

## 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](http://www.northcott.org.au)  
Email: [mikes@northcott.org.au](mailto: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](mailto:info@spinabifida.asn.au)  
Website: [www.spinabifida.asn.au/](http://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](mailto:bshead@spinabifida.org)  
Website: [www.spinabifida.org](http://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](mailto:library@yooralla.com.au)

Website: [www.sbav.org.au](http://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](mailto:sbawa@swannet.com.au)  
Website: [www.sbawa.asn.au](http://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](http://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](http://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.

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Passport to success

## 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](http://www.sbaa.org)

International Federation for Hydrocephalus and Spina Bifida  
[www.ifglobal.org](http://www.ifglobal.org)

## Spina Bifida & Hydrocephalus Association of Ontario

<http://www.sbhao.on.ca/>

Other sites of interest include:

Continence Foundation of Australia  
[www.confound.org.au](http://www.confound.org.au)

Australian Council of Stoma Associations  
[www.australianstoma.org.au](http://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

### Continance 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

## Continance organisations

### National Continance Helpline

The National Continance Helpline is a joint project of the Commonwealth Government and the Continance 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

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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](http://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](http://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](http://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](mailto:colostomy@primus.com.au)  
Website : [www.ostomy.org.au](http://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](http://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](http://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](http://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](mailto:library@yooralla.com.au)  
Website: [www.yooralla.com.au/library](http://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](http://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.