

# GUIDE

## *After GBS — Pain*

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

**by Dr B Lecky, Consultant Neurologist, Walton Centre, Liverpool. First published in *After GBS*, edited by Jane Tempest-Roe, Administrator GBS Support Group.**

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®), 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, 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.
- 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.

## Help sources

Pain Concern

01620 822572, [www.painconcern.org.uk](http://www.painconcern.org.uk)

British Pain Society

(020) 7631 8870, [www.britishpainsociety.org](http://www.britishpainsociety.org)

Pain Relief Foundation

0151 529 5820, [www.painrelieffoundation.org.uk](http://www.painrelieffoundation.org.uk)

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.

*giftaid it*

GBS Support Group, LCC Offices, Eastgate, Sleaford, Lincs, NG34 7EB

Tel: 01529 304615 E-mail: [admin@pbs.org.uk](mailto:admin@pbs.org.uk) Web site: [www.pbs.org.uk](http://www.pbs.org.uk)

© GBS Support Group



January 2005