



GUILLAIN BARRÉ SYNDROME



Recovery Advice

GBS Support Group New Zealand Trust

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Recovery

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The GBS Support Group is a registered charity and receives no government funding. If you have found this guide helpful and would like to help us to continue publishing copies for others affected by GBS and associated inflammatory neuropathies, please consider making a donation to us. Secure donations can be made online – see our website for details. Alternatively you can request a form from the Secretary.

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- Foot baths, good foot care. Massage / massage machines. Foot cradles at night-time to keep the bed clothes from touching the feet, or apply an ointment and loose fitting socks.
- Heat therapy (hot water bottles with cold or hot water). Freezer blocks. (Heat generally relieves soreness, aches and pains, and coldness lessens pain sensations caused by nerve damage).
- Support stockings/socks. Woollen socks, soft soled wide-fitting shoes, gloves.
- Complementary therapies/herbal remedies.
- Relaxation tapes or self-hypnosis.
- Gentle exercise encourages the production of endorphins, which can have a direct influence on the reduction of pain.
- Consult your GP about a local pain clinic and/or pain management programme.

Help sources

Pain Support Group www.painz.org.nz

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 orthoptist discussing with your doctor or physiotherapist whether you should be fitted with specially designed splints called 'ankle foot orthoses'. There are simple adjustable ready-made models, but it is 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.

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' 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).

GBS usually progresses for 2-4 weeks, then stabilises. After a further 2-4 weeks of stability recovery begins 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 up to 3 years; beyond that time people can learn new tricks to improve function but there is no further nerve recovery. Recovery is fastest during the first year the later stages the recovery are very slow. There are no medicines which have been shown to help recovery, 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, nortriptyline, tramadol, gabapentin, or other drugs. If the pain is coming from cramps, then quinine might help .

Fatigue

Although any patient could tell you that fatigue is common after GBS, 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 be 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. However, even patients who had mild weakness and make a full recovery of strength can still have persistent fatigue. It is also important to recognize that unrelated conditions such as anaemia, under-active

can sometimes be severe and may require strong analgesics (pain killers). It does however usually settle.

In the acute stage of the illness, if weakness is severe, many patients experience non-specific general discomfort because of the inability to move and obtain the normal relief of a more comfortable position of the limbs or body. This particularly applies to ventilated patients who have the added difficulty in communicating with their nurses. Although pain killers and tricyclic drugs such as amitriptyline (Tryptizol®) may be needed, particularly if sleep is very interrupted, this problem is considerably helped by nurses and physiotherapists being aware of the patient's discomfort and aiding movement.

Usually in the early recovery phase, some GBS patients experience painful pins and needles (paraesthesiae) or other unpleasant sensations, such as burning feelings in the hands and feet. These symptoms tend not to respond to analgesics, but can respond to drugs such as nortriptyline, amitriptyline or gabapentin. Other medications may be useful in a few cases. Pain does tend to resolve as recovery proceeds.

As pain can make one irritable and difficult to live with at times, it is important that family and friends are kept informed, so that they can understand the reason for such behaviour.

Remember that because the nerves to the hands and feet are the longest in the body, pain will linger in the extremities after it has left other parts of the body.

Some helpful suggestions

- Quinine may help cramps but is difficult to obtain in NZ.
- Over-the-counter analgesics: paracetamol/acetaminophen (Tylenol®), aspirin, ibuprofen may help mild pain. Stronger analgesics may sedate and be constipating.
- Capsaicin, a topical analgesic cream, made from peppers. (Note. This has been reported to cause nerve damage in some patients.)
- TENS machines (portable battery-operated powered devices) stimulate the skin and underlying nerves to block pain.

Exercise

The role of exercise in the ongoing rehabilitation for patients with GBS is still to some extent unclear and clinical trials are being carried out to improve our understanding. However, there is already some evidence that where weakness and fatigue are problems, participation in regular graded exercise can be beneficial.

It is important that prior to starting regular exercise you seek advice from your GP, consultant or a physiotherapist. For example, in some cases severe weakness around joints may make them vulnerable to damage during exercising and special splints or orthoses may be needed to protect such joints. In addition you should not exercise excessively as it is still unclear whether over-exercising may actually make some problems worse and may make you feel more fatigued.

However, where medical problems do not exist, then even patients with severe residual problems, including fatigue, may benefit from fatigue management and/or a graded exercise plan. Such a plan may include gentle strengthening exercises for weak muscles, specific functional activities eg walking up and down stairs, getting up from sitting to standing and back down again, and graded aerobic exercise eg walking, cycling, swimming or running etc.

Exercising in this way can help to improve your muscle strength and reduce your overall sense of fatigue. There are also general benefits of this type of exercise in boosting the immune system, helping your heart and lungs remain healthy and making you feel better about yourself. However, it may take weeks or even months before you feel the benefit of exercise so it is important to pace yourself. Therefore you should be encouraged to seek advice on whether and how to start regular exercise.

Pain in GBS may never be a problem but can occur in three main situations:

In the acute stage of the illness, some patients experience spinal pain, most commonly low back pain, and this may even be the presenting feature. The pain is thought to be due to acute inflammation of the nerve roots in the spine. The pain

thyroid, sleep disturbances, impaired breathing function and mild heart failure may contribute to fatigue and should be excluded before attributing the fatigue to the after effects of GBS. 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. It may seem paradoxical but a regular light exercise programme is the cornerstone of fatigue management. 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 such as sertraline and citalopram (and others) can 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.

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 NZ 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. See also our booklet *Immunisation*.

Hospital back-up care

There is a wide range of different practices 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 decreasing) 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%.

Diet

During illness, nutritional needs are at their peak, but it is not unusual for patients to lose their appetites or taste for food. Worry and fear often accompany illness and can also contribute to loss of appetite. Good nutrition can be a powerful ally in the process of recovery. If taste has been affected, this will usually improve with time. Plastic utensils can be used if bitter or metallic tastes are experienced whilst eating. Sometimes taste changes can be related to medications, but drugs should not be discontinued without first consulting your GP.

A sensible balanced diet is important but there is no specific diet and there are no specific foods that are harmful or beneficial to patients who have had GBS. Consultation with a dietitian can be helpful in designing the most appropriate diet.

The severity of GBS can be variable and this is true both for the speed and pattern of recovery. You may experience changes or improvements in your residual symptoms for some months, sometimes years after discharge from hospital or a rehabilitation unit.

During the recovery stages, physiotherapy, occupational therapy (OT) and speech and language therapy play a vital role in the rehabilitation process as well as maximizing functional ability. At some point during rehabilitation the rate of recovery will plateau and it is often at this point that patients will be discharged from all the support services on which they may have relied. It is also possible that patients may be placed 'on review'. This means that you may be followed up at regular intervals and can telephone for advice in-between but don't attend the clinic as often as you did before.

You may have some residual problems but, even if you appear symptom free, simple fatigue may become evident as you return home and take on more activities. It may therefore be wise to consider pacing yourself as you return to family life, work and hobbies and exercise may also be recommended.

to understand emotional reactions and to discuss appropriate treatments. These might include medication, to improve mood in the short-term and/or psychological therapy to help change the way you think and act.

Non-traditional therapies for mood disorders are of unproven benefit but many people feel that they help. They do have the benefit of being harmless.

Counselling.

- St John's wort (hypericum) a herbal antidepressant (also helps with nerve pain).
- Valerian a herbal sedative that can help with depression, insomnia, anxiety and nerve pain.
- Bach Flower Remedies Sweet Chestnut, Mustard, Rescue Remedy can all help with anxiety and depression.
- Relaxation or self-hypnosis tapes, visualisation.
- Exercise diverts the mind and alleviates mental stress, as well as increases blood flow to the brain. A regular routine should be established.
- Aromatherapy massage or by using essential oils in a bath, oil burner or on your pillow at night (clary sage, geranium, neroli, lavender).
- Amino acid D, L-phenylalanine (DLPA) has been found to alleviate depression.

The severity of both GBS and CIDP can be very variable and this could be said for both the rates and patterns of recovery. You may experience changes or improvements in your residual symptoms for some months, sometimes years after discharge from hospital or rehabilitating unit.

Hygiene and cleanliness **Some Common Problems**

Personal cleanliness for those who are unable to attend themselves fully can be a problem. Many returning home from hospital may have reduced use of their hands, usually temporary, but occasionally permanently. Many will be unable to wash themselves, brush their hair, use the lavatory, wipe their bottoms, brush their teeth, cut their nails etc.

It is important for both hygiene and self-esteem that these matters are attended to. There is no place for modesty here. Even if you are regaining function and attempting these aspects of care, ask for assistance if necessary.

Constipation

Lack of activity or a lazy bowel can cause bowel movements to be irregular and constipation is likely. Occasional treatment with laxatives is one solution, but a far better approach is to modify your diet to avoid constipating food and replacing it with roughage. If this is too much of a culture-shock, consider a bulking agent. You might be able to get this on prescription. Adequate fluid intake is also important.

Teeth

Through no fault of their own, many people's teeth are neglected during periods of serious illness. Once you have returned home from hospital, arrange an appointment with your dentist as soon as possible. There may be physical barriers making this difficult, as many surgeries have inadequate access for wheelchairs etc. If this is the case there may be a community dental service available that can help. Using an electric tooth brush can be helpful if you have residual weakness in your hands.

Feet

Being at the end of the longest nerves in the body, the feet are often the last to recover. It is important to pay special attention to them so that any problems can be attended to before they get out of hand. Toe nails should be kept trimmed and dead skin removed from between the toes and elsewhere. In-growing toenails can be a problem and should receive attention before any infection sets in.

Swollen ankles and feet should be elevated. TED stockings or intermittent compression therapy may help.

Emotional Aspects

To suffer GBS is to experience a massive change to the world in which you live. One day you are fit and healthy, doing the things you have chosen to do with the people you have chosen to be with. You are more or less in control of the direction in which your life is going.

The next day, out of the blue, you are in an unfamiliar hospital setting. You have little control over what is happening. Any certainty you had about the future is suspended. You neither know why GBS has happened to you, nor the prognosis. You might be seriously ill, facing even the possibility of death or permanent disability. Family members are stressed and know no more than you do. You can neither help your family nor undertake normal responsibilities. In short, just about everything is different and the future is uncertain. These, and the many other immediate consequences of GBS, such as pain, discomfort, and difficulty in communicating (if ventilated), are likely to be frightening. The human reaction to these kinds of threats to security and wellbeing is to feel anxious or angry. Anxiety and anger are normal emotions, and can be 'adaptive' (helpful) by giving the mental and physical energy that is needed to anticipate and tackle problems.

An acute stress reaction, in which people may be tense, jumpy, irritable, and preoccupied with worries about their situation, is widely recognised as an entirely normal part of the process of adjusting to a major life change. During this time, people will be coming to terms with the implications of the event and will also be developing a range of coping strategies for dealing with practical problems (eg making lifestyle adaptations), for understanding and keeping events in perspective, and for dealing with emotions.

The acute stress reaction to GBS will be more intense and will last longer for some people than others. This depends on many factors: eg the severity of illness, personality and emotional resilience; the way in which people are given information about what is happening to them; and the practical and emotional support they receive from family, friends, and

professionals. This stress reaction is not an illness to be treated, but there are things which can help to take the edge off it and perhaps reduce its duration.

It is important for you to increase your sense of personal control over the situation. Seek information and discuss issues which are worrying you. Other people, both family and professionals, may be able to help identify and find solutions to particular concerns or problems. At other times distraction, humour, or simple companionship are likely to be equally valuable in helping to relax and not let GBS take over.

Many people who suffer GBS, whether or not they make a full physical recovery, will also make a good psychological recovery. They will find ways of coping with any ongoing problems and will put behind them the fears and stress associated with the acute illness. However, it is becoming increasingly clear that in GBS, as in better-researched illnesses such as heart attack or stroke, a significant proportion of sufferers do continue to experience severe emotional disturbances.

Such disturbances include anxiety, where patients may have a frequent sense of apprehension that something bad could happen at any time; depression, a sense of helplessness and loss of control or grief about the aspects of life that have changed; or, in some cases, post-traumatic stress disorder in which anxiety and depression both occur, along with recurrent vivid memories or flashbacks to the illness and/or strenuous efforts to avoid thinking about it.

It is very easy to then get caught up in a vicious circle where low mood reduces ability to deal with practical difficulties, and these ongoing difficulties exacerbate low mood. It can also have an adverse effect on the ability to relate to the closest people. This makes people less able to support each other during periods that are already stressful enough.

If you have suffered from these kinds of feeling for more than a few months after the onset of GBS, consider seeking professional help. You will get back to a productive and rewarding lifestyle far more quickly if these emotional reactions are overcome. You and your family deserve this!

Explain your feelings to your GP or neurological consultant. They should be willing to refer you to a clinical psychologist or psychiatrist. These specialists have the skills and experience