

Please complete as much of the following as possible and the appropriate information will be sent to you.

YOUR DETAILS:

Name	
Address	
Town	
County and post code	
Tel	

PATIENT'S DETAILS:

Name			
Home address			
Town			
County and post code			
Tel			
Hospital			
Ward/unit			
Town			
Relationship to you			
Date entered hospital			
Diagnosis (if known)	GBS/CIDP/other(state)		
Ventilated	YES/NO	Age	

If you would like to receive a call from your local GBS contact, who will be pleased to offer support and/or arrange a hospital visit, please tick box.

If you think it would be helpful if we were to send the patient's GP one of our Information Packs, please fill in the GP's name and address in the box.

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Further Information

To obtain further information, either:

- complete the form (left) and send it to: **GBS Support Group, LCC Offices, Eastgate, Sleaford, Lincolnshire, NG34 7EB;**
- fax the form to, or telephone the Group's Office — **01529 304615***;
- e-mail admin@gbs.org.uk;
- call the free GBS/CIDP Helpline on **0800 374 803***;
- visit the Support Group's Web site at www.gbs.org.uk

***From the Republic of Ireland, call 0044 1529 304615 (Office) or 0044 1529 415278 (Helpline — normal UK rate applies).**

The term 'GBS' is also used in a medical context as an abbreviation for the illness 'group B streptococcus'.

For more details contact:

Group B Strep Support, PO Box 203, Haywards Heath RH16 1GF

Tel/Fax: 01444 416176

E-mail: info@gbss.org.uk

To obtain extra copies of this leaflet, please contact the Group's Office.

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GBS & CIDP

A Quick Guide to Guillain-Barré Syndrome and CIDP

(Chronic Inflammatory Demyelinating Polyradiculoneuropathy)

Sixth Edition 2000

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Guillain-Barré Syndrome Support Group
Registered Charity 327314

A Quick Guide to Guillain-Barré Syndrome and CIDP

What is GBS?

GBS is short for 'Guillain-Barré syndrome' (pronounced Ghee-lan Bar-ray). It is an acute disease of the peripheral nervous system in which the nerves in the arms and legs become inflamed and stop working. This causes sudden weakness leading to limb paralysis, and a loss of sensation, sometimes with pain.

What is CIDP?

Some patients have a similar but longer-lasting illness called CIDP (chronic inflammatory demyelinating polyradiculoneuropathy). CIDP, once known as 'chronic GBS', is now usually regarded as a related condition.

Who can get GBS and CIDP?

Anyone: young or old, male or female. The illnesses are neither hereditary nor contagious. GBS affects about 1500 people every year in the United Kingdom; the incidence of CIDP is perhaps one tenth that of GBS.

What causes GBS/CIDP?

This is a matter of much research. About sixty percent of patients suffer from a throat or intestinal infection, influenza or stress symptoms in the previous two weeks. These infections trigger an incorrect response in the immune system which attacks the nerves.

What are the symptoms?

First symptoms are usually tingling and numbness in the fingers and toes with progressive weakness in the arms and legs during the next few days. In the mildest of cases, the weakness may arrest and cause only moderate difficulty in walking, requiring sticks, crutches or a walking frame.

In some cases the weakness progresses and leads to complete paralysis of the legs, the arms may also be affected. In a quarter of cases the paralysis progresses up the chest and the patient is unable to breathe on his or her own and needs to rely on a mechanical breathing machine (ventilator). The throat and face may be affected making swallowing impossible and so the patient needs to be fed by tube up the nose or directly into the stomach.

For CIDP patients, the illness follows a longer course but respiratory failure is highly unlikely.

How are GBS and CIDP diagnosed?

From the history and clinical examination. This is difficult because the symptoms may be confused with those of other conditions.

Two confirmatory tests may be helpful and are performed in most cases:

- lumbar puncture — under a local anaesthetic, a needle is inserted between the lower back bones and a small amount of spinal fluid is drawn off for analysis; and
- electromyogram (EMG) — an electrical recording of nerve conduction and muscle activity.

What is the treatment for GBS?

GBS improves spontaneously. However, certain factors can assist recovery:

- good nursing and medical/intensive care;
- physiotherapy and hydrotherapy, therapies that relieve discomfort and prevent stiffness;
- immunoglobulin — the infusion of immunoglobulin proves successful with similar results to plasmapheresis;
- plasmapheresis — the exchange of blood plasma generally reduces the duration of the disease in severe cases if carried out in the first few days; and
- counselling to reassure the patient and encourage the patient towards recovery.

What is the treatment for CIDP?

Like GBS, CIDP can improve without treatment. However, recovery may be very slow and the illness can either get progressively better or worse, or can follow a relapsing/remitting course. Most patients are given treatment in the forms of plasmapheresis, immunoglobulin or corticosteroids. Other drugs may be used in difficult cases.

Do all patients recover?

Most patients (80%) make a total recovery but many spend three months or more in hospital and take a year to recover. Some patients do not recover completely and have residual weakness, numbness and occasional pain. A small number are unable to resume their normal occupation. Modern intensive care makes death from GBS a rare occurrence but it does occur in around 5% of cases, more commonly in the elderly. Death resulting from CIDP is highly unlikely. Uncommonly, GBS returns a second time or may turn into CIDP.

What more can be done to help?

- More research to help doctors diagnose and treat GBS/CIDP;
- more information for medical personnel and lay people; and
- improved counselling and support facilities for patients and their families.

Where can I get more information?

The GBS Support Group publishes a booklet: *Guillain-Barré Syndrome — a short guide for patients, relatives and friends*. Companion booklets include: *The Guillain-Barré Syndrome Patient in Intensive Care* (only applicable in cases where the patient is being ventilated) *Childhood GBS, CIDP, Peripheral Nerve Disorders*, and *After GBS*.

See overleaf how to contact the Support Group.

Can I talk to someone about GBS or CIDP now?

Yes. Call the GBS/CIDP Helpline on 0800 374 803.

Is it possible to arrange a hospital visit by a recovered patient?

Yes. Complete the attached form or ring the GBS/CIDP Helpline. There can be nothing more helpful to a patient's morale than to receive a visit from someone who has made his or her own recovery from the illness.

Is there a charge for the above information or services?

No. The Group is a national charity and its services are entirely free. Many who contact the Group subsequently become members but this is entirely optional.