

# Patient information from BMJ

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## Guillain-Barre syndrome

**Guillain-Barre syndrome is a rare condition that affects the nerves, causing muscle weakness, numbness, pain, and sometimes paralysis. With treatment most people make a full recovery. But it can cause long-term problems and is sometimes life threatening.**

### What is Guillain-Barre syndrome?

Guillain-Barre syndrome is a condition that affects the nerves, causing muscle weakness, problems with movement, and sometimes temporary paralysis (being unable to move at all).

We don't know for sure what causes Guillain-Barre syndrome, but it seems to be caused by problems with the immune system. Your immune system is your body's defence against infection by bacteria and viruses. When you get an infection, antibodies attack and kill the germs.

But with Guillain-Barre syndrome your antibodies start to attack the nervous system. It can happen to people of all ages but it seems to be slightly more common in men and boys than in women and girls.

In many people Guillain-Barre syndrome happens within a few weeks of having had an infection, such as a chest infection or a bad stomach upset (gastroenteritis). Guillain-Barre syndrome has also been linked to the Zika virus in recent years.

### What are the symptoms?

The symptoms of Guillain-Barre syndrome usually start in the arms and legs, with tingling and numbness in the hands and feet followed by weakness and difficulty bending your joints. These symptoms might get worse over several days. You might also notice:

- pain in your legs and back. The pain seems to be worse in children
- breathing problems
- trouble with your speech
- weakness or drooping in your facial muscles
- trouble swallowing

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- double vision.

Some people's symptoms are so severe that they become unable to move at all. This can last for several months while they have treatment and recover.

## Tests for Guillain-Barre syndrome

If your doctor thinks you may have Guillain-Barre syndrome he or she will want to do some tests to make sure.

Your doctor will test how well your nerves are working. This is done by testing how well your muscles react when the nearby nerves are stimulated by weak electrical signals. These electrical signals can be passed through sensors attached to your skin, or through tiny needles inserted into some of your muscles.

## Lumbar puncture

To help make a definite diagnosis your doctor will probably want to check a sample of the fluid in your spine (your cerebrospinal fluid). To do this, your doctor uses a needle to remove some of the fluid. This is called a lumbar puncture.

Before having a lumbar puncture you will have a scan to make sure that the procedure is likely to be safe and won't cause any damage.

You will also have a local anaesthetic to help reduce pain while the doctor draws out the sample of spinal fluid. But having a lumbar puncture is still likely to cause some discomfort. The whole procedure takes about 30 to 45 minutes.

## What treatments are available?

Most people with Guillain-Barre syndrome need to be treated in hospital, usually for at least several weeks. Some people may need to stay in hospital for several months.

As well as treatment to stop your immune system from attacking your nerves (called immunotherapy) you will be supported in other ways. For example, you may need help to keep you breathing properly while your nerves and muscles recover.

## Immunotherapy

Immunotherapy is the main treatment for Guillain-Barre syndrome. There are two types of treatment and they both seem to work about as well as each other.

The first is called **intravenous immunoglobulin** (IVIG for short). IVIG is made from donated blood and it contains healthy antibodies that won't attack your immune system. You are given this treatment through an intravenous (IV) drip. If you have IVIG you will probably have it every day for about five days.

The other type of immunotherapy you might be given is called **plasma exchange** (plasmapheresis). You are connected to a machine that filters the harmful antibodies out of your blood. If you have plasma exchange you will need to have this treatment several times over a few days.

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## Other treatments

Some people's muscles become so weak that, for a while, they need help to breathe properly. This can be done using a machine called a ventilator. About 30 in 100 people with Guillain-Barre syndrome need help with their breathing in this way.

You will also have regular checks to make sure your heart is working as it should: for example, your blood pressure will be monitored to check that it isn't getting too high.

Lying still for long periods can also increase your chance of deep vein thrombosis (DVT). This is when a blood clot forms in a vein. Your doctor might recommend that you have drug treatment to reduce the chance of this happening.

You might also be given drug treatments to help with any pain that is affecting your nerves.

If you have been unable to move much or at all for a while, you might need help with rehabilitation when you are able to move again. A physiotherapist will guide you through exercises to help you move your limbs and muscles properly once more.

## What to expect in the future?

About 85 in 100 people who get Guillain-Barre syndrome make a good recovery. But older people, those whose muscles have been badly damaged, and those who needed ventilator treatment are less likely to make a good recovery.

Some people will have muscle weakness that lasts for several years and some people may not be able to walk again for many months.

Some people die from Guillain-Barre syndrome. This is more common in older people and in people with more severe symptoms.

Your doctor will want to check on you every few months after you have recovered, and then every year. Some people become ill again and need to have more treatment.

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