

GUIDE

After GBS — Recovery Advice for Patients

This series of guides is produced by the Guillain-Barré Syndrome Support Group. We are a registered charity that supports those affected by the Guillain-Barré syndrome (GBS) and related conditions in the United Kingdom and the Republic of Ireland. The related conditions include chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) and Miller Fisher syndrome (MFS).

Our guides are easily downloaded from our Web site at www.gbs.org.uk in PDF format and may be both read and printed using free Adobe Reader software. Alternatively, you can request printed copies from our office.

For information and support, ring our helpline on 0800 374 803

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Residual symptoms

While most patients make a very good and often complete recovery, it is no use denying that others are left with a wide range of residual symptoms. No two individuals are left with quite the same problems, therefore it is helpful to consider groups of related symptoms.

Weak feet, ankles and legs

The longest nerves are the most likely to be damaged and take the longest to regrow. Consequently, some patients are left with weak ankles causing the feet to 'drop', or catch when walking. In mild cases, this footdrop can be helped by wearing boots which support the ankles, but in more severe cases it is worth consulting a surgical appliance officer or orthotist, to be fitted with specially designed splints called 'ankle foot orthoses'. There are simple adjustable off the peg models,

but it is usually better to have a pair specially made. They are very light and are worn inside shoes (which means you have to get a bigger pair), and are inconspicuous if you wear trousers. A physiotherapist is the best person to advise whether ankle foot orthoses will help, although a hospital consultant has to write the prescription.

Weak hands with loss of the muscle bulk

In some people the hand muscles are slow to recover. This usually means that although the grip strength returns, fine manipulation remains difficult. The fingers can tend to bend, or 'claw', to use the familiar but unpleasant medical jargon. A physiotherapist will show you how to minimise this by gently, but firmly, stretching the fingers into a fully straight position. To get round the problems of weak fingers, an occupational therapist will help you find devices which help and also recommend alterations to your home. Working hand splints help with finger correction, whilst allowing the fingers to be mobile.

Loss of feeling

In some people who have severe damage to the sensory nerve fibres, three groups of problems present. Firstly, the loss of feeling contributes to difficulty placing your feet or controlling your hands. Secondly, the loss of awareness of pain and temperature means that you have to take especial care not to damage your fingers and feet. You should be particularly aware of hot utensils in the kitchen and inspect your feet each night to make sure you have not cut them or got an infection. Thirdly, the distortion of the sensory fibres may cause pain (see foot discomfort below).

The recovery usually begins about two to four weeks after the start of GBS, and then continues steadily. Some patients get better very quickly within six weeks, but most have to reckon with three to six months, and some more than a year. For those who are very severely affected, improvement continues for many, many months. While the recovery is fastest during the first year, further recovery certainly continues during the second, third and fourth years and sometimes even longer. During these late stages the recovery is very slow. There are no medicines which have been shown to help recovery during these late stages, but a sensible regimen of exercises tailor-made for you by a physiotherapist is worthwhile.

Foot discomfort

Some people have persistent discomfort in their feet. This is because partial damage to peripheral nerve fibres distorts the input to the central nervous system and is interpreted by the brain as pain. It can indicate the fact nerves are regrowing and the 'raw ends' are beginning to transmit messages again. Consequently, it may settle down eventually on its own. There is no universal cure for this symptom. Everyone finds out what simple measures help for themselves rubbing the feet, not letting anything touch the feet, keeping the feet warm, keeping the feet cold, having comfortable, broad-fitting shoes, not wearing shoes, resting, walking. Try them all and see what helps you. You can also try simple pain killers from the chemist: paracetamol [acetaminophen/Tylenol®], aspirin or ibuprofen. Your doctor may prescribe amitriptyline, carbamazepine, mexilitene, tramadol, gabapentin, or other drugs. If the pain is coming from cramps, then quinine is magic.

Fatigue

Although any patient could tell you that fatigue is common after GBS, it is only recently that a formal Dutch study has shown that two thirds of patients have high levels of fatigue for a long time after GBS. The reasons vary from patient to patient and can have to do with emotional factors including depression, grieving the loss of health and anxiety, as well as the physical components of having to make more effort to perform tasks which would have been trivial before your illness. It is best to approach the problem with an open mind as to the ingredients of the fatigue and a preparedness to approach both the emotional and physical components. Patience is a virtue in dealing with this problem. Consult your doctor, your neurologist and your physiotherapist. Plan a gradually increasing programme back to health. Do not expect too much too soon. Set yourself reasonable goals and remember that there is every reason to expect continued improvement. Ask your doctor if you should try an antidepressant since small doses of some antidepressants, especially amitriptyline, help fatigue even in the absence of clinical depression. Do not use your illness as an excuse not to do things, but do not set yourself unreasonable targets and make yourself ill by trying to do too much. Try to strike a happy balance.

Recurrent symptoms in GBS

It is normal to complain of persistent symptoms for weeks and sometimes months after you have been discharged from hospital with GBS. These symptoms vary enormously from patient to patient and include weakness, tingling, painful tingling, aching in the limbs, cramps and tiredness. It is normal for these symptoms to fluctuate a bit, being worse when you are tired, stressed or affected by an intercurrent illness, such as a cold, sore throat or flu. They gradually wear off, but you may feel some of them coming back in a milder form at times of stresses like that for a year or two. This does not usually mean that the GBS is coming back as recurrence is very rare indeed. Coping with these recurrent symptoms can be difficult. You need to be sensible about them and rest when necessary, but try to keep them in proportion and not let them get on top of you; easier said than done sometimes, and counselling can in some cases be helpful.

Preventative measures

There is nothing which can be done to alter the very, very small risk of recurrence of GBS. Although there has been concern that some immunisations might have precipitated GBS, there is no hard evidence to support this notion with immunisations which are in common usage in the UK today. However, it would seem unwise for someone whose GBS had come on within six weeks of an immunisation to receive the same immunisation again. Furthermore, many neurologists advise patients not to have immunisation for a year after the onset of their GBS, just in case. Since GBS occurs after infections, you might think it desirable to avoid contact with infections. To try to do so would be a practical impossibility, and anyway, not worthwhile since you will now be immune to whatever infection triggered your first attack of GBS.

Hospital back-up care

There is a wide range of different practice regarding hospital follow-up visits. Unless you are taking medicines on account of intercurrent medical illnesses, or unless you are being prescribed medicines for pain or complications, you do not need to attend for prescriptions. In fact the

person you are likely to need to see more than anyone else is your physiotherapist, rather than a neurologist. However, if you have been very ill and are recovering from a frightening experience such as GBS, it is appropriate to continue to consult a neurologist at appropriate intervals (gradually increasing) until your health is back to normal, or you have learned to cope with whatever disability the illness has left you with.

General prognosis

Despite all the above comments it is possible to be optimistic about the future for most people. Most people will get back to their previous activities, return to school, return to work or return to running the home. Even if you are left with weakness and numbness of your limbs, your mental faculties will not be affected. The chances of GBS coming back again are very small indeed, although it is difficult to give a precise figure. This is because there is some confusion between GBS and a closely related condition chronic inflammatory demyelinating polyradiculoneuropathy (CIDP). Also, modern treatment may interfere with the course of the illness and make it seem as if the illness, which is basically just one illness, actually has an early relapse. A ballpark figure for a real recurrence would be that the life time risk for another attack of GBS is about 2%.

If after reading this guide you still have anxieties and unanswered questions, telephone our helpline on 0800 374803 (UK) or 0033 1529 415278 (RoI). Alternatively, you can e-mail us or register for support on-line

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