

After GBS

***Information for patients recovering from
Guillain-Barré syndrome***

(includes Carer's Guide)

by Jane Tempest-Roe

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with contributions by Professor RAC Hughes, Dr Jane Powell, Dr Bryan Lecky, Claire Strickland, Christina Robillard, Andy Leitch and members of the GBS Support Group.

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Introduction and Acknowledgments

The Guillain-Barré Syndrome Support Group was founded in 1985 by Glennys Sanders MBE. The Group provides a lifeline to sufferers and their relatives of the inflammatory neuropathies Guillain-Barré syndrome (GBS), chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) and related conditions.

The Group publishes information about the illnesses and has a network of local contacts consisting of former sufferers, who visit patients and their families in hospital or at home. A helpline is also run by former patients and is an invaluable support service for both patients and their carers. The Group continuously strives to increase awareness of the syndrome amongst the medical profession and the public at large. Over the years large sums of money have been raised to fund research into GBS and CIDP.

This particular booklet has been especially written to fill a gap in the Group's literature which, until its publication, concentrated on the early aspects of GBS and not on the problems associated with recovery. I have taken the opportunity to include a Carer's Guide as this was another subject on which the Group had little published material.

Whilst this booklet is primarily designed for people recovering from GBS (an acute condition), much of the content is of a practical nature and applicable to those who have been diagnosed with CIDP. The information provided is current at the time of print and the GBS Support Group cannot be held responsible for data which may have changed subsequently.

I would like to thank the specialists who took the time to write their professional contributions. I would also like to thank members of the Group's NEC for their help and encouragement, Group members for their hints and tips, and Howard Gregory for the delightful cover illustration.

Jane C R Tempest-Roe

January 2000

Publications

Other booklets available from the GBS Support Group are:

- *Guillain-Barré Syndrome* — a guide for patients, relatives and friends;
- *The Guillain-Barré Syndrome Patient in Intensive Care* — a guide for relatives and friends;
- *Childhood Guillain-Barré Syndrome* — a guide for parents and carers;
- *CIDP* — a guide for patients, relatives and friends;
- *Peripheral Nerve Disorders* — an explanation for patients, relatives and friends; and
- *Jenny's Story* (a beautifully illustrated booklet for children with GBS).

For copies of these booklets, write to the address below. Booklets will only normally be mailed to addresses in the UK and the Republic of Ireland. The contents of the booklets and further information can be seen on our Web site.

Free Helpline

If you are presently suffering from GBS or a related condition, or are a relative or friend of a sufferer, and wish to talk with someone now about the illness, call the Free GBS Helpline on **0800 374 803** (UK only). From the Republic of Ireland call 00 44 1529 415278 (normal UK rate applies).

Our Helpline volunteers are themselves former patients or their carers who are able to understand your anxieties and answer your questions.

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Sleaford
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NG34 7EB

Tel/fax: +44 (0)1529 304615.

E-mail: **admin@gbg.org.uk**

Web site: **www.gbs.org.uk**

Carer's Guide

Life in Hospital

Whilst loved ones are being cared for in hospital, it should not be underestimated that life for the carer can be very difficult, emotionally as well as physically. Notwithstanding the general upheaval and worry, carers have to cope and continue with everyday living — and more. Hospital visiting must be scheduled alongside running a home, holding down a job, often looking after children, as well as other daily tasks. You should not battle on heroically, trying to juggle everything alone. Seek and accept help from friends, family and support organisations.

Find out as much as possible about the illness and make it known to the ward staff that ward packs containing literature about GBS are available on request from the GBS Support Group. You may wish to become involved with some of the nursing care, which as well as assisting the staff, will help you to feel you are contributing something and being useful. Ask the staff what you can do to help.

If patients are unable to eat or drink without assistance, ensure that all the shift-workers on the wards are made aware of this. Also make it known that if patients are immobilized, they will need help with regular turning, to avoid bed sores and general discomfort. These practices should, of course, be second nature to the permanent staff of wards that regularly deal with GBS patients. But due to a number of reasons, not everyone may be familiar with these aspects.

Some patients experience acute pain when they are touched, especially when being lifted or turned. If this is the case, visitors should be forewarned. For those who are not hypersensitive, gentle massaging of the affected areas can be comforting and helpful. Ladies may appreciate some feminine attention (someone to paint their nails, apply a little make-up and perfume etc). Men can benefit from being shaved, having their hair cut and by having a splash of aftershave applied. Visits from friends and relatives should be kept short, as patients tend to tire easily.

GBS is a frightening experience and patients need plenty of encouragement and support from loved ones: lots of hugs, kisses and kind words. Communication will be difficult if the patient is on a ventilator. If the eyes are unaffected, the

'blinking' system can be applied, whereby the patient blinks once for 'yes' and twice for 'no' (but don't forget a special code for 'error, start again'). If the ward or speech therapy department have no communication devices available, the GBS Support Group can loan out or sell a set of communication cards.

Where possible, try to keep patients in touch with the outside world. Some patients may find solace in listening to their favourite tapes on portable Walkman machines. Others may find comfort from being read to, if they are unable to do this themselves. Support stands to place onto the patient's bed can sometimes be obtained from the hospital librarian. Audio books are another option, as are automatic page turners. Flowers, photographs and children's pictures can all be uplifting. Roll-on lavender sticks applied to the forehead and arms can be calming and help the patient to sleep. GBS patients often feel very hot. If this is the case, ask ward staff to place a fan by the bedside.

Sitting out can be beneficial, but when patients become uncomfortable they should be moved back to bed. They will gradually be able to sit out for longer periods. It is important that the patient's feet are well looked after. Massaging with lotion can help to prevent dryness and will hopefully assist to recover more feeling into them. Ingrowing and infected toenails can result from immobility, so it is important to ensure the nails are correctly cut.

Keep a record of the patient's progress in order to provide a perspective of the illness.



Life at Home

When the patient returns home, be mindful of the fact that the recovery process will be on-going, and that the patient will tire easily and may have some uncomfortable residual effects to contend with. Try to empathize with uncharacteristic mood swings and feelings of frustration the patient may experience. Help by being reassuring and encouraging open talk about his/her experiences and fears. It can take several months, or more, before regular fitness levels are restored, and it has to be said that whilst the majority of people do make

good recoveries, some never escape from residual problems. These may be minor and niggling, but they can sometimes be very serious and result in profound and permanent disability.

Considerable patience is required as the body has suffered a significant disturbance and cannot be expected to recover overnight. To add to the frustration, many patients experience erratic recovery patterns, whereby for example, days of reasonable fitness can be succeeded by less optimistic ones. It helps to be aware that many people recovering from GBS look fitter than they actually are, and an understanding and patient attitude on the carer's part can make a significant difference to a patient's well-being and state of mind.

Equally, patients should try to empathize with the carer's difficulties. Open communication should be encouraged at all times.

A good deal of patience will be required from you and there will be many adjustments to make until working routines are established and you both come to terms with the challenging sequential life changes of the past, present and future.

If you are finding things difficult, you are entitled to a need's assessment, whereby on request, an assessor will visit your home to discuss your needs and will design a 'care package' for you.

Here are a few practical steps that can help to counteract the stresses and strains of caring for someone suffering from GBS:

- Gather support from family and friends. Invite help from the local social services.
- Contact a local caring organisation providing support services in your area.
- Contact the GBS Support Group to arrange to speak to, or be visited by, a local contact. Tel: 01529 304615.
- Telephone the GBS Support Group free help-line to talk to a recovered patient. Tel: 0800 374803.
- Try to be organised. Keeping on top of things can help to alleviate stress.
- Take a rest from your duties and allow yourself some personal space. Go for a walk, listen to relaxing music, visit friends etc. Generally take care of yourself, eat healthily, get plenty of sleep. When friends or relatives visit the patient, take this as an opportunity to have a break and use this time to do something for yourself.

- Take the pressure off by putting some activities on hold.
- Be mindful of the patient's limitations.
- Communicate with each other. Talking is therapy and you may also find it useful to speak to an external source: friends, relatives, caring organisations, the GBS Support Group etc.

Help sources:

- Crossroads. Crossroads offers respite to carers with trained care assistants. Tel: 01788 573653. 10 Regent Place, Rugby CV21 2PN.
- Carers National Association. The Association provides publications and advice on all caring issues, including benefits, community care, housing and equipment. Tel: 0808 808 7777 (freephone) or 0345 573369. 20/25 Glasshouse Yard, London EC1A 4JT. **internet@ukcarers.org**
- Princess Royal Trust for Carers. The Trust gives information, advice, emotional support and community consultation. Tel: 020 7480 7788. 142 Minories, London EC3N 1LB. **www.carers.org**
- Social Services. Contact your local Social Services department for home assessments, home help, adaptations to the home, meals, temporary respite care, placement at day care centres and advice on benefits.
- Benefits Helpline. Tel: 0800 882200.
- Citizens Advice Bureaux.
- Benefit leaflets are available from post offices.



Carer's Check List

- Get organized. Investigate benefit entitlements with the hospital social worker and/or Social Services. Liaise with the hospital occupational therapist (OT) about equipment arrangements. If necessary, rearrange the home, ie move the bed downstairs.
- Arrange for a regular backup physiotherapy programme before discharge, if considered necessary. You can ask for telephone numbers (physiotherapist,

OT), in case you need advice in the future.

- Be temperature conscious if the patient is suffering from lack of sensation, ie run and test the bath water.
- Taste buds may be affected for awhile, so prepare meals to suit the patient. Vitamin supplements can be included if a balanced diet cannot be achieved.
- Beware of falls brought about by weakness or unsteadiness.
- Be mindful of potential accidents resulting from weakness and/or numbness (ie dropping things). Care should be taken when the patient is using hot appliances, such as when cooking or ironing. A microwave oven is a very convenient, safe way of preparing food.
- Help the patient with daily exercises. Ensure that everything is done in moderation and that the patient does not start rushing around too soon.
- Encourage the patient to talk openly about his/her experiences and fears.

After GBS

Recovery Advice for Patients

by Professor RAC Hughes, Professor of Neurology, Guy's, King's and St Thomas' School of Medicine, London

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, 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%.



Exercise

by Claire Strickland, Chartered Physiotherapist, St Bartholomew's Hospital, London

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.

During the recovery stages, physiotherapy, occupational therapy (OT) and speech and language therapy play a vital role in the rehabilitation process, as well as maximising 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 (physio, OT, speech and language therapy etc), on which they have relied to a lesser or greater extent, often for long periods. If there are still persistent symptoms at this point, it may be possible to be placed 'on review'. Patients are then followed up on a three- or six-monthly basis, and can ring for advice in-between.

You are likely to be left with a number and variety of residual problems, which no one can predict. Even if you appear symptom-free, simple fatigue will become evident as more activities are taken on and exercise recommenced.

Before being discharged by the physiotherapist, seek advice and request a graduated programme of activity. You are likely to be generally unfit and ‘deconditioned’ (muscles and joints simply cannot work as strongly as previously). This is true following even short periods of incapacity and inactivity.

Important. Do not attempt to take up their former activities or sports without advice. It is imperative to start slowly and build up. This applies to walking, as much as swimming or working out in the gym: ie one length swimming, two minutes cycling, 100 yards walking, ‘gentle’ exercise. Never exercise to your maximum ability. All these exercises are excellent provided advice is taken first. Some fitness gyms have a chartered physiotherapist on the premises and advice should be sought.

Exercising too quickly causes fatigue and fitness will not be achieved. If this is allowed to continue, fatigue will become chronic and all the more difficult to overcome. If this happens it is even more important to seek advice, as it will require a change not only in the levels of exercise, but may also necessitate some adaptations to the whole daily life, in order to break out of this cycle.

Notwithstanding the obvious physical benefits, moderate daily exercise can also help to boost the immune system and can make everyone feel better about themselves.



Emotional Aspects of GBS

by Dr Jane Powell, Lecturer in Psychology, Goldsmith’s College, London

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 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.

Treatments are also available privately, but you are advised to check that those you approach are appropriately qualified. To find private treatment, most libraries hold the *Directory of Chartered Psychologists*, which lists private practitioners. If you have difficulty locating the directory, contact the British Psychological Society. Tel: 0116 2549568 or 2548824.

Help sources:

- Depression Alliance. The Alliance produces publications on depression and has a written advisory service offering support and understanding. It also organises self help groups. Tel: 020 7633 9929. 35 Westminster Bridge Road, London SE1 7JB. www.depressionalliance.org
- Depressive Associates. Tel: 020 8760 0544.

Also consider:

- 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.



Pain

by Dr B Lecky, Consultant Neurologist, Walton Centre, Liverpool

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 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 usually respond to some anticonvulsant drugs such as carbamazepine (Tegretol), sometimes with amitriptyline. The problem does tend to resolve as recovery proceeds.

Some helpful suggestions:

- Quinine is helpful for cramps.
- Over-the-counter analgesics — paracetamol, aspirin, ibuprofen — may help mild pain. Stronger analgesics may sedate and be constipating. Natural aspirin is available.
- 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.
- Foot baths, good chiropody. 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, whereas coldness lessens pain sensations by numbing the affected areas).
- Support stockings/socks. Woollen socks, soft soled wide-fitting shoes, gloves.
- Complementary therapies/herbal remedies (see page 39)
- 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.
- 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.

Help sources:

- Pain Concern. Pain Concern is a registered charity that offers help and support to sufferers of chronic pain. Tel: 01293 552636. PO Box 252, Crawley RH10 3GY.
- Pain Society. The Society helps to relieve suffering of pain by promotion of education, research and training. It provides information on pain clinics locally and abroad. Tel: 020 7636 2750. 9 Bedford Square, London WC1B 3RA.
www.staff.ncl.ac.uk/r.j.hayes/painsoc.html painsoc@compuserve.com
- Pain Relief Foundation. The Foundation produces information packs on pain. Tel: 0151 5231486. Rice Lane, Liverpool L9 1AE. **www.liv.ac.uk/pri**
pri@liv.ac.uk



Diet

by Christina Robilliard, Nutrition Consultant, Dip ION. Member of BANT.

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.

All auto-immune illnesses start in the adrenal glands which produce the body's own steroids. It is vital therefore that they are supported by maintaining an even blood sugar level. This can be achieved by eating small, frequent meals, always containing some form of protein. Stimulants such as tea, coffee and refined products should be kept to a minimum, as these play havoc with blood sugar levels, and ultimately deplete the body of nutrition. Sugar in any form should be avoided. Any food allergies or intolerances will also further challenge an immune

system that is out of balance and should be identified, and the offending foods eliminated. The most common culprits in Europe are wheat, dairy products and citrus fruits.

Protein is important for growth, health and recovery. If illness has made red meat less appealing, the following have excellent sources of protein: tuna, mackerel, herring, sardines, salmon, chicken and tofu (these foods are also more beneficial than red meat). Extra meat or fish can be added to soups, casseroles or stews.

An anti-inflammatory diet is recommended, containing many essential fatty acids, known as 'EFAs', found in oily fish, nuts, seeds and their oils and olive oil. The two families of essential fats are Omega 3 and Omega 6. These fats are necessary for the integrity of the myelin sheath that surrounds the nerves (Neuro epidemiology 1992: 11:214-25).

Energy foods are those rich in the B complex, such as whole grains, millet, buckwheat, rye and quinoa, corn, barley and fresh vegetables. Foods rich in vitamin A (such as fruits and vegetables), and vitamin E (avocados, sesame seeds, pumpkin seeds) can help to reduce inflammation. Magnesium exists in all green vegetables — the darker the better. Zinc is found in eggs, fish, sunflower seeds and lentils. There is copper in brazil nuts, oats, salmon and mushrooms. Bromelain is an anti-inflammatory found in pineapple and nuts. Apples and pears are good fruits to eat as they release their sugar slowly. Strawberries, kiwi fruit and sweet potato are rich in vitamin C. Foods containing bioflavonoids, which support vitamin C production, are found in yellow and green vegetables.

Foods to be avoided are those that interfere with energy production (and with mood). Such foods stimulate adrenalin and ultimately deplete vitality. Examples of these are: alcohol, tea, coffee, fizzy drinks, cakes, biscuits and sweets.

Pro-inflammatory foods are also to be avoided, but for a different reason. These are rich in Pg2, a prostaglandin that promotes inflammation. They include animal and dairy products, margarines (hydrogenated fats), hard fats, fried foods, burnt fats and shortening in pastries, biscuits, cakes and crackers. It has been shown (Lancet 1990 338:37-39) that a low saturated fat diet slows down deterioration of the myelin sheath. Such foods disturb the balance and stop the body making use of the beneficial 'essential' fats, as discussed above.

Help source:

- Christina Robilliard. 48 Warwick Avenue, London W9 2PU. Tel/Fax: 020 72865070.

Some Common Problems

Hygiene and cleanliness

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 completely. 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 such as Fybogel or Isogel. You might be able to get this on prescription.

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.

Help source:

- British Society of Dentistry. Tel: 029 2074 2417. Heath Park, Cardiff CF14 4XY.

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 may help and, **provided your doctor agrees**, a Flowtro n® or similar system that can intermittently squeeze the feet and calves may be a good investment.

Help sources:

- Huntleigh Healthcare. Intermittent compression products. Tel: 01582 413104. www.huntleigh-technology.com/healthcare/compfram.htm
- The Society of Chiropractors & Podiatrists, 53 Welbeck Street, London W1M 7HE Tel: 0171 486 3381 www.feetforlife.org

Personal

Some people encounter sexual difficulties following GBS, which can be attributable to residual weakness, nerve damage or depression. Such problems should be discussed with your doctor, who will ascertain whether it is physical or psychogenic, before deciding on an appropriate course of treatment. Often, problems will ameliorate with time, as your general state of health improves.

- Come to terms with the fact that you have a problem.
- Talk to your partner (if you have one). Be open and frank; trying to conceal your problem will only make matters worse.
- See your doctor; if necessary, ask for referral to a specialist.

Help sources:

- SPOD. SPOD aims to aid the sexual and personal relationships of people with a disability. The organisation provides information, counselling, advice and publications. Tel: 020 7607 8851. 286 Camden Road, London N7 0BJ.
- Impotence Association. PO Box 10296, London SW17 7ZN. Tel: 020 8767 7791. www.impotence.org.uk

- Relate. National Marriage Guidance. Tel: 01788 573241.
- Continence Foundation. The Foundation has an incontinence information helpline and details of local continence advisors. Tel: 020 7831 9831. **continence.foundation@dial.pipex.com**
- Incontinence Information helpline. Tel: 0191 213 0050. This Organisation also has details of local continence advisors.



Severe GBS

Predicting at an early stage whether a patient will have a residual disability or not is difficult. Though there are indications that an experienced doctor will note, no hard and fast rules exist. Making too much of these possibilities at an early stage can be the cause of a great deal of unnecessary worry.

To that end, the remainder of this section is printed separately in the *Coping with Severe GBS* supplement available from the office, or on our Web site at **www.gbs.org.uk/severe.html**. For most readers, there is no need to refer to the supplement. However, should you feel that recovery is not going as fast as you had been led to expect, it is recommended that you discuss the matter with the consultant neurologist in charge before reading the supplement.

Help source:

- GBS Support Group. Contact the office and request to be put in touch with a severe GBS specialist contact.



Equipment and Adaptations

When sufferers of GBS are discharged home from hospital, it is perhaps inevitable that some equipment to facilitate daily living will be necessary. In some cases,

adaptations to living environments will need to be undertaken. Some patients may require wheelchairs or walking aids, usually on a short-term basis but sometimes for a longer term, or even permanently. Clearly, the amount of equipment or adaptation needed can be very wide and a good degree of common sense needs to be applied. It would be pointless buying a state-of-the art wheelchair or making major adaptations to a house if a patient is expected to eventually make a good recovery.

The capabilities of the carer should also be taken into account when assessing requirements. For example, some carers might be able to transfer a person from a bed to a wheelchair, while others would need to use a hoist of some type.

What follows is applicable to those patients who are expected to make a reasonable or complete recovery. If a patient or carer is advised that the condition is liable to result in severe permanent disability, then they should read the *Coping with Severe GBS* supplement available from the Group's office.

Before a patient returns home, an occupational therapist (OT) employed by the local social services department will usually make a home assessment. The OT will obtain equipment and organise adaptations. Alterations in the home might include the fixing of hand rails and exchanging door knobs for levers. Equipment provided will range from raised toilet seats, bath seats and hoists, shower chairs and bed elevators to tap turners and kettle tippers. It might be necessary to obtain a hospital bed.

Some homes are not very suitable for those with disabilities, especially those who need wheelchairs. It may be necessary, for example, to convert a downstairs room into a bedroom and provide a commode.

If necessary, a ramp for wheelchair access will need to be constructed. The recommended slope is no greater than 1 in 12, but sometimes this is practically difficult to achieve. Furniture should be rearranged for easy access through rooms; this applies whether the patient uses a wheelchair or not. If a wheelchair has been provided, even on a temporary basis, it must be ensured that the chair is suitable for its purpose. A good seat cushion is important too. Back home, chairs can be bolstered with folded blankets placed under seat cushions or at the back or sides for comfort.

Resources at the various hospitals and regional authorities vary enormously. Some hospitals and most rehabilitation units have assessment centres on site, where you can test equipment and aids. Sometimes these centres have a small apartment

attached, where you and your carer can spend a day or two getting used to the home environment.

Campaign to get what you need before returning home and make sure that requirements are based in accordance with conditions on the 'worst' days, not the 'best'. Only then will you receive the maximum assistance to which you are entitled.

Some social service departments have assessment centres where equipment can be tried out. Disabled Living Centres (DLCs) throughout the UK have a wide range of equipment on show. The equipment can be tried and expert advice is given about personal needs.

Some large branches of chemists sell basic aids for eating, drinking and bathing. Most have incontinence aids available for purchase. There are several mail-order companies which provide a similar service. But before parting with a great deal of money, check first with your local social service department or GP to see if the items are available through the department, or by prescription.

Local authority education departments (LEAs) sometimes provide equipment for use in schools.

Help sources:

- Disabled Living Foundation (DLF). The DLF provides general information and advice about all types of equipment. Helpline: 0870 603 9177. 380-384 Harrow Road, London W9 2HU. **www.dlf.org.uk** **dlfinfo@dlf.org.uk**
- Disabled Living Centre Council (DLCC). 1st Floor, Winchester House, 11 Cranmer Road, London SW9 6EJ. Tel: 0171 820 0567. **www.lbro.ac.uk/info/usabilitynet/dlcc.html**
- RADAR (Royal Association for Disability and Rehabilitation). The Association provides all kinds of information and advice. Tel: 020 7250 3222. Unit 12, City Forum, 250 City Road, London EC1B8AF. **www.radar.org.uk** **radar@radar.org.uk**
- The Disability Information Trust. The Trust specialises in the assessment and testing of disability equipment and the publication of independent, verified in-depth information about it. Tel: 01865 227592. Nuffield Orthopaedic Centre, Headington, Oxford OX3 7LD. **home.btconnect.com/ditrust/home.htm** **ditrust@btconnect.com**

Returning to College or Work

General

If you are recovering from GBS, you may need to seek advice from your GP, physiotherapist or consultant about the right time to resume further education or employment. Should you be experiencing significant residual effects of weakness, fatigue, poor concentration etc, doctors may recommend a deferment until both physical health and stamina have improved. Each case must be judged on its own merit, recovery rates being variable.

Further education

Students, whose studies have been set-back by GBS, may be able to negotiate with a college/university to study from the home for a period of time.

The Further Education Funding Councils for England and Wales (FEFCs) are responsible for ensuring there are places on further education courses for young people and adults with disabilities. If there is no suitable provision in an FEFC-funded college, funding councils may be willing to pay for a place in an independent specialist college. Disability statements are obtainable from further education colleges, and give details of the provision available for people with disabilities.

People with disabilities have the same entitlements to grants and loans from local education authorities as do other students. Grant applications should be made to the local education authority (LEA).

Help sources:

- GBS Support Group. Call the office if you would like to be put in touch with a 'young adult' contact, who has suffered from GBS.
- Skill (National Bureau for Students with Disabilities). The Bureau publishes a range of fact sheets and publications. Tel: 0800 328 5050. 336 Brixton Road, London SW9 7AA.
- The Student Loans Co Ltd. The Company provides information on student loans. Tel: 0800 405010. 100 Bothwell Street, Glasgow G2 7JD.
- The Open University. PO Box 200, Milton Keynes, MK7 6YZ. Tel: 01908 653231. **www.open.ac.uk** **ces-gen@open.ac.uk**

Work

Residual weakness, discomfort and fatigue, can interrupt work performance and it is not wise therefore to return to work before being fully able to cope. However, this has to be balanced with the very real fears of job security. In many cases a compromise is met where a return to work can be made either by working part-time or by undertaking lighter duties.

The majority of GBS patients are able to return to their former occupations but there will be some, especially if their work was particularly physical, who will not. The help sources below should be able to help.

Help sources:

- Disability Employment Advisers (DEAs). Contact the DEA at your local job centre for help with work difficulties as a result of disability.
- The Careers Service. The Service provides specialist advice for clients with special education or training needs.
- RADAR (Royal Association for Disability & Rehabilitation). RADAR provides fact-sheets and publications concerning employment and disability. Tel: 020 7250 3222. 12 City Forum, 250 City Road, London EC1V 8AF.
www.radar.org.uk radar@radar.org.uk



Children with GBS

For information about children with GBS in hospital, please refer to our publication *Childhood GBS — A Guide for parents and carers*.

Going home

Before children are discharged from hospital, key members of staff should provide contact telephone numbers. Occupational therapists will discuss the suitability of the home environment and any specialised equipment needs. Children's walking frames on wheels are sometimes available and can be very useful. If considered

necessary, arrangements are made for physiotherapy to continue, and advice given on daily and recreational exercise programmes. Parents who are not completely satisfied with the arrangements should make their reservations known.

Hydrotherapy and swimming are very helpful. Cycling is also a good form of exercise. Horse riding helps with balance (contact 'Riding for the Disabled', tel: 024 7669 6510). Any exercise is beneficial as long as children are willing. Since they are usually very active and move around without thinking, this is a good indicator of their capabilities.

Nerve-endings can become extremely sensitive and the slightest pressure can result in pain or discomfort. Recovery can be a drawn-out process and some symptoms can linger for many months. However, there are ways of helping children to cope. Doctors can prescribe medication to counter pain. Rest, relaxation, massage and physiotherapy are all helpful.

Tiredness is an obvious symptom. Children listen to their bodies as adults do and may prefer to sit and watch endless television. If this is how they relax and cope with exhaustion, then so be it. Children will feel miserable if forced to be active when not feeling up to it. Children are often affected by temperature changes. Cold weather can sometimes bring on muscle aches or stiffness, whereas warm weather can ease them. Colds and bugs are more common in the wintertime and GBS symptoms such as tingling may recur if children are under the weather. This does not indicate a recurrence or relapse, though this is an outside possibility.

If regaining weight is a problem, build-up drinks may be prescribed. Alternatively, they are available from chemists and health food shops. Consult your child's GP about vitamin supplements if a normal diet cannot be achieved. If children lose their appetites when they are not feeling well, it is less stressful all round if they are given a small portion of something they like. Bartering can work wonders. The 'finish your peas for one chocolate and the rest for two' method can be used. This turns meal times into fun times, especially if brothers and sisters join in the game. Star charts can be a useful incentive for any activity, including meal times, bedtimes and exercises.

The trauma of GBS may have had a temporary affect on children's overall behaviour. They may become frustrated, angry and upset at not being able to do everything that their friends can. Some children become clingy, whilst others may appear to be more independent than they were before their illness. Embarrassment, self-consciousness and loss of confidence may also be evident. It is best for you not to make too much of these mood swings and to treat these

times as normally as possible, as well as to try not to give too much preferential treatment over siblings. Lots of hugs, reassurance and understanding are required, without over-fussing. Children should be listened-to. Beneath the mixed-up emotions they are the same people inside. Keep in mind that these problems are temporary and will improve in due course. Supply your child's GP with GBS literature to file away for future reference.

It is very important, if you are at home with a sick child, to take breaks and to ask for help from family and friends. Respite periods, however short, can be extremely beneficial. If you feel calm and in control you will be better equipped to help your child. Parents should also try to spend time out alone with each other, for they are both experiencing similar emotions.

Jenny's Story is a book describing the illness from a child's perspective, and is available from the GBS office. It can be also seen on the Group's Web site along with other pages about GBS specially written for children. If the school is linked to the Internet, give the teacher the address of the pages: www.gbs.org.uk/kidzone

School

Returning to school on a part-time basis is one approach that might be considered. If the time off school has been considerable, then it may be necessary to miss a year. Expecting a child to work extra hard at this time to catch up with the rest of the class would be, in many cases, unreasonable.

If you are concerned about your child missing school, ask the teacher to send some work home. There are also a wide variety of work books available in shops and libraries. It can be beneficial, both academically and socially, to take children to school for as little as an hour at a time during recovery. Even a social visit is helpful as they can miss their friends and the whole atmosphere of school life.

School facilities should be checked that they are suitable for your child's needs. Depending on the speed of recovery and/or the amount of residual disability, it may be necessary for your child to return to school in a wheelchair. If this applies it is important to check there is access to the toilets and that there is sufficient space. Chairs and desks need to be comfortable and of the right height to prevent back pain. Writing and eating difficulties can be facilitated by attaching insulation pipe (foam) around pencils, pens and cutlery. A welfare officer from the local education authority (LEA) can visit to arrange adaptations, and can sometimes

provide equipment for use in schools. Like any other institution, the ability of the school to cope depends on the willingness of those involved, as much as the building's design and facilities.

Before your child returns to school, arrange a consultation with the teacher and headmaster. Provide them with literature about the illness and to discuss your child's needs. Emphasize that whilst your child may appear to have recovered well, children after GBS typically have some residual weakness and general discomfort, particularly in the extremities.

If tiredness is an issue, your child may need rest breaks throughout the day. Strict bed and rest times are beneficial as a week at school can be exhausting. Control out-of-school activities to avoid overwhelming your son/daughter. A busy weekend can take its toll on Monday morning.

Physical limitations may temporarily prevent your child from participating in physical activities. If splints have been provided, make sure they are used exactly as instructed. It is most important that they are worn.

It is helpful if the teacher can explain about the illness to the class and to mention the limitations your child may be facing at that time. Teachers should try to ease your child gently back into the classroom environment with a minimum of fuss and should be aware of the difficulties that young children may face in being labelled 'different' from their peers.

Keep in regular contact with the teachers, without worrying about being a nuisance. Locums and new teachers should be told about your child's illness at the beginning of each new term. Should problems arise, ask to see the school's special needs policy and remember that you have rights.

Help sources:

- GBS Support Group. Contact the office if you would like to be put in touch with a 'child/parent contact', whose own child has suffered from GBS.
- Contact a Family. This Organisation provides support for families who care for children with disabilities and special needs. Tel: 020 7383 3555. 170 Tottenham Court Road, London W1P 0HA. www.cfamily.org.uk
- Parentline. Parentline is a national telephone helpline for parents. Tel: 0800 800 2222.
- Association of Wheelchair Children. The association gives help and advice on specialised wheelchairs or equipment for children. 33 Humberstone Road, London E13 9NL. Tel: 020 8552 6561.

- Whizz-kidz. Whizz-kidz supplies mobility aids to disabled children under 18 and can help where NHS provision is inadequate. Tel: 020 7233 6600. 1 Warwick Road, London SW15 5ER. www.whizz-kidz.org.uk
- JABS. JABS offers support to parents whose children have a health problem after vaccinations. Tel: 01942 713565. 1 Gawsorth Road, Golborne, Warrington WA3 3RF. www.argonet.co.uk/users/jabs



Help for People with Disabilities

Driving

If you hold a driving license and have an impairment that affects your ability to drive, you are required by law to inform the Drivers Medical Branch, Driver and Vehicle Licensing Agency (DVLA), Swansea SA99 1TU. If you are unsure as to whether or not this is applicable in your case, consult your GP. A form will be sent for details of your disability, and for permission for your doctor or specialist to make a report to the department's medical advisers. A recommendation will then be made about the continuance of the license. If your condition is stable and non-progressive, the license will normally be retained and considered valid, or the case could be further reviewed at a later date.

Every effort is made by the DVLA to allow you to continue to drive. Your license will only be withdrawn if it is apparent that your condition is such that driving could be potentially hazardous to yourself and other road users. You have a right to appeal against such a decision.

If you are thinking of returning to driving with a new or on-going disability, it is advisable to have an assessment of your driving ability and/or advice on the sorts of controls and equipment you may need to overcome any physical limitations. 'MAVIS' (see below) can give details of local assessment centres. Some manufacturers offer discounts on new cars to registered disabled people. Motability is an organisation that help disabled people purchase or rent new or second-hand cars. For more information about organisations that can help provide financial assistance, contact 'MAVIS'.

Parking

The Orange Badge scheme provides a national system of parking concessions for people with severe disabilities who travel either as drivers or passengers. It allows badge holders to park closer to their destination. The badge is issued from local social service departments.

Public transport

For those with mobility problems, who plan to make a journey by train, it is best to telephone the station in advance to let staff know the type of assistance they will require. Some taxi firms have wheelchair-accessible vehicles for hire. Buses can be difficult for people with severe mobility problems, but some companies have introduced special low-floor accessible buses, and there are some special mobility buses that can take wheelchairs. A local disability project can give more information and provide details of concessionary fares in the appointed area.

County guides are now available in many areas, giving useful information about local transport for people with mobility handicaps (normally obtained from county councils). A growing number of 'shopmobility' schemes have been set up in towns and cities to give disabled people maximum mobility when shopping there, by making available wheelchairs and scooters (usually free of charge) in particular locations (see address below).

Voluntary help

Some voluntary organisations offer help with local, and sometimes long-distance trips, using volunteer drivers. To find out about local schemes, contact a local disability project, Council for Voluntary Service (CVS) or Citizens Advice Bureau (CAB). Many areas operate a 'Dial a Ride' service for local residents, where specially adapted minibuses or cars can be used to transport the elderly and those with mobility handicaps.

Help sources:

- Disabled Drivers Association (DDA). The DDA gives advice on issues affecting disabled motorists. Tel: 01508 489449. National Headquarters, Ashwell

Thorpe, Norwich NR16 1EX.

- MAVIS (Mobility Advice and Vehicle Information Service). MAVIS provides practical advice on driving, car adaptations and car choice. Tel: 01344 661000. 0 Wing, Macadam Avenue, Old Wokingham Road, Crowthorne, Berkshire RG45 6XD. **www.mobility-unit.detr.gov.uk/mavis.htm** **mavis@detr.gov.uk**
- British School Motoring (BSM) for Disabled. The BSM provides assessments on simulators to assess your needs and advise on car adaptations. 1 Forest Road, Feltham, Middlesex TW13 7RR. Tel: 020 8917 2500.
- DETR (Department of the Environment, Transport and the Regions) Mobility Unit. The Unit can advise on the orange badge scheme, as well as other issues affecting disabled motorists. Zone 1/11, Great Minster House, 76 Marsham Street, London SW1P 4DR. Tel: 020 7890 6800. **www.mobility-unit.detr.gov.uk** **mu@detr.gov.uk**
- Motability. Motability helps with the purchase of new or second-hand cars. Tel: 01279 635666. Goodman House, Station Approach, Harlow, Essex CM20 2ET. **www.motability.co.uk**
- Tripscope. Tripscope gives free travel information for anyone who finds travelling difficult. Tel: 08457 585641. The Courtyard, Evelyn Road, London W4 5JL. **tripscope@cable.net**
- RADAR (Royal Association for Disability and Rehabilitation). Tel: 020 7250 3222. 12 City Forum, 250 City Road, London EC1V 8AF. **www.radar.org.uk** **radar@radar.org.uk**
- National Federation of Shopmobility. Tel: 01905 617761. 85 High Street, Worcester WR1 2ET.

Holidays

There are now a wide variety of holidays available to disabled people, both at home and abroad, with many companies specialising in this area. Whilst many tour operators now cater for people with disabilities in their package tours, it is important to ensure that the accommodation is suitable for your needs.

It is particularly important to ensure that you are fully insured against any eventualities. Most providers of travel insurance will provide cover for those with a disability provided that the trip is not made against 'doctors orders'. But should the person travelling require a carer and should the carer be taken ill during the holiday, will the policy provide another carer?

Help sources:

- Holiday Care Service. The service provides information on a wide range of holidays and on all aspects of taking a holiday. Tel: 01293 774535. Imperial Buildings, 2nd Floor, Victoria Road, Horley, Surrey RH6 7PZ.
holiday.care@virgin.net
- RADAR (Royal Association for Disability and Rehabilitation). RADAR publishes holiday guides. Tel: 020 7250 3222. **www.radar.org.uk** **radar@radar.org.uk**
- Camping for the Disabled. The organisation gives details of adapted UK and European campsites and equipment advice. It has an European route planner service. Tel: 01743 761889. 20 Burton Close, Dawley, Telford, Shropshire TF4 2BX.
- Tripscope. Tripscope provides a travel information and advice service. Tel: 0345 585641. The Courtyard, Evelyn Road, London W4 5JL.
tripscope@cable.net.co.uk



Helpful Information

Complaints

If you wish to register a complaint against a hospital, first write to the chief executive there. You have the right to have your complaint investigated and to receive a full and prompt written reply. If after this you are still dissatisfied, write to the Health Service Ombudsman, who is completely independent of the NHS, asking for the case to be investigated. A booklet is available describing the services of the Health Service Ombudsman (see address below). A copy of the letter of complaint should be kept, along with anything else in connection with it.

In pursuance of a complaint against a GP, dentist, optician or pharmacist, having first written to the chief executive concerned, contact the local health authority (HA). CHCs (Community Health Councils) are independent bodies which can provide advice and support to people wishing to make a complaint. Their telephone numbers will be found in the telephone books.

To obtain a copy of the *Patient's Charter*, write to: Patient's Charter, FREEPOST

NEA 959, Wetherby, West Yorkshire LS23 6YY. Many health authorities and hospitals have their own charters, adding to and improving on national standards. All hospitals should openly display information on their charter performance in public places.

Help sources:

- Community Health Council. The Council gives independent help and advice on making complaints. The telephone number is in the phone book.
- Health Information Service. Tel: 0800 665544.
- Health Service Ombudsman. Millbank Tower, Millbank, London SW1P 4QP. Tel: 020 7217 4051.
- Action for Victims Medical Accident and Negligence (AVMA): Tel: 020 8686 8333. 44 High Street, Croydon CR0 1YB.
- Disability Alliance. The Alliance has a rights and advice line. Tel: 020 7247 8763. 1st Floor East, Universal House, 88-94 Wentworth Street, London E1 7SA.

Insurance

Those looking at taking out policies for life assurance cover, having made complete recoveries, should receive cover at a company's normal rates. However, if you have recently been ill, a life assurer may not accept the risk at that time, but may reconsider your application in six or twelve months. Where there are residual medical problems, the company will seek advice from its medical officers to ascertain whether they constitute an additional risk to normal mortality. In some instances, it will impose a 'loading' on the premium to reflect its underwriter's view of the severity of the case. Each case is evaluated on its individual merit, but ultimately it is sensible to wait until you have essentially recovered before seeking life assurance. It is also wise to consult a registered insurance broker, who is able to approach a number of life assurance offices on your behalf. There are a number of insurance companies that specialise in holiday insurance for people with physical disabilities.

A list of insurance firms offering vehicle insurance to disabled motorists is obtainable from MAVIS (Mobility Advice and Vehicle Information Service), tel: 01344 661000.

Benefits

As there are frequent changes within the welfare system you are advised to consult current information regarding benefits from the agencies listed below. With the benefit system being very complex, professional advice should be sought to ensure that you are claiming all that you are entitled to. The forms are often lengthy and laborious, but do not be put off by this. A photocopy can be used as a draft. Each question should be considered carefully and advice sought where necessary. Do not boast about what you can do. Stress your disability and if it is painful to do certain things, indicate as such. Where there are boxes, all that apply should be ticked. Many people make the mistake of not ticking all the boxes which apply to their cases, but go into written detail in the comment sections. The adjudicators do not actually see these comments as they are screened from view by templates. Furthermore, they have a fixed time to spend on each application, so ensure the forms are clear and unambiguous. A copy of the form submitted should be kept.

If your application does not succeed, appeal. Appeals in the first instance go to another adjudicator. If still dissatisfied, you can appeal to an independent Tribunal. In some cases the Benefits Agency will review the case and make the award requested without the applicant having to actually go before the Tribunal. It may take some months before the appeal is heard, but awards made by the Tribunal will in most cases be back-dated to the time of the original claim. There is currently no fee involved in the Tribunal process. Appeal forms are obtainable from local DSS offices. These should be accompanied by a letter of support from a GP or (preferably) a Consultant. It is recommended that advice be taken before submitting an appeal.

Help sources

- Benefits Helpline. The Helpline gives confidential advice and information on all social security benefits. Tel: 0800 882200.
- Assistance with completing forms. Tel: 0800 441144.
- Citizens Advice Bureaux. Your local CAB telephone number is in the phone book.
- Post Offices. Benefit leaflets are available in post offices.
- Disability Alliance. The Alliance has a rights and advice line. Tel: 020 7247 8763. Universal House, 88-94 Wentworth Street, London E1 7SA.

Financial help and grants

The Directory for Social Change publishes *A Guide to Grants for Individuals in Need*. This is a practical guide to sources of money available from various trusts and charities, with references to organisations that do a lot of fund-raising. These usually donate to organisations rather than individuals, but will sometimes consider individual applications, especially if put forward by a welfare officer or social worker. The following are some head office telephone numbers, where one can request the details of local representatives:

- Lions Clubs International. Tel: 0121 441 4544.
- Rotary International. Tel: 01789 765411.
- The Ancient Order of Foresters. Tel: 01703 229655.
- Other channels worth investigating are ‘the Directory of Grant Making Trusts’ and the ‘Foundation Directory’.
- The Directory of Social Change. Tel: 020 7209 4949. 24 Stephenson Way, London NW1 2DP.

The GBS Support Group has a Help Fund to provide emergency financial assistance at the most critical of times. The fund has not been established to pay for care and equipment, provision of which are the responsibilities of the statutory services, nor can it make ongoing grants to supplement statutory benefits. Requests should be made in writing to the GBS Support Group, and be supported by a covering letter from a health professional.



Complementary Therapies

Many people are now looking to complementary therapies to assist their recoveries. Any good practitioner will advise that these therapies should be used in collaboration with, and not replace, conventional medicine. Your GP should be consulted before embarking upon any therapy, and be kept informed throughout the treatment. A therapy should be chosen relevant to your needs — one that

appeals most in terms of its philosophy and technique.

It is important that a chosen practitioner is fully qualified. The likely cost and availability of a practitioner are also important considerations. Instant results should not be expected and be prepared to commit to a full course of treatment, and also to stop having it if after awhile it is not found to be helpful. It is possible to combine therapies, but the GP and individual practitioners should all be made aware of this.

Most complementary therapies are ‘holistic’, meaning that they promote self-healing by working on the person as a whole: mentally and emotionally, as well as physically. Their aim is to treat the cause of the illness, rather than its symptoms, and to awaken the body’s innate ability to heal itself. There are many complementary therapies to choose from — here are just a few:

Aromatherapy

One of the most popular methods of employing aromatherapy is the use of massage, using fragrant essential oils. Whilst aromatherapy is a ‘holistic’ therapy as described above, there are a number of practical benefits from the massage alone. For instance, it can improve blood and lymph circulation; remove toxins; relieve aches, pains, cramp and fluid retention; and can help to maintain flexibility and suppleness. Aromatherapy also has relaxing and soothing qualities, releasing tension alongside the accumulated knots and nodules. The essential oils used are blended in a base carrier oil, and these too have individual therapeutic attributes. These oils can also be used in baths, oil burners and inhalers, as well as being useful in some methods of first aid, ie compresses.

Reflexology

Reflexology is a form of manipulation to pressure points on the feet or hands that are believed to be linked to areas and organs of the body. Gentle pressure is applied treating the whole of the foot or hand and if there is slight discomfort, it is an indication to the practitioner that there is a blockage in the corresponding area of the body. This therapy can be very powerful and is not always suitable for chronic conditions. Caution must also be exercised where there are circulatory disorders of the lower limb present, such as deep vein thrombosis, leg ulcers or phlebitis.

Homeopathy

Remedies are taken from plant, animal and mineral substances. The principle of homeopathy is that 'like cures like'; thus a substance causing symptoms when taken in large doses, is used in dilute doses to cure the same symptoms.

Acupuncture

Very fine needles are used to stimulate the body's subtle energy (known in China as chi) at one or more of hundreds of points situated along the 14 meridians (energy channels), said to run through the body. This process is believed to balance out the flow of subtle energy in the body and so help its natural self-healing tendency.

Yoga

Yoga is not so much a complementary as a self-help therapy, and is a series of gentle stretching exercises performed slowly in unison with a controlled breathing pattern and a focused mind. Such a combination is thought to bring about a sense of equilibrium, as well as overall physical suppleness and well-being. It is neither competitive nor pressurised, as the aim is to perform the exercises within your own comfortable limit.

If you are looking for a practitioner in your area, your doctor or local Health Authority may recommend somebody. Many health food shops now hold records of practitioners, or you can try your local newspaper, yellow pages or library. Failing that, contact the parent organisation for your chosen therapy.

Vitamin supplements

Most doctors argue that taking extra vitamins is not necessary provided a well-balanced diet is being achieved. If a doctor thinks a patient needs extra vitamins, then they will be prescribed. So while from a medical point of view, buying extra vitamins is often considered unnecessary, there is plenty of anecdotal evidence to support it and, with few exceptions, it will do no harm. A good quality multi-nutrient, available from chemists or health food shops will contain most of the

supplements thought to be beneficial: A, C, E, B-complex, magnesium, calcium, selenium minerals, omega-3 and omega-6 fatty acids (eg fish oils, flaxseed/linseed oil and starflower/borage oil). Vitamins take time to work, so instant results should not be expected.

High-doses of vitamin B6 can actually cause a neuropathy, so it should only be taken in small quantities.

Other supplements which some may find helpful:

- Valerian helps with nerve pain, anxiety, depression and insomnia;
- St John's wort helps with anxiety, depression and nerve pain;
- Ginkgo bilabo helps to improve the blood supply to the nervous system and the brain, and is an anti-oxidant. It also helps to enhance mental performance, clarity, alertness and combats fatigue and depression;
- Garlic helps to strengthen the blood vessels and aids circulation;
- Aloe vera stimulates, supports and modulates the immune system and is good for skin problems; and
- Astragalus is a natural tonic and energizer.

NB Always seek professional advice before embarking on a herbal remedy course.

Help sources:

- Paula Mullins. Paula Mullins is a qualified aromatherapist, reflexologist and massage therapist and can advise on these therapies. Flat 7, Dover House, Anerley Road, Penge SE20 8EN.
- British Medical Acupuncture Society (BMAS). The BMAS gives advice and details of local practitioners. Tel: 01925 730727.
www.medical-acupuncture.co.uk bmadmin@aol.com
- International Federation of Aromatherapists. The Federation has a directory of practitioners. Tel: 020 8742 2605.
- Association of Reflexologists. The Association has a directory of practitioners and gives information. Tel: 01273 479020.
- British Homeopathic Association. The Association has a specialist library and a publication list. Tel: 020 7935 2163.

Tips . . . from fellow sufferers

- Do not be afraid to ask for help from hospital, other agencies, family and friends. Take one day at a time.
- When I first went home from hospital I was underweight and suffered from the cold. As it was very important to keep myself warm to alleviate aching muscles, I found several layers of light clothing plus a tracksuit was the best solution.
- I took up regular swimming once I had found a warm water pool. This is very important as cold water is quite unsuitable. Once in the pool the distressing feeling of pins and needles was diminished and I felt much more normal. Also, swimming undoubtedly helped me in the longer term to build up stamina. I constructed a programme for myself of short spells of swimming, at least three times a week, and these spells got longer as time went by. It was immensely helpful in my recovery.
- I also took up yoga, which I had never done before and did not have any particular expectations. However, I was amazed at how helpful it was. I informed the teacher beforehand about what had happened to me, which was important as I had limited abilities. However, it definitely helped me slowly stretch out my muscles and relax them out of the tension that I felt was residual from the paralysis. Also, it so concentrates the mind that for short spells I lost the constant sensations of pins and needles, which was a great relief. It also helped lift my spirits and ward off depression.
- One of my residual symptoms was ataxia — a constant tremor, particularly in my hands. I found it useful to attempt small intricate actions, such as sewing, picking up pins from a glass table and writing a short diary entry every day. Such activities helped me regain my dexterity, build strength in my hands and build my confidence. Typing and/or using a word processor is also constructive, as well as being an aid to concentration.
- From my own experience I would like to warn people about the dangers of heat. Recovering patients should be careful when they get home about cooking and ironing — it's very easy to sustain a burn or other minor accident, such as dropping something hot. These activities are best avoided until the patient is absolutely confident in this department.

- At times I have endless tingling and sensations of heat in my feet. At other times they are very cold, but this is easier to control. To reduce the heat I bathe my feet in warm water and wrap them in flannels dipped in cold camomile tea. To prevent the skin feeling tight and dry I find calamine and witch hazel cream the most successful of all the ones I have tried. Others appear to ‘shut’ in the heat sensations.
- It is very important to keep the skin well hydrated. If you allow it to become very dry, the nerves may become inflamed and it will take a long time to return to normality. Zinc and castor oil cream can be very useful in the early stages, often with a cortisone preparation. Once the skin is back to normal aqueous cream is very helpful.
- There are times when the pain can be very severe, and one of the most relaxing remedies I find, is to listen to a book that is liked and familiar. There are many tapes of literature available. ‘Chivers’ supply many different titles, and they are all unabridged. ‘Isis’ are able to supply different titles. If you are a keen classical music lover as I am, Classical FM is very good.
- Whilst doctors are unlikely to recommend Chinese herbal preparations, I have found ginkgo biloba very useful. It may take a few days to work, but it can be very useful in helping to mask the pain.
- Exercise at whatever level you can, accepting that this can vary from one day to the next. Do not, however, embark on rigid exercise campaigns. Keeping fit is important mentally as well as physically.
- At times I suffer from chronic pain and I find the drugs dosage I require has an uncomfortable sedative effect on me. I find that distraction behaviour helps, by keeping busy rather than giving in to the pain.
- When my feet are burning I find a refreshing foot spray helps. I also use an aromatherapy foot lotion, which is a combination of peppermint and kanuka essential oils. Sometimes, a muscle fatigue bath oil is useful. On occasions I have reflexology treatment, which can be uncomfortable at the time, but it seems to relax me and generally tones me up.
- Always wear softish, pliable shoes/sandals etc, because muscles over contract/cramp. I have found exercise-type sandals with velcro fasteners giving toes space useful, also soft slippers so that upward projecting toes have room. Make sure shoes have firm soles, so that they are suitable for driving in.

- At times being in a horizontal position can make my legs and feet uncomfortable. When this is so I find it more comfortable to sleep on the settee, with an array of cushions and pillows, positioning my feet on the floor.
- When my legs feel tight I use deep relief ibuprofen gel with stockinette leg supports for 2-3 hours.
- Eat wholesome and healthy foods, giving your body the best chance to recover. By doing so, will also help your mental state. Try to avoid foods containing too many additives; also stimulants such as tea/coffee and alcohol. Try herbal tea.
- If you are not very fit physically, try to avoid watching too much television, which is overly passive when you are trying to be positive in thought. Take advantage of the time to study something . . . read books.
- Try to find a quantitative measure to record your progress from week to week (eg time to climb the stairs, or how far you are able to walk). This is very useful evidence to present to doctors.
- Concentrate on what you can do now. Do not dwell on what you used to be able to do.
- Keep a record or diary of your illness to gain a true perspective of your illness.
- There are enormous emotional effects upon sufferers and a return to normal life is not easy. The support of a loving partner is a very big plus and a big problem for those people who do not have one. However, the support of family and friends holds great sway and patients should positively encourage those close to them to come to an understanding of GBS. People cannot help and support you unless they realise what happened.
- Do not make any plans — take one step at a time.
- Set yourself a goal, if you do not achieve it . . . keep trying until you do.
- Be able to laugh at yourself.
- Adopt nonchalant postures, such as leaning on a bar to save energy.
- Take rest opportunities as they arise and plan ahead to be certain of rest.
- If you are in poor health and your job is stressful, give it up. The stress of work, coupled with the frustration of not being able to do ones job efficiently only exacerbates the problem.

- Tell friends and relatives that you have caught a virus and that you will get over it. It is normally too difficult to explain about the illness. Also, from personal experience I have found that some people do not like to associate with people who are ill.
- Following a very bad period I had a lot of prayer support from friends at church just before departure on holiday. All I can say is that it worked!
- Accept that you may be incapacitated for some time. Face up to the reality of the situation and accept it.
- Adapt hobbies and interests to limitations (eg automatic gearboxes are not sissy!)
- Do not decline invitations, adapt and enjoy.
- Take up new hobbies as therapy, or do those things you always wanted time to do.
- Learn to dissemble so that you appear as normal as the situation allows.
- Play down your problems. People get fed up with moaners very quickly.
- Do not blame others or make them feel bad, it is **not** their fault.
- You have a huge recovery possibility, but do not expect miracles overnight.
- When you feel bad or down, **tough**. You're alive aren't you?
- Things could be a lot worse, you could have a more debilitating disease.
- Remember, whatever happens to your shell, you are still **you** inside.
- You are still **valuable**.
- Laugh a lot . . . laugh again.
- Though the goal posts may have shifted, or the game has changed, you can still score.

Gadgets and ideas to make life that little bit easier:

- Velco fasteners for clothes and clothes.
- Double-handed cup (eg children's beaker).
- Child's first spoon.

- Long-handled tongs for picking things up.
- Play-dough/squeeze ball to improve hand strength.
- Hand held massage machines.
- Comfortable shoes from specialist companies.
- Cordless or mobile phones to carry about with you.
- Loudspeaker 'hands-off' telephones.
- Use a trackball instead of a computer mouse.
- Electrically-heated pads and 'boots'.
- Long-handled bath brushes.
- Long-handled shoe horns.
- Lap trays.
- Bunches of elastic bands around bottle tops for grip to avoid dropping.
- Electric can-openers.
- Soap on a rope (drill hole through bar of soap and thread cord through) or use liquid soap.
- Sponges for easy cleaning.
- Full-length bath mats (with suckers underneath for safety).
- Jar openers.
- Foam attached to cutlery and pens etc to aid grip.
- Electric tooth brushes.
- Support gloves, stockings or socks.
- Bank thumbs can make page turning easier.
- Attach key ring or a ring from a key ring to zips for easy pulling, ie handbags, trousers, skirts.
- Useful gadgets catalogue Active and Independent from Boots PLC.

Further Sources of Information

- Health Information Service. Tel: 0800 665544.
- Department of Health.
- Department of Social Security.
- DIAL. Disability information line. Find your local number in the phone book or telephone DIAL UK, 01302 310123.
- Disability Network. A registered charity run by people with disabilities offering advice on all health matters. Tel: 0800 0730171.
www.disability.network.org.uk **disability.network@virgin.net**
- Age Concern. Fact sheets and advice on a wide range of subjects relevant to older people. Tel: 020 8679 8000. Astral House, 1268 London Road, London SW16 4ER. **www.ace.org.uk** **infodep@ace.org.uk**
- Help the Aged. Practical advice and support for older people. SeniorLine 0808 8679 8000 — a freephone advice line for older people and their carers. St James' Walk, Clerkenwell Green, London EC1R 0BE.
www.helptheaged.org.uk **info@helptheaged.org.uk** Leaflets on website.
- Disability Scotland. Tel: 0131 229 8632. **www.disabilityscotland.org.uk**
enquire@disabilityscotland.org.uk
- Disability Wales. Tel: 029 2088 7325. **info@dwac.demon.co.uk**
- Disability Sport England (DSE). 020 7490 4919. **info@dse.org.uk**
- Medic Alert Foundation. Emergency identification bracelets and alarm systems for the elderly. Tel: 020 7833 3034. **www.medicalert.co.uk**
info@medicalert.co.uk
- Communication Matters (ISAAC-UK). Tel: 0870 606 5463.
www.communicationmatters.org.uk
admin@communicationmatters.org.uk
- Foundation for Communication for Disabled. Tel: 01932 336512.
www.abilitynet.co.uk **enquiries@abilitynet.co.uk**
- British Red Cross Society. Tel: 020 7235 5454. **www.redcross.org.uk**