

# GBS

Guillain-Barré Syndrome Support Group  
of the United Kingdom Registered Charity 327314

## Peripheral Nerve Disorders

An explanation for patients, relatives and friends

First Edition 1999

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# Peripheral Nerve Disorders

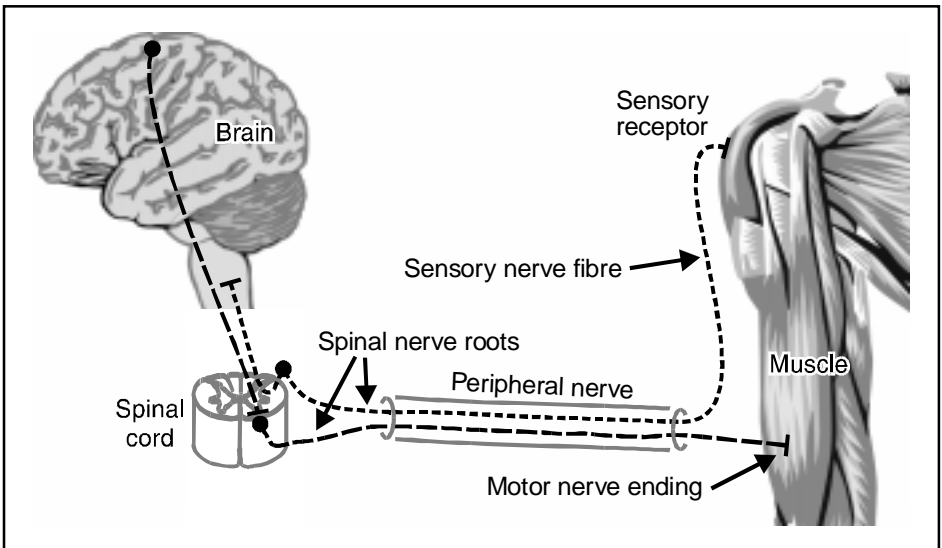
*An explanation for patients, relatives and friends*

## Introduction

The peripheral nerves connect the central nervous system (the brain and the spinal cord) to the periphery (the sensory receptors and muscles). An illness of the peripheral nerves is called a 'peripheral neuropathy'.

## How peripheral nerves work

Peripheral nerves are made of bundles of nerve fibres, which can be regarded as living telephone wires. They are kept alive by their cell bodies. The cell bodies of the motor nerves lie in the spinal cord within the spinal column

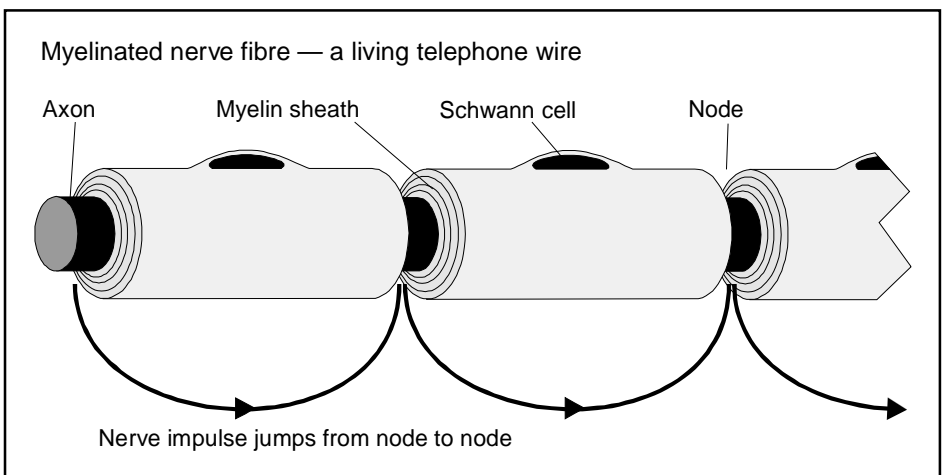


or in the base of the brain. The cell bodies of the sensory nerves are in bunches, called ganglia, connected to the nerve roots on the back of the spinal cord or brain stem.

The motor nerve cell body has a long fibre called an axon, which extends from the central nervous system to the muscles. The longest axons can be as much as a metre long, for example the nerves to the muscles in the feet. The connection between the motor axon and the muscle fibre is a specialised nerve ending, which contains tiny packets of a chemical. The motor nerve impulse stimulates the motor nerve ending to release the chemical and make the muscle fibre contract. If a peripheral neuropathy affects the motor nerves, the muscles become weak because they do not receive the messages to move.

The cell body of a sensory nerve has two axons. One goes into the spinal cord and delivers messages to the brain. The other goes out to specialised receptors in the skin, joints and muscles. The receptors sense changes in pressure, position, or temperature or pain. The receptor translates the stimulus into a nerve impulse. The sensory nerve fibres relay the impulses to the brain.

The fastest conducting nerve fibres are like telephone wires and have their own insulating sheaths. The sheaths are made of myelin, a fatty substance made by special cells, called Schwann cells. Nerve fibres conduct nerve



impulses very quickly because the myelin sheath has gaps about every millimetre, which allow the nerve impulse to jump from gap to gap and travel faster. These fast conducting myelinated nerve fibres control rapid movement and allow fine touch discrimination. There are also many nerve fibres without myelin sheaths. These unmyelinated fibres conduct nerve impulses more slowly. They signal pain and temperature and are important for the control of blood circulation and sweating.

## Different types of peripheral neuropathy

Most types of peripheral neuropathy usually come on very slowly over several months or years, a clinical course called **chronic**. Sometimes a peripheral neuropathy comes on very rapidly over the course of a few days, which is called **acute**. Intermediate courses, about four to eight weeks, are called **subacute**.

A peripheral neuropathy often affects all the nerves more or less together. Because the longest nerves are the most vulnerable, the feet and then the hands are most affected. Such a symmetrical pattern, affecting the feet and hands more than the hips and shoulders, is called a **symmetrical polyneuropathy** (poly- means many). If only one nerve is affected, the condition is called a mononeuropathy (mono- means single). If several discrete nerves are affected, the condition is called a **multiple mononeuropathy** (the old-fashioned term ‘mononeuritis multiplex’ is also used). Sometimes the nerve roots (the name for parts of the nerves next to the spinal cord) are affected as well which gives rise to a **polyradiculoneuropathy** (radiculo- means root). Polyradiculoneuropathy occurs in the common form of Guillain-Barré syndrome and in chronic inflammatory demyelinating polyradiculoneuropathy (see page 8).

A peripheral neuropathy usually affects sensory and motor nerve fibres together so as to cause a **mixed sensory and motor neuropathy**. Sometimes the **autonomic** nerve fibres are also affected. These control sweating, pulse, blood pressure, bladder, sexual and bowel function which may become affected. Sometimes a peripheral neuropathy just affects

sensory nerve fibres, causing a **pure sensory neuropathy**. Finally the motor nerve fibres may be affected on their own, producing a **pure motor neuropathy**.

Nerve fibres may be damaged in four main ways:

1. Most commonly the delicate long axons lose their energy supply because of a chemical upset in the nerve cell body causing the axon to shrink. This is called an **axonal neuropathy**.
2. Less commonly the problem lies in the insulating myelin sheath. This is called a **demyelinating neuropathy**.
3. Vasculitis (inflammation of the blood vessels) may affect the nerves and cause a **vasculitic neuropathy**.
4. Sometimes unusual chemicals or cells collect in the nerves and cause an **infiltrative neuropathy**.

## **Symptoms of a peripheral neuropathy**

A peripheral neuropathy may be very mild. **Many people do not have any symptoms at all** but are discovered to have a peripheral neuropathy when they have a medical examination. The doctor may find signs of such mild neuropathies during a routine medical examination.

The first symptoms of a symmetrical neuropathy are usually very slight loss of feeling together with pins and needles in the toes and the soles of the feet, like an anaesthetic wearing off or like the feeling after having crossed your legs for too long. Some patients cannot feel their feet, others feel as though they are wearing socks or have cold feet. If the peripheral neuropathy worsens, similar feelings may affect the fingers. Sometimes a peripheral neuropathy is painful. The pain is often pricking or stabbing and made worse by touching. It may also be aching or burning. Strangely an area, which is numb, may be painful or even supersensitive, so that a slight touch, which would not normally hurt, feels very unpleasant.

If the motor nerve fibres are affected, weakness may occur. This may

cause difficulty running or walking fast. The toes may tend to catch in pavements. Slight unsteadiness may become a problem, especially in the dark or on rough ground. In more severe cases the hands become weak so that unscrewing jars or turning keys becomes difficult. If the weakness spreads to affect the knees and hips then getting out of chairs and climbing the stairs become troublesome. If the wrists, elbows and shoulders become affected then tasks such as lifting and brushing hair become a problem.

Peripheral neuropathies do not affect the brain, vision, or the sense of smell. They almost never affect hearing and taste. Most sorts of peripheral neuropathy do not affect breathing or swallowing.

## **Investigation of a peripheral neuropathy**

- **The first consultation**

The first essential in diagnosing the cause of a peripheral neuropathy is a careful medical history and full examination. The history needs to include medical information about all close relatives (because peripheral neuropathies may run in families), previous illnesses, alcohol consumption, diet and drugs being taken. It is a good idea to bring all your current medicines (from the doctor, chemist or health food store) to the consultation. Exposure to poisonous chemicals, especially solvents, insecticides and lead paint, is an occasional cause. Bring a list of any possibly poisonous chemicals with which you have contact to the consultation.

The consultation includes a full medical examination and careful testing of the nervous system. The consultation usually narrows down the long list of possible causes to one or two likely culprits but confirmatory tests are almost always needed. If the diagnosis does not quickly become clear a larger number of tests may be needed.

- **Nerve conduction tests**

Most patients with a peripheral neuropathy will be referred to a consultant neurophysiologist for nerve conduction tests, often called an EMG (short for electromyogram). This test involves stimulating the nerves in the

forearm and lower leg with little electric shocks. The recording electrodes are small pads on the muscles and sensory nerves in the hands and feet. The doctor (and you if you want) can see the results on a television screen. A computer helps calculate how many nerve fibres are working and how fast they are conducting their messages. In axonal neuropathy there are too few nerve fibres and the remaining fibres conduct more or less normally. In a demyelinating neuropathy the nerve fibres do not disappear but they conduct too slowly. Sometimes it is necessary to record the electrical activity in the muscles with a very fine needle. The pattern of electrical activity can show whether the fault really lies in the peripheral nerves or somewhere else, possibly in the muscles or the spinal cord.

- **Urine test**

This a routine part of a thorough medical examination. It shows up diabetes and kidney disease.

- **Blood tests**

Blood tests can diagnose lots of diseases. Here are some common ones:

	<b>Test</b>	<b>Conditions detected</b>
Haematology	Blood count	Anaemia
	Sedimentation rate	Inflammation
	Vitamin B12	Vitamin deficiency
Biochemistry	Kidney function	Kidney failure
	Liver function	Alcoholism
	Thyroid function	Thyroid deficiency
	Serum proteins	Abnormal proteins
Immunology	Autoantibodies	Autoimmune diseases
Genetics	Special DNA tests	Hereditary neuropathies

- **X-rays**

A chest X-ray is often needed as part of a thorough medical investigation. Various sorts of inflammation in the chest can cause a peripheral neuropathy. In smokers the possibility of lung cancer may have to be considered.

- **Lumbar puncture**

In acute neuropathies and in severe chronic neuropathies a lumbar puncture is helpful. This involves coming into hospital for the day. You have to lie on your side and the doctor gives you a local anaesthetic injection into the lower part of the back. Then he or she pushes a very fine needle through the numb area of the skin into a large hollow space in the spine. This allows collection of the spinal fluid, which bathes the nerve roots. The cell and protein content of this spinal fluid help diagnose inflammation. Most hospitals ask you to lie flat for an hour or two after but it is not usually necessary to stay in hospital. Lumbar puncture sometimes causes headache for a day or two. The headache goes away if you lie down.

- **Nerve biopsy**

If the diagnosis has not become clear from the other tests, a nerve biopsy may be necessary. It needs a local anaesthetic and involves a cut about an inch long on the outer side of the ankle. It is best to rest in bed for a day or two afterwards, not necessarily in hospital, and to avoid strenuous exercise for at least two weeks. The stitches usually come out after 10 to 14 days. The test is only done as a last resort because it may cause pain on the side of the heel and foot for several weeks. This only happens in about 10% of cases and is less likely if the foot is very numb in any case.

## **Causes of a peripheral neuropathy**

Many diseases can cause a peripheral neuropathy and this list shows only some of the most important.

### **Some important causes of a peripheral neuropathy:**

diabetes mellitus  
vitamin B12 deficiency  
underactive thyroid  
kidney failure  
alcoholism  
Guillain-Barré syndrome

chronic inflammatory demyelinating polyradiculoneuropathy  
vasculitis (inflammation of blood vessels)  
paraproteinaemia (abnormal blood protein)  
hereditary motor and sensory neuropathy (Charcot-Marie-Tooth disease)  
idiopathic axonal neuropathy.

**Here are some examples:**

### **Guillain-Barré syndrome**

This is an uncommon acute neuropathy which usually affects the motor more than the sensory nerves. It reaches its worst within one or two weeks, four weeks at the most. It should be treated as an emergency. Most people make a very good recovery. Further information is available from the Guillain-Barré Syndrome Support Group (see page 15).

### **Chronic inflammatory demyelinating polyradiculoneuropathy (CIDP)**

This is an uncommon chronic neuropathy which also usually affects the motor more than the sensory nerves. It lasts for several months and may disappear on its own or with treatment and then come back. In about half the cases it clears up in the end. Further information is available from the Guillain-Barré Syndrome Support Group (see page 15).

### **Vasculitis (inflammation of blood vessels)**

This usually occurs as part of another disease affecting blood vessels in several parts of the body. Examples are rheumatoid arthritis, systemic lupus erythematosus, polyarteritis nodosa and Churg-Strauss syndrome. Churg-Strauss syndrome is worth special mention because it commonly affects the peripheral nerves. It causes asthma and produces an acute peripheral neuropathy with the pattern of multiple mononeuropathy. Further information is available from the Arthritis Research Campaign, the Stuart Strange Trust and the Churg-Strauss Syndrome International Support Group (see pages 14-15).

### **Paraproteinaemia (abnormal blood protein)**

Sometimes one family of antibody-producing bone marrow cells gets out of control and churns out large amounts of exactly the same antibody. This

antibody, also called an immunoglobulin, may damage the nerve fibres. This may either cause a peripheral neuropathy, a bit like CIDP, or a rather mild and very slowly progressive sensory peripheral neuropathy. Treatment is available but may not be necessary because it is so mild. Information on CIDP should prove helpful (see above).

### **Hereditary motor and sensory neuropathy (Charcot-Marie-Tooth disease)**

It is quite common for peripheral neuropathy to run in families. Hereditary neuropathies usually show up during childhood or adolescence with difficulty running, high foot arches and toes curling. The foot problems may make it difficult to buy comfortable shoes. Often hereditary peripheral neuropathies are so mild that people do not realise they are affected. Occasionally it does cause slowly progressive weakness of the ankles and then the hands which may affect everyday activities. There are different patterns of inheritance but the commonest, hereditary and motor sensory neuropathy type 1, is inherited as an autosomal dominant condition. This means that it is passed on from parent to child. Each child, regardless whether the child is a boy or a girl, has a 50% chance of being affected. Further information is available from the Charcot-Marie-Tooth Disease International UK (see page 14).

### **Idiopathic axonal neuropathy**

If no cause for the peripheral neuropathy can be discovered, doctors call it 'idiopathic' which means 'of its own cause'. This label probably covers a number of different causes which future research may uncover. With rare exceptions, idiopathic peripheral neuropathy occurs in older people, only worsens very slowly (and sometimes remains stationary), and does not become disabling. It is most commonly a sensory neuropathy causing numbness, tingling and discomfort in the feet which may gradually spread up the shins. People may become slightly unsteady and weakness of the ankles may develop. The amount of pain is variable. Some people have very little pain but more weakness. Others have little weakness but more pain. Further information on idiopathic axonal neuropathy and other peripheral neuropathies not listed above is available from the Neuropathy Trust (see page 15).

# **Coping with a peripheral neuropathy**

## **Specific treatment**

It is very important to discover the cause of a peripheral neuropathy because specific treatments and often cures are available.

## **Foot care**

If your feet are numb, take great care of them.

- Wear well fitting shoes made of soft material, with ankle supports if necessary
- Inspect your feet every night for cuts and sore places, including the soles, between the toes and under the toenails
- Consult your practice doctor or nurse promptly if it looks as if an infection is developing
- Change your shoes if a sore place is developing
- Consult a chiropodist or podiatrist if you have problems
- If you have difficulty getting shoes to fit, ask whether specially made surgical footwear would help. They are usually provided by hospital surgical appliance officers

## **Ankle supports**

If you need ankle support, wearing boots, either leather or baseball boots may help and be fashionable. If you have a very weak ankle or ankles causing footdrop, you might like to try special light weight splints, called 'ankle foot orthoses' (AFOs) or 'cosmetic splints'. There are several sorts including off the peg, adjustable models and special made-to-measure moulded designs. You get these from the hospital surgical appliances department upon the prescription of a hospital doctor.

## **Diet**

No special diet is necessary if you have a peripheral neuropathy. It makes obvious sense to keep your weight down. Being overweight can only make the problem of coping with weak ankles worse. Taking extra vitamins is not necessary if you are already eating a balanced diet. Sometimes doctors recommend extra vitamin B1 (thiamine) for special sorts of neuropathy.

One word of warning. Vitamin supplements often contain vitamin B6 (pyridoxine) which actually **causes** a peripheral neuropathy when given in very large doses. There is a current argument about the safe upper limit for the dose of pyridoxine. Since there is no evidence that it does any good, it does not seem worth the risk of taking any extra.

### **Alcohol**

If your peripheral neuropathy was caused by excess alcohol, your doctor will advise you to abstain from alcohol completely and permanently. If not and you enjoy social drinking, then there is no need to stop, but don't start drinking in excess!

### **Medicines**

It is often not helpful for people with a peripheral neuropathy to take medicines, but some conditions are helped by medication. For example, patients with CIDP take steroids and other drugs to suppress their immune systems and some patients take drugs to counter pain. With rare exceptions there are no medicines which you should avoid. The exceptions are drugs which themselves cause a peripheral neuropathy. Vincristine, cis-platinum and taxol, all drugs used in the treatment of cancer, may make a peripheral neuropathy worse.

### **Using a stick**

If you are becoming unsteady, you should seriously consider using a stick. It would be sensible to consult a physiotherapist about the best sort and correct height. If your hands are weak the physiotherapist may recommend crutches. Having a peripheral neuropathy is bad enough, falling over and bruising yourself or breaking a bone would be worse. If you really do not want to be seen with a stick, then a shopping trolley or stout umbrella may do the job, and you can get folding sticks for use in emergency.

### **Physiotherapy**

If your peripheral neuropathy is beginning to impair your activity, ask whether referral to a physiotherapist would be helpful. Physiotherapists are especially helpful with difficulties with gait and balance. They will

want to assess your difficulties, suggest exercises and recommend the best ankle supports and walking aids.

### **Occupational therapy**

If you have problems with activities involving your hands, ask whether a referral to an occupational therapist would be helpful. Occupational therapists may be able to recommend wrist or other splints to help cope with weakness and are the best source of information about appropriate aids, utensils and household or office modifications to help you continue to participate in everything. Your local Disabled Living Centre can provide impartial information and advice. For your nearest centre see contact addresses, page 14.

### **Driving**

If you have a progressive medical condition which might impair your ability to drive, you must advise the driving license authority in Swansea. Ask your doctor whether this applies to you. It is rare for most forms of peripheral neuropathy to prevent driving, but it is sometimes necessary to change to an automatic car. If in doubt it is worth having an assessment at a special centre for drivers with disabilities (see contact addresses, Banstead Mobility Centre, page 14).

### **Allowances**

If your peripheral neuropathy seriously impairs your activities, discover whether you are eligible for a disability living or attendance allowance. You can apply for this yourself. Application forms are available in post offices, surgeries and outpatient clinics and local social service departments.

For possible benefits you may be entitled to in different situations see below:

<b>Problem</b>	<b>Benefit (or known as )</b>
Short term illness	Statutory sick pay
Long term illness	Incapacity benefit
	Income support
	Severe disability allowance
Walking / mobility	Disability living allowance (mobility component)

Personal care	Disability living allowance if younger than 65 (care component) Attendance allowance if over 65 years (care component) Invalid care allowance
Low income	Income support Family credit Disability working allowance Housing benefit Council tax benefit
One-off costs (eg bedding, furniture)	Social fund (if you receive income support)
Work injury	Industrial injuries / diseases benefit

Note: The above details were believed to be correct at the time of going to press. The publishers and writers can take no responsibility for their accuracy now or in the future. Contact your local Citizen's Advice Bureau for further assistance and the latest information.

## More help

You can obtain more help from a medical social worker, for instance with adaptations to your home. Contact your social worker through your local council authority and ask for the Social Work Department in Social Services. The social worker can arrange for a community occupational therapist to assess you at home and advise about equipment to suit your needs.

## Further reading

Booklets can be obtained from relevant hospital departments (physiotherapy, occupational therapy, chiropody, surgical appliances), hospital outpatients, General Practitioners or by contacting the appropriate association or group (see contact addresses, below). Your local social services will be able to provide you with local information about services available in your area.

## **Contact addresses**

### **Arthritis Research Campaign**

Copeman House, St Mary's Court, St Mary's Gate, Chesterfield,  
Derbyshire S41 7TD

Tel: 01246 558033 Fax: 01246 558007

E-mail: [info@arc.org.uk](mailto:info@arc.org.uk)

Web site: [www.arc.org.uk/](http://www.arc.org.uk/)

### **Banstead Mobility Centre**

Damson Way, Fountain Drive, Carlshalton, Surrey SM5 4NR

Tel: 0181 770 1151 Fax: 0181 770 1211

### **Charcot-Marie-Tooth Disease International UK**

Mrs Margaret Read, Secretary

121 Lavernock Road, Penarth, S Wales CF64 3QG

Tel/Fax: 01222 709537

E-mail: [mereadcmt@aol.com](mailto:mereadcmt@aol.com)

Web site: [www.cmt.org.uk/](http://www.cmt.org.uk/)

### **Churg-Strauss Syndrome International Support Group**

Gary Todd, European Coordinator

Lee School House, Long Framlington, Morpeth,

Northumberland NE65 8JG

Tel: 01669 570029

E-mail: [CSSISG@blackpigs.freemove.co.uk](mailto:CSSISG@blackpigs.freemove.co.uk)

Web site: [www.challengenet.com/~CSSISG/](http://www.challengenet.com/~CSSISG/)

### **Disabled Living Centres Council**

1st Floor, Winchester House, 11 Cranmer Road, Kennington,

London SW9 6EJ

Tel: 0171 820 0567 Fax: 0171 735 0278

E-mail: [dlcc@dlcc.demon.co.uk](mailto:dlcc@dlcc.demon.co.uk)

**Glaxo Neurological Centre**

NortonSt, Liverpool L3 8LR

Tel: 0151 2982999 Fax: 0151 2982333

E-mail: [mnt@gnc.u-net.com](mailto:mnt@gnc.u-net.com)

Web site: [glaxocentre.merseyside.org/](http://glaxocentre.merseyside.org/)

**Guillain-Barré Syndrome Support Group of the UK**

LCC Offices, Eastgate, Sleaford, Lincolnshire NG34 7EB

Tel/Fax: 01529 304615 Free helpline: 0800 374 803

E-mail: [admin@gbs.org.uk](mailto:admin@gbs.org.uk)

Web site: [www.gbs.org.uk/](http://www.gbs.org.uk/)

**Neuropathy Trust**

PO Box 26, Nantwich, Cheshire CW5 5FP

Tel/Fax: 01270 611828

E-mail: [info@neuropathy-trust.org](mailto:info@neuropathy-trust.org)

Web site: [www.neuropathy-trust.org/](http://www.neuropathy-trust.org/)

**RADAR (Royal Association of Disability and Rehabilitation)**

12 City Forum, 250 City Road, London EC1Z 2AF

Tel: 0171 250 3222 Fax: 0171 250 0212

E-mail: [radar@radar.org.uk](mailto:radar@radar.org.uk)

Web site: [www.radar.org.uk/](http://www.radar.org.uk/)

**Stuart Strange Trust**

14 Elthorne Way, Newport Pagnell, Buckinghamshire MK16 0JH

Tel/Fax: 01438 360565

This booklet has been published by the Guillain-Barré Syndrome Support Group of the United Kingdom. The Group provides information and support for sufferers of Guillain-Barré syndrome (GBS) and related conditions. These illnesses are characterised by symptoms of peripheral neuropathy caused by a dysfunction of the immune system.

Although this booklet will be of interest to sufferers of other peripheral neuropathies, the Support Group regrets that it can only provide further information and support to those affected by the GBS family of illnesses. Contact information for other support groups is printed on pages 14 and 15.

Until 1998, the Group provided a contact and information service for those affected by Churg-Strauss syndrome, (generic) peripheral neuropathy and a myopathy called transverse myelitis. Fortunately, organisations now exist specifically to cover these conditions\*. The Group's former publication *Other Neuropathies* is obsolete and copies should be withdrawn.

Other booklets in this series are:

- *Guillain-Barré Syndrome — a guide for patients, relatives and friends*
- *The Guillain-Barré Patient in Intensive Care — a guide for relatives and friends*
- *CIDP — a guide for patients, relatives and friends*
- *Childhood GBS — a guide for parents and carers*
- *GBS Guidelines... ...for doctors and other health professionals*

\*Churg-Strauss syndrome: Churg-Strauss Syndrome International Support Group or the Stuart Strange Trust (see pages 14-15). All peripheral neuropathies: Neuropathy Trust (see page 15). Transverse myelitis: Transverse Myelitis Association (USA), call 00 1 253 565 8156.

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