

Coping with Guillain-Barré Syndrome (GBS)

Putting you
in control
of your life

Patient information

What is Guillain-Barré Syndrome (GBS)?

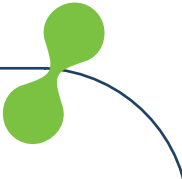
Your doctor will have told you that you may have a disease that affects the nerves of your arms and legs called Guillain-Barré Syndrome, or GBS for short.

GBS can affect men, women and children of all ages and, in the UK, about 1,500 people are diagnosed as having the disease each year.

GBS is a short-term ('acute') inflammation of the nerves that control your arms and legs.

The exact cause of GBS is not fully understood. It has been noticed that patients have often suffered from an infection of the throat or intestine in the weeks before being diagnosed as having GBS. Sometimes, GBS has been known to follow a period of great stress. For this reason, it is thought that GBS may have its root cause in the immune system.

When foreign particles like viruses or bacteria enter your body, the cells of your immune system prevent serious infection taking place by producing, among other substances, special proteins called 'antibodies' which seek out and destroy any such invading foreign particles. However, if you have GBS, your antibodies not only attack and destroy the invading foreign particles, they also begin to attack and destroy your own nerves, particularly the nerves of your arms and legs. The damage that these antibodies do to your



nerves causes the tingling and short-term paralysis symptomatic of GBS. Once your immune system notices that the rogue antibodies are attacking your own nerves, they are quickly destroyed or inactivated.

GBS is neither hereditary nor contagious, so you can rest assured that you will not pass it on to either your family or friends.

Signs and Symptoms

The first indication that you may have GBS is a slight tingling (pins and needles) or numbness in the fingers and toes. Over the next few days, this spreads to the legs and arms, resulting in a weakness that can cause movement difficulties. When this happens, you may require sticks or crutches to help support you. You may find it hard to grip and to perform simple tasks with your hands.

Sometimes, the legs and arms become temporarily paralysed. This paralysis can also creep into the chest, resulting in breathing difficulties and can also affect your throat and face with the result that eating may become difficult.

Diagnosis

As the symptoms of GBS can be confused with other illnesses, diagnosis needs to be confirmed.

Your doctor will want full details of any recent infections or contact with toxins you may have had.

A full medical examination will be supported by blood tests, and an electromyogram (EMG) to check how active your nerves and muscles are. If you have GBS, the EMG will show that your nerves are not conducting signals to your muscles as fast as they should.

The EMG test takes about half an hour to complete and, though slightly uncomfortable, is not at all harmful.

Analysis of your spinal fluid will also be carried out to look for increased levels of protein. This involves having a Lumbar puncture, whereby fluid is drawn from the spine under local anaesthetic.



Treatment

The initial symptoms of GBS appear over a few days, but may take four to six weeks to develop fully. These symptoms will then remain for the next few days or weeks, when you will need plenty of rest. It is likely that during this period, you will spend some time in hospital.

Thereafter, symptoms will gradually recede and you will regain feeling and strength in your limbs. This process can take anything from a week to 6 months.

80% of GBS patients make a full recovery within 1 year, with the remainder being left with only minor numbness or weakness that does not interfere with normal daily activity. In a very small number of cases, weakness in the arms and legs persists longer than 1 year and can affect normal life.

The symptoms of GBS can improve without treatment, however, there are a number of ways in which these symptoms may be eased.

Possible treatment options are as follows:

- **Infusion of Intravenous Immunoglobulin**

Intravenous Immunoglobulin is a preparation of purified human antibodies (otherwise known as immunoglobulins) supplied by blood plasma donors. These are injected into your veins each day through a drip over 3 to 7 days. The large variety of antibodies injected help to cancel the effect of the antibodies in your circulation that are attacking your nerves.



- **Plasma Exchange**

This treatment involves the gradual exchange of your own plasma, which contains the antibodies that are attacking your nerves, with albumin or plasma that is free from these dangerous antibodies. This procedure is usually repeated daily for 5 days.

These two treatments are generally undertaken in the first two weeks of the illness and tend to be given to those patients experiencing the more debilitating form of this disease. On average, they will halve the duration of the illness but will not prevent it running its course, and should not be regarded as a cure!

Some patients find that GBS causes pain in the legs and arms whilst other patients feel no pain at all. If you are in pain, your doctor can prescribe a pain killer. Physiotherapy is also recommended to keep your joints supple over the period of the illness.

If in doubt... ..ask!

Remember – the great majority of GBS patients recover fully within a year, and some within a few months.

If you have any questions or worries about GBS, always ask your GP or Hospital Consultant, who will be able to explain in more detail.

Your consultant is:

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Contact phone number:

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Don't worry, you're not alone!

The Guillain-Barré Syndrome Support Group is a self-help patient group dedicated to improving the care of GBS patients.

For further information, you can contact the Guillain- Barré Syndrome Support Group at the address below:

LCC Offices
Eastgate
Sleaford
Lincolnshire
NG34 7EB

Telephone: 01529 304615

Helpline: 0800 374803

E-mail: admin@gbs.org.uk

Website: www.gbs.org.uk

Patient information

A Patient Information Service from:



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