A young person's guide to spina bifida by Lutkenhoff M, Oppenheimer SG. Woodbine house, 1997.

A young person's guide to all aspects of spina bifida including incontinence and sexuality. Excellent resource for teenagers with spina bifida.

Hoath L, Gilbert S. Oops. A common sense approach to toilet training a child who has a 'problem'.

This excellent plain language guide covers all aspects of the management of urinary and faecal incontinence. Although written for children and young people, it contains much information of use for the adult with spina bifida.

Nolan T. Fitness training diary. Royal Children's Hospital. 1996.

This resource contains information and a diary to help manage faecal incontinence and is available from the Royal Children's Hospital, Melbourne.