Helping people affected by Guillain-Barré syndrome, CIDP & associated inflammatory neuropathies

The road to recovery

Helpline: 0800 374803 (UK) 1800 806152 (ROI)
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Moving on – Rehabilitation and Home

Patients and their relatives and friends will have been given a good idea of what to expect in the recovery phase of the illness. In most cases, these expectations are borne out and a steady improvement will be noticed. But sometimes improvement is just too slow and it becomes obvious that recovery will not happen within a few months. There are some rough pointers as to what may happen. Elderly patients with an explosive onset in the acute stage and those who need ventilation, especially for an extended period, tend to do less well. But these are only indicators. Some very old patients do very well. Some patients ventilated for long periods do recover completely or almost completely. Some patients who are not ventilated are left with significant disability.

If recovery remains slow, doctors may order some electrical tests to ascertain axonal damage, if they have not already done so. If the phrase ‘axonal damage’ is mentioned, then it would certainly be worth asking for an interview with the consultant neurologist to discuss the possible implications.

It is a matter of concern, that in the twenty-first century the Charity still receives stories concerning the thoughtless treatment of some patients. Thankfully, stories of praise are far more common but this does not diminish the unnecessary anguish suffered by a minority. Most problems stem from a lack of finance or plain ignorance. The slow recovery often associated with GBS sometimes leads to premature discharge on the grounds of ‘lack of progress’. Other examples include patients being transferred for rehabilitation to units specialising in inappropriate disciplines.

If a patient is being transferred to a rehabilitation unit, seek reassurance that it is one which is appropriate for people with purely physical problems and not one which is designed for brain damaged patients or even for people with spinal injuries. Their needs are quite different which may make it difficult for the patient’s special needs to be understood, especially by junior members of the rehabilitation team.

Another problem arises when poorly informed staff compare one patient with another. A patient who fails to progress as another has progressed is liable to be branded as lazy and uncooperative. The ignorance of the possibility of long term disability can be a cause of considerable anguish.
Perhaps too much is expected of rehabilitation. If a patient is making slow progress, a transfer to a rehabilitation unit will not speed it along. Indeed, a regime of intensive therapy is as likely to do as much harm as good. Ideally, once able to leave the acute hospital, the patient should be admitted to a specialist neuro-rehabilitation unit that understands the problem. It could be that the patient may take years to maximise potential. It would be asking too much of the unit to expect a patient to stay that long and it would be bad for the patient too. But the patient should be given the time to obtain a high degree of the expected potential. This will make the eventual return to the home environment less challenging as the patient will have obtained valuable extra independence.

The consequences of severe illness are rarely discussed. All too often it is assumed that the patient will be discharged home to the care of a spouse, a partner, parents etc. But some patients will be profoundly disabled: unable to walk, dress, feed themselves, use a lavatory etc. These patients will need full-time care though the requirement may become less as improvement continues. But suppose a patient has no-one who is prepared to be a carer? What happens if a patient was in a rocky relationship before being taken ill? The chances are that the relationship will have long since ended. Suppose a spouse has to continue working to maintain an income? Parents may be too old or infirm to cope.

This is a very complicated area and no two cases are ever the same. Inevitably in these ‘social’ cases, the social services will become increasingly involved.

A good source of help is Disability Rights UK. It covers statutory services, benefits, aids and equipment, independent living, caring, housing, education and employment, motoring and mobility, holidays, arts, sports and leisure, sex and personal relationships, and access. It also covers relevant legislation, information and legal services and useful contact organisations.

Care during the day may not need to be continuous. Many confined to wheelchairs will be quite capable of being left alone for an hour or two, maybe longer, provided they have access to back-up should it be needed. Your local social services will appoint a social worker to the case who will co-operate closely with the hospital staff. In spite of your fears, a patient will not be
discharged without sufficient care being provided, though should you have any cause to question this, you must discuss it.

If you find that this is going to be a long term condition, GAIN has a booklet called *Living with a Long Term Condition*.

**The Carer – from hospital to home**

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. If main bread winner or self-employed life can be very difficult, but there is help available.

Find out as much as possible about the illness and make it known to the ward staff that information about GBS, CIDP and associated inflammatory neuropathies is available on request from GAIN or can be downloaded from its website at www.gaincharity.org.uk. 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 try and arrange for family members to feed or help feed patient – this helps everyone and gets one involved, but 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 patients suffering from GBS and associated inflammatory neuropathies. But due to a number of reasons, not everyone may be familiar with these aspects. However, nursing staff do not want to be told how to do something, even if you do know better so use tact!

Some patients experience acute pain when they are touched, especially when being lifted or turned. If this is the case, visitors should be forewarned. If someone does hold or press your hand it can be agony and if ventilated you cannot shout. 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.

This can be 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’). It is very important to try and find a way to communicate with the patient – after all their brain is not dead, they just cannot move. If the ward or speech therapy department have no communication devices available, GAIN can provide a simple communication card.

Where possible, try to keep patients in touch with the outside world. Some patients may find solace in listening to their favourite music or books on MP3 or iPOD. Don’t forget that the patient may not be able to operate the device which can be very frustrating. 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. 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. Use pillows or splints to avoid foot drop, which can be difficult to correct. Massaging with lotion can help to prevent dryness and will hopefully assist to recover more feeling into them. Ingrown 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. It is often better to look back two weeks or a month rather than days as one can then see the improvement.
The Social services/social work department in the hospital should be in contact before discharge to discuss practical and financial help.

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 when recovering 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. Remember that one minute the patient can do something and the next they cannot, even eating food. The patient constantly needs extra help and it is very frustrating.

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. If the carer is not fit and lacks sleep they cannot look after the patient, so it is most important to get all the help you can.
Here are a few practical steps that can help to counteract the stresses and strains of caring for someone suffering from GBS and associated inflammatory neuropathies:

- Gather support from family and friends. Invite help from the local social services/social work department both practical and financial.
- Contact a local caring organisation providing support services in your area. They will often help to bath and dress patient, providing a respite so that the carer can go shopping or have a bit of time of their own.
- Contact **GAIN** tel: 01529 469910, to arrange to speak to a volunteer.
- Telephone the **GAIN** free help-line to talk to a recovered patient. tel: 0800 374803 (UK) or 1800 806152 (ROI).
- 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, and 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 you.
- 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, **GAIN** etc.
- Get organized. Investigate benefit entitlements with the hospital social worker and/or Social Services/Social Work Department. Liaise with the hospital occupational therapist (OT) and physiotherapist about equipment arrangements. If necessary, rearrange the home; for example, 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. This also applies to the cooker, iron etc. as there may be no sensation and a patient can get burnt or scalded very easily.
- Taste buds may be affected for a while, 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.

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.

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.

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.

Foot discomfort

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

Foot care

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. Ingrowing 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.

Weak hands with loss of 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.

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. 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, and 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. See also our booklet *Immunisation*.

**Hospital follow-up**

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 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%.

**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. 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.

**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.

**Emotional aspects**

To suffer from one of these disease 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 this 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, such as pain, discomfort, and difficulty in communicating, 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 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, 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, as in better-researched illnesses such as heart attack or stroke, that 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, 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.

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-hynosis 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-phenylalnine (DLPA) has been found to alleviate depression.

**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.

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.\(^1\)

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

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\(^1\) Neuro epidemiology 1992: 11:214-25
containing bioflavinoids, 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\textsuperscript{2} 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.

**Exercise**

The severity 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 are likely to be left with 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.

\textsuperscript{2} 1990 338:37-39
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**

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

In the acute stage of GBS, 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®), and gabapentin (Neurontin®) sometimes with amitriptyline. The problem 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 is good for cramps.
- 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.
- 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, and coldness lessens pain sensations by numbing the affected areas).
• 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.

**Sexual relationships**

If Hollywood is to be believed, sexual intercourse is the most important part of life, ranking just below breathing in terms of necessity. And if you can't perform sexually, you might as well have no life. But in reality, not only is life more than a single biological function, but sex itself is much more than just the physical act of intercourse. That's good news for those of us with GBS, CIDP and related disorders.

Anyone who has had to deal with a long-term disability can tell you that it can create a great strain on any relationship. Where once partners were equals, sharing in all aspects of life and responsibility, suddenly one partner is partially or totally dependent upon the other. Even without the actual physical disability, the emotional upheaval can interfere with a couple’s sex life. To complicate matters, many couples find talking about sex difficult. What once was a close, intimate relationship can become distant and stressful for both partners.

The information in this guide explores some of the issues that may arise in dealing with sex, provides a few tips on how to cope with problems, and gives suggestions of other sources of information and help. Recognising that the subject is delicate and difficult to discuss without upsetting the sensitivities of some, and the author has attempted to be frank and to the point, while discrete.

**Communication**

Ask any counsellor (or any happy couple who’ve been together for a long time), and they will tell you the most important part of a relationship isn’t sex, but instead is communication. The best sex is with someone with whom you
are comfortable, with whom you can talk about all aspects of life, both good and bad. That’s true not only for people with disabilities, but for everyone. So, start by reading this with your partner and talking about it.

People with GBS, CIDP and its related disorders often have numerous physical problems with which they have to deal. But often these are exacerbated by the emotions that disabilities can bring. Some are afraid that talking about their problems may sound as if they are complaining or whining. Some fear that they are a burden to their partner, particularly if that partner has to take on the role of carer. Talk about it. Tell your partner how you feel, and get them to talk about their thoughts and emotions as well.

Communication is vital for the health of any relationship and it is important for both partners to accept that it may take time and a lot of effort on both parts before things improve. But all relationships have to go through hard times as well as good times, and most come through stronger than before. Bottling up your emotions, ‘being strong’ and holding it inside, will only lengthen the time needed for improvement and weaken the relationship as a whole. So talk.

Of course, for most of us, sex is not a topic of general conversation, and couples who can discuss just about anything else have trouble discussing sex. They can have sex; they just can’t talk about it. But when something like GBS or CIDP invades their lives, it is imperative that they overcome this normal embarrassment and open up.

So talk to your partner. Talk about what your body is doing and what it’s not doing. Talk about what feels bad, what feels good and what you can’t feel at all, and get them to talk as well. Nothing is taboo here, nothing off-limits. Talk.

**Physical problems**

GBS, CIDP or any other peripheral neuropathy can bring on problems in any relationship; sexual relationships certainly aren’t excluded. Weakness in the legs and arms, changes in physical sensations and discomfort because of ‘pins and needles’ are common; and vaginismus (a painful spasm of the vagina) and vaginal dryness in women and impotence in men are not unseen. Couple this with changes in your feelings about yourself and/or your partner, and it’s understandable that the result could be a lack of libido. But all is not lost; people with all sorts of disorders carry on sexual relationships that are fully satisfying to both partners. If one organ of the body doesn’t work well
enough, others can provide satisfaction to both partners. If penis or vagina has problems, there are still hands and mouths; the only hindrance is lack of imagination.

**Impotence**

Erection problems can, of course, have both physical and psychological sources; in neuropathies, damage to nerves in the pelvis can make erection difficult and can limit sensations. However, erection means that the penis has enough blood to sustain it throughout intercourse; orgasm and ejaculation can be achieved without an erection so impotence does not mean that men cannot have a sex life. In addition, there are now several ways of managing erection problems, such as Viagra, regarding which your GP, neurologist or urologist should be able to advise you. Normally, such treatments are not available on free NHS prescription for GBS or CIDP, but your doctor may be able to prescribe these drugs on the basis of the disorder having caused ‘severe pelvic injury’.

**Vaginal Dryness and vaginismus**

Vaginal dryness is a problem faced not only by women with neuropathies but also by those in menopause, and occasionally by women in general. It can be remedied with one of the various water-based lubricants sold over the counter for this problem, and the application of the lubricant can actually be used as part of foreplay.

In vaginismus, the muscles of the entrance to the vagina spasm, making sexual intercourse difficult or impossible. Often the cause is psychological: worry over some aspect of sex can itself cause the vagina to spasm. However, in those suffering from GBS and its related disorders, the cause can be the disruption of nerve impulses. Longer foreplay, particularly with more manipulation of the vaginal opening before attempting penetration, may help. Otherwise, it may be necessary, at least in the short term, to use other means to bring orgasm. More important is loving gentleness and the assurance that intercourse isn’t as important as the closeness and intimacy that sex brings.

**Incontinence**

Some people, both those with these disorders and others in the general population, have problems with incontinence — as is seen from the number of adverts on television for special underwear. During sex, the fear of wetting can
be a special problem, but protective bedding can be used. It should also be 
borne in mind that the sensation of wanting to pass urine can be a response 
and part of orgasm, and thus is not necessarily unusual in sex.

**Strange sensations**

Few sufferers of neuropathies manage to avoid the odd sensations that 
demyelinated nerves bring. Burning, tingling, pain, the feeling of running water 
over your body or insects crawling across your legs — these don’t stop for 
sex. Sensation can be increased to the point of painfulness, or decreased to 
the point of non-existence. First, talk about it with your partner. Tell them what 
feels good and what doesn’t. Explore your body with your partner (and explore 
your partner’s body, too) to discover what gives pleasure.

For sensations that are painful or cause burning and tingling, there are 
medications that can help. In addition, if you’re finding that sensation is 
decreased, you might find a sex aid helpful. It isn’t cheating to use a vibrator or 
other stimulation device, and when the partners use them together, they may 
well find both experience better sex. There are a great many sex aids 
available through mail order and over the Internet, or for the more courageous, 
in sex shops — and perhaps even your local chemist, since Boots is planning 
a range of sex aids.

**Fatigue**

One of the biggest problems for people with GBS and its related disorders is 
fatigue. Even a little exercise can completely deplete what little energy the 
person has, and fatigue can be greatly exacerbated by weakness in the arms 
and legs. Physical disability can severely limit the physical exertion needed for 
sexual intercourse even though everything else is willing! As a consequence, 
‘traditional’ intercourse might be difficult or impossible. This does not mean 
that satisfying sex is impossible, though it may need a change of approach. 
Different positions are less tiring than others, and the couple may find it 
beneficial to arrange a ‘date’ that will allow the disabled person to get 
additional rest beforehand.

**Physiological problems and lack of libido**

Impotence and vaginismus, numbness and tingling particularly in normally 
erogenous areas, severe illness where all dignity has been lost, disability in
which the partner becomes a carer: it is hardly surprising that GBS and CIDP can interfere with a person’s sex life, both physically and psychologically.

Those with these disorders may take a long time coming to terms with their disabilities and suffered indignities, and even longer rediscovering themselves as sexual beings. Their partners may be weary from their increased duties, or even fear complicating the recovery or course of the disorder. Others may be overly amorous, particularly if sex has been long delayed. Again, talk about it; if necessary, include your neurologist or GP in the discussion, since they may be able better to describe the effects of the disorder.

Some people find it hard to communicate any affection or physical love, particularly after going through a disabling illness. If the ‘want’ aspect of lovemaking has diminished, professional counselling or sex therapy may help you find ways through this.

**Conclusion**

There are many ways to give and receive pleasure and there is more to lovemaking than penetration; finding alternatives can be fun. Some people find pleasing their partner satisfying enough when their own libido is diminished. It is important that you maintain your view of yourself as a whole person, including your sexuality, and focus more on what you can do, rather than what you cannot, as well as remembering that people love people for who they are. Social pressures can affect the way you feel and you may feel less attractive or desirable because your self-image has been dented. But with a little love, communication and experimentation, you may end up having a better sex life than you had previously.

All those things your mother warned you about: forget them. There are many books on the market, sold openly by major book retailers, that discuss everything from emotions to lubricants to positions to sex toys to problems in sex. There are sex aids and medicines. Sex is not the be-all of Hollywood lore, but the intimacy and oneness it provides is important, particularly in a relationship that has to endure the results of one of these disorders. Let go of your preconceptions of what should and should not happen in a sexual relationship and experiment. Who does what to whom does not matter; mutual enjoyment is what counts.
And keep a sense of humour: sex is supposed to be fun, not an agonising performance. Things will go right, and things will also go wrong. Learn to laugh together.

A former GBS patient said that while he was still in hospital, his doctor told him that he needed to be adventurous in bed. Not bad advice!

Generally:

- Be open with your friends and family about aspects of the disorder. Do not assume that people understand the condition; discuss it with them.
- If you suffer mood swings, do not push your family away.
- If you have disabilities or loss of sensations, it does not mean you have less to offer. You may have more.
- Try to keep a sense of humour in your relationships.

Sexually:

- Give your partner individual attention when able and needed.
- Try to understand each other verbally and non-verbally and ask your partner to explain when you do not understand.
- If you have a broad mind, try an Internet search on the keywords ‘sex’ and ‘disability’. Amongst the dross may be some gems. In addition, try searching Amazon.co.uk using the same keywords. There is a huge amount of printed material available.
Other sources of help

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<td>The Princess Royal Trust for Carers</td>
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<td>British Pain Society</td>
<td>0131 669 5951</td>
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<td>Pain Relief Foundation</td>
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<td>Crossroads Association</td>
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