



# GUILLAIN BARRÉ SYNDROME



## A Guide for Carers

### GBS Support Group New Zealand Trust

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# Carer's Guide

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

## 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. 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 and associated inflammatory neuropathies is available on request from the GBS Group or can be downloaded from its website at [www.gbsnz.org.nz](http://www.gbsnz.org.nz) 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 to 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

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.

## Help sources

**WINZ:** [www.workandincome.govt.nz](http://www.workandincome.govt.nz)

**Ministry of Health – Disability Support Services**

[www.moh.govt.nz/disability](http://www.moh.govt.nz/disability)

**There are local offices in most areas but under local names.**

**CCS Disability Action** [www.ccsdisabilityaction.org.nz](http://www.ccsdisabilityaction.org.nz)

**Disability Information centres** [www.weka.net.nz](http://www.weka.net.nz)

**Access** [www.access.org.nz](http://www.access.org.nz)

**Enable** [www.enable.co.nz](http://www.enable.co.nz)

- 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 the Group National Co-ordinator to arrange to speak to, or be visited by, a local contact.
- 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, 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, members of the Group in your area etc.

#### **Carer's Check List**

- Get organized. Investigate benefit entitlements with the hospital social worker and/or WINZ. 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

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 to 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, the Group can provide a communication card.

Where possible, try to keep patients in touch with the outside world. Some patients may find solace in listening to their favourite tapes on MP3 or IPOD players. Don't forget that the patient may not be able to turn the player off or on, 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 but remember that many intensive care units ban flowers so ask the nursing staff. 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 Disability Support Service department in the hospital should be in contact before discharge to discuss practical and financial help.

## 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 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