

# spina bifida

Passport to success

General health in spina bifida: The facts and how to stay well and happy

If you're sick, you won't be happy. Improving continence is only one part of staying well if you have spina bifida.

## How can I stay well and happy?

- Look after yourself.
- Keep fit.
- Don't get fat.
- Make sure that you attend a specialist spina bifida clinic to prevent problems.
- Don't come to the clinic when you are sick. It might be too late.
- Remember, prevention is better than cure.

## General health in spina bifida: Other health problems

### Obesity: Getting fat

Many people with spina bifida put on weight as they get older.

Lack of mobility is a major contributing factor to the development of obesity in spina bifida.

It is crucial that you are able to manage your weight and that you do **not** get fat.

If you put on too much weight you will:

- lose mobility, including ability to transfer, and lose independence
- develop arthritis in your legs, arms and spine
- have trouble breathing
- lose your energy.

Stay physically active to keep your weight down. Sport and exercise, as well as keeping you active and slim, can be a major opportunity for social contact, peer support and meeting prospective partners. Are you aware of how many different sporting activities are possible for you?

- |                 |                 |
|-----------------|-----------------|
| • Archery       | • Baseball      |
| • Basketball    | • Billiards     |
| • Cricket       | • Fencing       |
| • Handball      | • Lawn bowls    |
| • Power lifting | • Road racing   |
| • Rugby         | • Shooting      |
| • Swimming      | • Table tennis. |

What about wheelchair dancing?

Sound like fun?

## Skin care and pressure sores

Skin problems are common in spina bifida, especially when you are in a wheelchair.

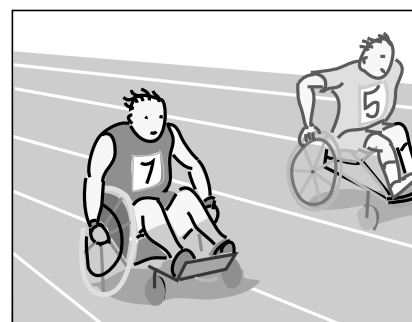
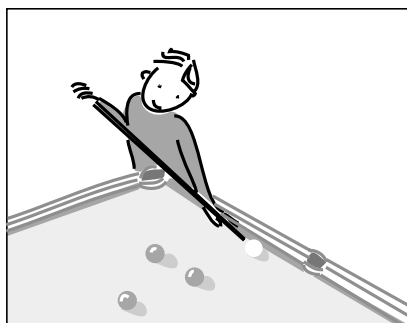
### What skin problems occur and why?

The major problems are:

- poor mobility
- reduced sensation from damaged nerves
- naturally thin skin
- poor circulation
- difficulty reaching down to clip toenails and staying clean
- badly fitting shoes, aids and wheelchairs.

### How can I prevent skin problems?

- Exercise and maintain mobility.
- Don't get fat.
- Move your weight regularly when sitting, and check your skin for telltale signs of a pressure sore.
- Attend your specialist clinic. They can make sure that your shoes, aids and wheelchair are OK.
- When you get a skin problem, see your doctor immediately. Never delay.



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## Latex allergy

Allergies to latex (common rubber) are more common in people with spina bifida than the general population. Reactions may vary from mild skin irritation to severe anaphylactic shock (where you can't breathe).

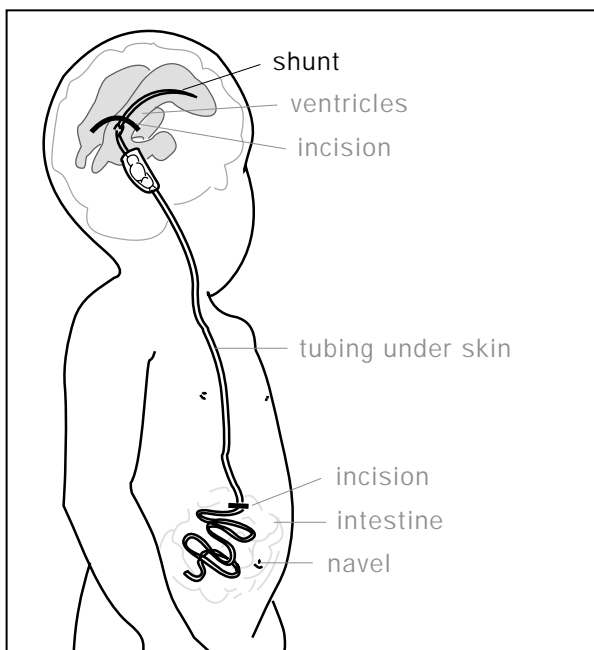
Care must be taken to avoid the use of rubber gloves and any other latex items, such as catheters and condoms. Most hospitals have a latex free operating theatre for procedures for allergic patients.

Through your spina bifida clinic, ask to have yourself tested for a latex allergy reaction so you know how badly affected you are.

## Tethered spinal cord syndrome

See the special section on this important condition, page 18.

## Hydrocephalus and the blocked shunt



Hydrocephalus and the V-P shunt

Many people with spina bifida have excess fluid in the chambers of the brain (hydrocephalus). Most people with hydrocephalus have a drain tube inserted when they are babies. This tube is called a V-P shunt and drains excess fluid from the brain to the abdomen. V-P shunts often block and have to be replaced. A blocked V-P shunt is a medical emergency. If the V-P shunt is not replaced, you can go blind.

Symptoms of a blocked V-P shunt are:

- headache
- nausea and vomiting
- loss of continence
- personality changes
- disorientation and memory loss
- blurred or double vision
- fits
- generally feeling unwell.

If you think you might have a blocked shunt, see your doctor urgently or go to your local hospital.

The treatment is to replace the shunt.

## Social isolation and not knowing where to turn: How to overcome this

I feel isolated by having spina bifida. What can I do about the feeling of being cut off from people?

You need peer support. An excellent way to obtain this is to belong to your local spina bifida association. These excellent organisations provide contact between members by means of regular newsletters and events and will provide you with many opportunities for socialising.

Spina bifida associations are more than just social groups. They create a forum where members can offer each other mutual support and identify important common issues. Some of you may become very active in one of these organisations and find participation a very fulfilling part of your life. (See the following Resources section for contact details.)

**Join your local spina bifida association now!**

Peer support is one of the most important ways in which you can learn to adopt healthy behaviour and take part in various activities. If you do not already belong to your local SBA — **join now!**

The following section covers the resources available to you in your state.

**STAY WELL!**

**STAY HEALTHY!**

**STAY HAPPY!**

