



Dedicated to helping people affected by  
Guillain-Barré syndrome, CIDP &  
associated inflammatory neuropathies

**My child has been diagnosed  
with Guillain-Barré syndrome,  
CIDP or the one of the  
associated variants**

Helpline: 0800 374803 (UK) 1800 806152 (ROI)

# **GBS and CIDP in children**

## **What is GBS?**

Guillain-Barré syndrome is one of several Acute Inflammatory Demyelinating Poly(radiculo)neuropathies which affect the peripheral nerves. This causes weakness and loss of sensation that usually recovers completely, or almost completely, after a few weeks or months.

GBS usually occurs only once. Recurrence is rare, especially in children. GBS is not genetic or contagious

## **What causes GBS?**

The disease is due to inflammation of the peripheral nerves, often termed 'neuritis', hence GBS is called a 'polyneuritis'. The peripheral nerves connect the central nervous system to the muscles and to the sensory organs in the joints and skin. When these are damaged the muscles and sensory organs stop working, although they are in themselves undamaged.

The most likely explanation for the inflammation is that immune cells called lymphocytes start attacking the nerves in error, instead of concentrating their energies on fighting off infections. It is believed that the immune system has been tricked into making this mistake by an infection that often precedes GBS. Eventually the immune system realises its mistake and stops the attack on the nerves. A disease in which the immune system attacks its host's own body is called an autoimmune disease and GBS is one of many diseases affecting the nervous system in this category.

## **How it can affect your child**

GBS usually occurs around two weeks after a respiratory (eg a cold or 'flu) or a gastro-intestinal (eg diarrhoea or vomiting) infection. More rarely it may follow other infections such as chicken pox.

The typical pattern of development is a gradual onset of symmetrical weakness starting in the feet and sometimes hands and slowly spreading upwards.

They can also experience

- cramping muscle pain
- pain on touch
- back ache
- facial weakness with loss of facial expression.
- difficulty moving the eyes, swallowing and talking
- speech may take on a nasal quality.

Less common is

- difficulty with breathing.
- problems with autonomic system (blood pressure, heart rhythm, bladder, bowels and temperature control).
- pain in their muscles (usually arms and/or legs).

Don't forget your child is conscious and needs to be told what is happening and will be reassured by familiar faces and voices. Your child could be more tearful and moody than normal and continue to have fluctuating mood swings sometime after recovering from GBS.

The weakness usually worsens over a one to two-week period in most children until it reaches its peak, which may last from a few days up to several weeks. This is called the 'plateau period'. Following this plateau, recovery begins.

### **How is GBS diagnosed?**

The diagnosis of GBS is made from

- the clinical history (the story you tell your doctor)
- medical examination
- tests such as blood tests, a lumbar puncture or electromyogram (EMG).

### **A bit more about the tests**

The lumbar puncture tests for protein levels in the spinal fluid and involves lying on one side and having a needle inserted into the base of the spine under local anesthetic.

The electromyogram is an electrical recording of muscle activity and is a very important part of making the diagnosis of GBS. Often in GBS, nerve conduction is slowed or even blocked altogether. The test usually lasts about half an hour. Some patients find the electrical stimulation rather uncomfortable but it is entirely harmless.

Occasionally the diagnosis can be delayed for a few days while they are checking the results, and your doctor may start the treatment just to be on the safe side.

### **Differential diagnosis – what else could it be?**

Not all children present with the classical history described above. It is very important for everyone to feel confident with the diagnosis of GBS as this would affect the management of your child. Some children can have many signs in common with GBS but not have the condition.

### **How is your child's condition managed?**

It is important your child is managed in a centre familiar with GBS and with intensive care facilities, so your child may be moved to a hospital you do not routinely use. Most of your child's care will be 'supportive' for breathing, feeding, bowel or bladder functions. Physiotherapy is needed to ensure good joint mobility and to keep the chest clear.

The team involved in your child's care are:

- you, your child and your family;
- nurses (for the neurology ward and the children's intensive care unit);
- doctors: paediatricians,
- paediatric neurologists (consultant, senior registrar/registrar, senior house officer),
- paediatric intensive care doctors,
- neurophysiologist (who does the nerves conduction study);
- physiotherapists (to help with movement and breathing);
- speech therapist (to help with feeding and communication);
- occupational therapist (to help maximise recovery);
- clinical psychologist; and
- dietician.

## **Is there a cure or any treatment for GBS?**

Trials have shown that, on average, for severely affected patients in the first week or two of the illness the following alternatives can halve the duration of the illness although they do not necessarily lead to an instant cure and some patients will continue to get worse.

- Plasmapheresis, where plasma is exchanged over 5 days
- Intravenous immunoglobulin (IVIg)

The above two treatments are probably not worthwhile in mildly affected patients, ie those who can still walk across a room unaided.

The longer the delay in starting treatment, the less likely it is to be effective and some experts feel it is not worth giving any treatment after the first couple of weeks, unless the patient is still deteriorating.

Occasionally patients require two courses of treatment.

Although they do seem to shorten the duration of the illness, particularly the time on a ventilator and the time to walk unaided, they are a help rather than a cure. Since GBS usually gets better on its own, a very important part of treatment is general nursing and medical care with physiotherapy and, if necessary, intensive care. No drugs have been proven to make any difference to the speed of recovery at this point in time.

## **What is Paediatric intensive care?**

Around 10% of children with GBS will become so weak that they cannot breathe without the support of a ventilator. Understandably this can be a frightening situation for a child who is still fully aware of everything going on around him or her. Parents and carers must provide the child with all the positive support needed to avoid unnecessary trauma.

## **Things you can do to help**

Talk about things that matter to your child (a pet, the football results, family events). Bring a favourite toy. Your child may become extremely frustrated especially if he or she cannot speak. Try to work out ways of communicating. (eg picture cards for eye pointing). Remember, everything you say in front of your child is likely to be heard

# So what happens next?

## Outcome/rehabilitation

The majority of children with GBS make a full recovery without any signs of having had the condition. However, a small number may have some persisting problems - most common is weakness of the hand and foot muscles. Most recovery is seen in the first few months. However, children can continue to improve for up to two years after the illness.

## Going home

Recovery can be a drawn-out process and some symptoms can linger for many months. However, there are ways of helping children to cope. Doctors can prescribe medication to counter pain. Rest, relaxation, massage and physiotherapy are all helpful. Occupational therapists will discuss the suitability of the home environment and any specialised equipment needs.

Hydrotherapy and swimming are very helpful. Cycling is also a good form of exercise. Horse riding helps with balance (contact 'Riding for the Disabled', tel: 0845 658 1082 or [www.rda.org.uk](http://www.rda.org.uk)). Any exercise is beneficial as long as children are willing. Since they are usually very active and move around without thinking, this is a good indicator of their capabilities.

Your child may feel the cold and get tired more easily, or may lose their appetite but don't worry as this is quite normal. The trauma of GBS may have had a temporary effect on children's overall behaviour. They may become frustrated, angry and upset at not being able to do everything that their friends can. Children should be listened to. Beneath the mixed-up emotions they are the same people inside. Keep in mind that these problems are temporary and will improve in due course.

## Back to School

School facilities should be checked that they are suitable for your child's needs. Depending on the speed of recovery and/or the amount of residual disability, it may be necessary for your child to return to school in a wheelchair. A welfare officer from the local education authority (LEA) can visit to arrange adaptations, and can sometimes provide equipment

for use in schools. Like any other institution, the ability of the school to cope depends on the willingness of those involved, as much as the building's design and facilities.

Before your child returns to school, arrange a consultation with headteacher and SENCO to explain what if any limitations they have. Teachers can always look at the GAIN website for further information

### **Are there other organisation that may help?**

<b>Contact a Family</b>	0808 808 3555	<a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a>
<b>Family Lives</b>	0808 800 2222	<a href="http://www.familylives.org.uk">www.familylives.org.uk</a>
<b>Go Kids Go</b>	01482 887163	<a href="http://Go-kids-go.org.uk">Go-kids-go.org.uk</a>
<b>Whizz-kidz</b>	020 7233 6600	<a href="http://www.whizz-kidz.org.uk">www.whizz-kidz.org.uk</a>

### **Are there other variants?**

As mentioned earlier, not all children conform to the typical pattern. A very small number may follow a more slowly progressive form of weakness which tends to cover months rather than weeks of illness involvement. This is referred to as chronic inflammatory demyelinating poly[radiculo]neuropathy (CIDP); it is very rare in childhood. Another very rare condition in childhood is the Miller Fisher syndrome. This consists of ataxia (being very unsteady), areflexia (loss of reflexes) and ophthalmoplegia (difficulty moving the eyes) and problems with feeding, swallowing and speaking. It is felt to be a variant of GBS.

Lastly the nerve itself (the axon, rather than simply the nerve sheath) may be involved. This is referred to as acute axonal neuropathy. This is important since recovery takes longer and may not be as complete as for typical GBS.

You may hear of some of these conditions referred to during your child's admission but it remains extremely unlikely any of them would occur.

This guide has been written by the GAIN Medical Advisory Board and gives an honest account of the conditions. Not all content will apply to you and if you need more information ask your consultant or GP.

To find out what other help we can provide please contact us or visit our website.

### **Guillain-Barré & Associated Inflammatory Neuropathies (GAIN)**

Woodholme House  
Heckington Business Park  
Station Road  
Heckington,  
Sleaford  
Lincolnshire, NG34 9JH



+44 (0) 1529 469910



office@gaincharity.org.uk



Monday to Friday 9am – 3pm

# [www.gaincharity.org.uk](http://www.gaincharity.org.uk)

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