

GUIDE

After GBS — Emotional Aspects

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 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

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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.

Other help sources

- Depression Alliance
0845 123 23 20, www.depressionalliance.org

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.

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.

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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January 2005