

# GUIDE

## *Carer's Guide*

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

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

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

In the Republic of Ireland, call 0044 1529 415278

### **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 information about GBS is available on request from the GBS Support Group or can be downloaded from its Web site at [www.gbs.org.uk](http://www.gbs.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, 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.

### **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.

## Help sources

Crossroads Association

0845 450 0350, [communications@crossroads.org.uk](mailto:communications@crossroads.org.uk), [www.crossroads.org.uk](http://www.crossroads.org.uk)

The Princess Royal Trust for Carers

020 7480 7788 (London), 0141 221 5066 (Glasgow), 01257 234 070 (Chorley)

[info@carers.org](mailto:info@carers.org), [www.carers.org](http://www.carers.org)

Carers UK (England)

020 74908818, [info@carersuk.org](mailto:info@carersuk.org), [www.carersor.uk](http://www.carersor.uk)

Carers Scotland

0141 2219141, [info@carerscotland.org](mailto:info@carerscotland.org), [www.carerscotland.org](http://www.carerscotland.org)

Carers Northern Ireland

028 90439843, [info@carersni.demon.co.uk](mailto:info@carersni.demon.co.uk), [www.carersni.org](http://www.carersni.org)

Carers Wales

029 20811370, [info@carerswales.org.uk](mailto:info@carerswales.org.uk), [www.carerswales.org](http://www.carerswales.org)

The Carers Association (Ireland)

056 21188, [info@carersireland.com](mailto:info@carersireland.com), [www.carersireland.com](http://www.carersireland.com)

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

The GBS Support Group is a registered charity and receives neither government nor Lottery funding. If you have found this guide helpful and would like to help us to continue publishing copies for others affected by GBS and its related conditions, please consider making a donation to the Support Group. Secure donations may be made on line. Alternatively you can request a form from our office.

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