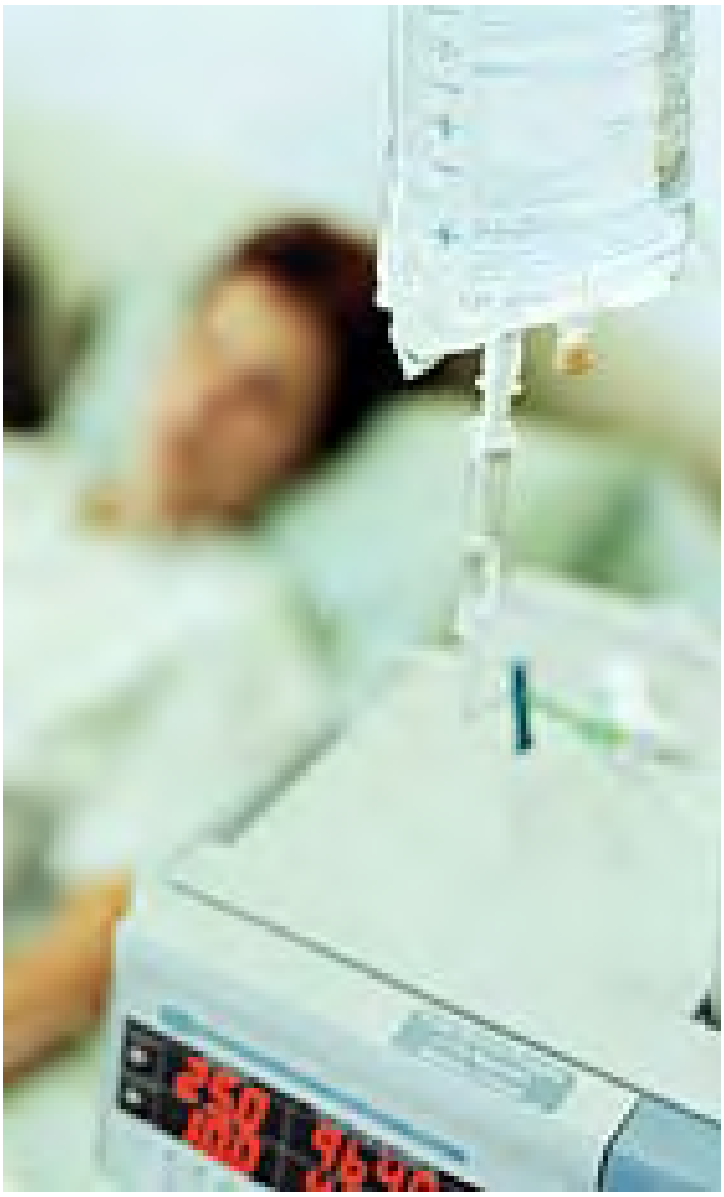
Dedicated to helping people affected by Guillain-Barré syndrome, CIDP and the associated inflammatory neuropathies



Guillain-Barré syndrome and related conditions

About this booklet

Most people have never heard of Guillain-Barré syndrome until they find themselves affected by it. The symptoms come on very rapidly, may differ in different people, and may be mistaken for other neurological conditions, so diagnosis of this rare autoimmune disorder somewhat difficult. The road to recovery is often long and the future uncertain. This can be a confusing and frightening time, but we at GAIN are here to provide information and support for as long as it is needed.

In addition to our information booklets and factsheets, we can provide a hospital communications book for people who are on a ventilator or unable to speak, help with the cost of frequent hospital visits for a family member, and arrange contact with a volunteer with first-hand experience of living through this distressing condition. We also have a website with information to read and download, and a friendly Facebook community you can join.

This guide has been approved by the GAIN Medical Advisory Board and provides an accurate account of the conditions. Not all content will apply to you as symptoms, severity and the timescale for recovery may vary from one person to another. If you need more specific information about your condition, please talk to your consultant or GP. If you need further help from GAIN, please get in touch or visit our website.

This version revised April 2021 by Dr Rob Haddon

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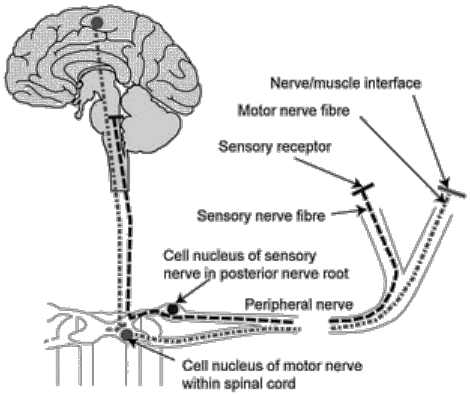
Introduction

Before we explain the acute conditions in more detail, it is worth understanding a little about how the peripheral nerves work and how that affects you.

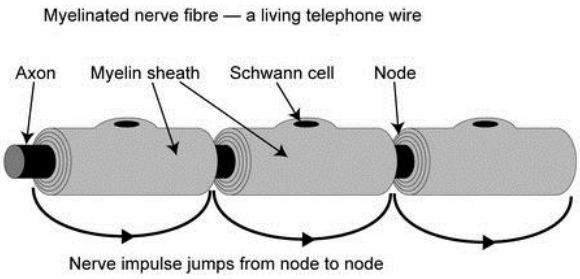
The peripheral nerves connect the central nervous system (the brain and the spinal cord) to the periphery (the sensory receptors and muscles). An illness of the peripheral nerves is called a 'peripheral neuropathy'.



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 around 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 in length, 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 transmits messages from specialised receptors in the skin, joints and muscles. The receptors sense changes in pressure, position, or temperature or pain and translate the stimulus into a nerve impulse, which is relayed to the brain by the sensory nerve fibres. 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 are called unmyelinated fibres and 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 term 'mononeuritis multiplex' might also be used). Sometimes the nerve roots (the name for parts of the nerves next to the spinal cord) are also affected, which gives rise to a polyradiculoneuropathy (*radiculo* means root). Polyradiculoneuropathy occurs in the common form of Guillain-Barré syndrome (GBS) and in chronic inflammatory demyelinating polyradiculoneuropathy (CIDP).

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:

- 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.
- Less commonly the problem lies in the insulating myelin sheath. This is called a demyelinating neuropathy.
- Vasculitis (inflammation of the blood vessels) may affect the nerves and cause a vasculitic neuropathy.
- Sometimes unusual chemicals or cells collect in the nerves and cause an infiltrative neuropathy.
- 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.

What is Guillain-Barré syndrome?

Guillain-Barré (pronounced ghee-yan bar-ray) Syndrome, or GBS for short, is a rare and serious inflammatory neuropathy that damages the peripheral nerves. It affects one to two people per 100,000 per year (around 1,300 people each year in the United Kingdom).

People of all ages can develop GBS, but it is more common in adults, and in men than in women. It is neither hereditary nor infectious, so you can't pass it on to your children, or transmit it to someone else.

Guillain-Barré syndrome is thought to be caused by an over-reaction of the immune system, the body's natural defence against illness and infection. Normally the immune system attacks any germs that get into the body. A disease in which the immune system attacks its own body id called an autoimmune disease. In people who develop Guillain-Barré syndrome, the immune system experiences a sort of allergic reaction to the infection and it mistakenly attacks the peripheral nerves.

The immune reaction in GBS causes the myelin to become inflamed and may also damage the axons. This prevents signals from the brain travelling along the nerve fibres properly, which can cause numbness, weakness and pain in the limbs. Because many nerves are inflamed, GBS is called a 'polyneuropathy'.

GBS worsens for up to four weeks. Unfortunately, recovery usually takes much longer than this. Most people will eventually make a good recovery, but it can be life-threatening, and some people are left with long-term problems, from severe fatigue to dexterity and mobility issues. GBS is a one-off condition which usually does not happen again, except in around 3% who may suffer GBS more than once, perhaps many years later.

Symptoms of GBS

Early symptoms

Symptoms of Guillain-Barré syndrome usually develop rapidly, starting in the feet and legs before spreading to other parts of the body. These symptoms affect both sides of the body at the same time, usually symmetrically.

At first you may have:

numbness	pins and needles	muscle weakness
poor co-ordination	problems with balance	pain in back and legs

Later symptoms

The symptoms may continue to get worse over the next few days or weeks, typically reaching the worst point, or nadir, within two weeks and always within four weeks.

Some people are only mildly affected, but others may have:

difficulty walking	paralysis	difficulty breathing	severe pain
Weak arms	problems speaking or swallowing	bowel problems or constipation	facial weakness & loss of expression

The worst degree of weakness is usually reached within two to four. Some people worsen very rapidly to severe paralysis within a few days, but this is uncommon. The person then stays the same (plateau or stabilization) a few days or weeks. Many people are so weak that they are unable to get out of bed. However, it is very important that someone keeps all the joints moving to stop them stiffening up. A physiotherapist may advise relatives and friends on what they can do to help.

Around 20% of people with GBS develop weakness of the breathing muscles and need mechanical ventilation. Cardiac arrythmia (irregular heartbeat), very high or low blood pressure and constipation may occur if there is inflammation of the autonomic nerve, supplying internal organs. About 2-5% of people with GBS die.

Is there more than one type of GBS?

Yes. The word ‘syndrome’ in GBS means it is not a single disease but includes several different diseases which may look similar.

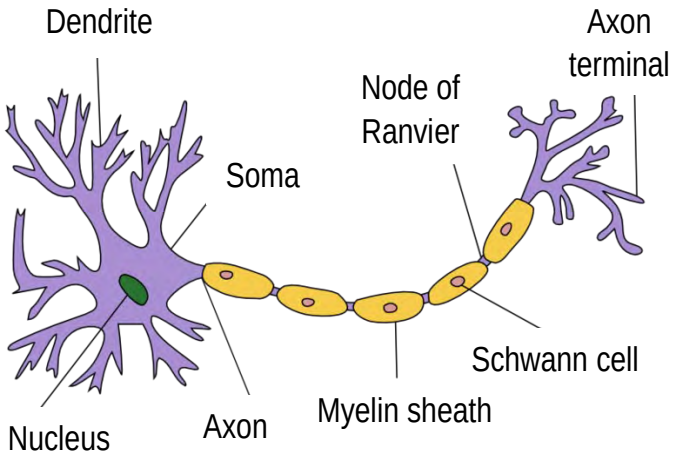
AIDP

The most common type of GBS is acute inflammatory demyelinating polyneuropathy or AIDP. ‘Acute’ means starting quickly, ‘Inflammatory’ means a reaction of the

immune system, for example when your skin is inflamed it looks red and feels uncomfortable. 'Demyelinating' means damage to the myelin. 'Polyneuropathy' means a disease affecting the nervers. The myelin sheath is mand and repaired by cells called Schwann cells. People with AIDP typically have numbness/tingling as well as weakness. In more severe forms of AIDP, both the axon and the myelin may be damaged, giving slower recovery.

AMAN and AMSAN (axonal GBS)

The axon is the conducting core of the nerve, equivalent to the copper wire within electrical cables. In AIDP this is usually not damaged. However, in the variants called AMAN (acute motor axonal neuropathy) and AMSAN (acute motor and sensory axonal neuropathy), the axon is damaged too. Recently, variants of axonal GBS have been discovered in which the axon is temporarily blocked by antibodies without much damage, which can therefore recover more quickly. These may be called paranodopathy, acute motor conduction block neuropathy, or reversible conduction failure.



The structure of a typical neuron

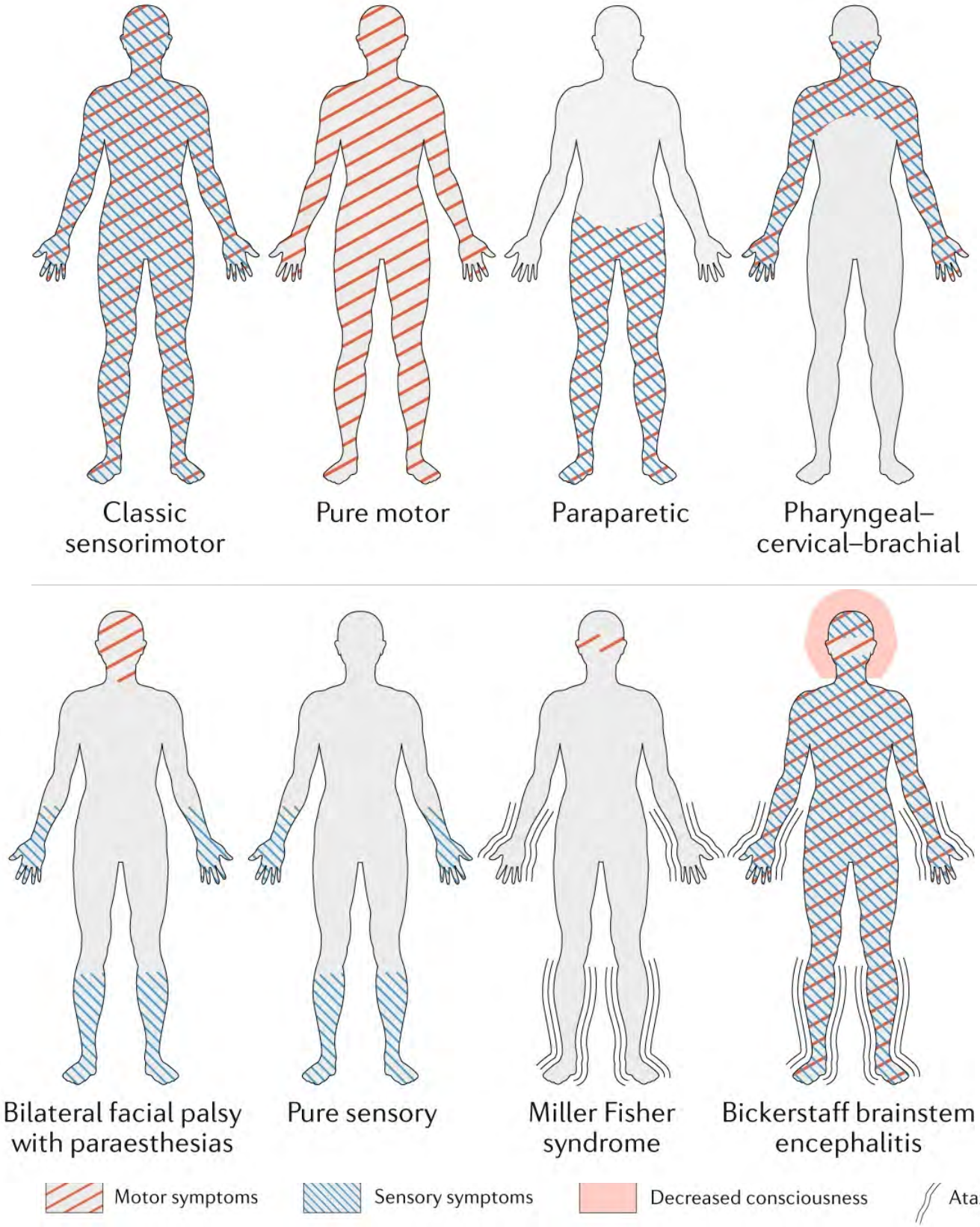
The speed of recovery depends on the type and severity of damage. Demyelination, inflammation and antibodies usually improve within week. If there is damage (degeneration) of the axons, recovery takes many months or up to three years, and is often incomplete. If the muscles have become very thin (wasted) this usually indicates axonal damage and a slower recovery. Axonal degeneration may occur in either AIDP or axonal GBS. The distinction between AIDP and axonal GBS does not affect treatment or the speed of recovery. The factors which usually indicate a slower recovery are: more severe weakness, older age, and diarrhea just before GBS starts.

In some cases, an initial diagnosis of GBS may later be changed to CIDP, a chronic variant in which nerve inflammation lasts for years. 'Chronic' means continuing for a long time. CIDP stands for Chronic Inflammatory Demyelinating Poly(radiculo)neuropathy. By definition, in CIDP the symptoms continue to worsen more than 8 weeks after onset, usually after improving first. If someone with severe GBS is not improving, this is more likely GBS with axonal damage than CIDP. CIDP

and other chronic variants are described in the GAIN booklet *CIDP and associated chronic variants.*

Although the commonest (classical) form of GBS causes weakness and sensory loss throughout the whole body, some people with GBS may have one of several variants which look different.

Pattern of symptoms in variants of Guillain–Barré syndrome



These variants include:

- weakness without sensory loss (pure motor variant, usually AMAN)
- weakness only in face and cranial nerves (facial palsy with paraesthesias):
    - weak face, tingling in the arms/legs but no weakness in the arm/legs,
- weakness only in arms, neck and throat (pharyngeal–cervical–brachial variant)
- weakness only in legs (paraparetic variant)
- Miller Fisher syndrome (MFS).

GBS variants are rarely 'pure' but often overlap in part with classical GBS. Antibodies to molecules called gangliosides are found in many of these variants, but not usually in classical AIDP.

Miller Fisher syndrome and variants

Miller Fisher syndrome (MFS) is also known as Fisher's syndrome. MFS typically causes

- abnormal coordination ('ataxia', such as clumsiness and poor balance as if drunk),
- paralysis of eye movements ('ophthalmoplegia', which may cause difficulty reading or double vision), and
- absent tendon reflexes ('areflexia', detectable by a doctor but causes no symptoms).

Often there is weakness of the face but many people have no weakness.

Variants of Miller Fisher syndrome

- Some people with MFS also have weakness of the whole body and are then considered to have an overlap of both MFS and GBS. The speed of recovery is largely determined by the severity of the GBS.
- If GBS causes weakness of eye movements (which it usually doesn't) this is also an overlap with MFS.
- Rare milder variants of MFS may have weakness only of eye movements ('acute ophthalmoparesis').
- Bickerstaff's brainstem encephalitis (BBE) means MFS with additional inflammation of the brainstem. This typically causes drowsiness or reduced consciousness, often with whole-body weakness, and may be shown on MRI scanning or by neurological examination. BBE is the only variant of GBS affecting the brain; otherwise GBS and MFS affect only the peripheral nerves not the brain.

Antibodies to ganglioside GQ1b (IgG type) are found in most patients with MFS and its variants (but not other types of GBS), suggesting they are all closely related.

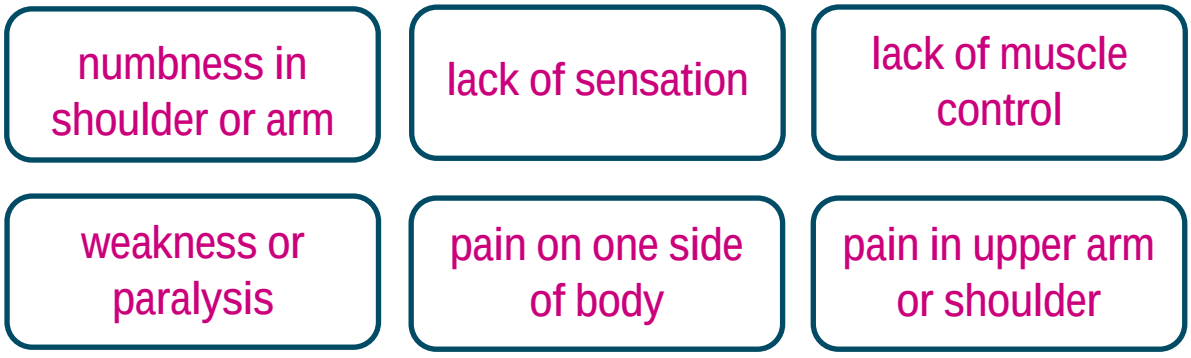
Other acute inflammatory neuropathies

These are not variants of GBS but different diseases. We include them here because they are ‘acute’, meaning starting rapidly within weeks, and caused by nerve inflammation.

Brachial neuritis

Brachial neuritis, also known as neuralgic amyotrophy or Parsonage-Turner syndrome, is a localised severe form of peripheral nerve inflammation causing pain then weakness in one shoulder, arm or hand. It affects 1-2 people per 100,000 per year and occurs unexpectedly. Typically it starts suddenly with sharp, severe pain in one shoulder or arm. The pain improves after a few weeks leaving weakness (and perhaps numbness) in the same place. The muscles become thin.

It affects nerves in the brachial plexus, which is a bundle of nerves in the shoulder travelling between neck and arm. It usually affects just one side, but sometimes affects both arms, or the diaphragm (a breathing muscle) and almost never the legs. The cause is unknown except sometimes it is genetic.



It typically improves slowly over 1-2 years but may leave some permanent weakness. It usually never happens again.

How is brachial neuritis diagnosed?

Brachial neuritis is difficult to diagnose early because the pain is often thought to be a shoulder joint injury or nerve compression. It is diagnosed by neurological examination, usually supported by an EMG test. An MRI may be needed to rule out other conditions. Your GP may refer you to a hospital specialist.

Treatment

There is no proven treatment. Painkillers are usually needed. Corticosteroids may be given if it is diagnosed early, but probably don’t help after the pain has gone. Physiotherapy often helps. Over time, brachial neuritis will improve on its own.

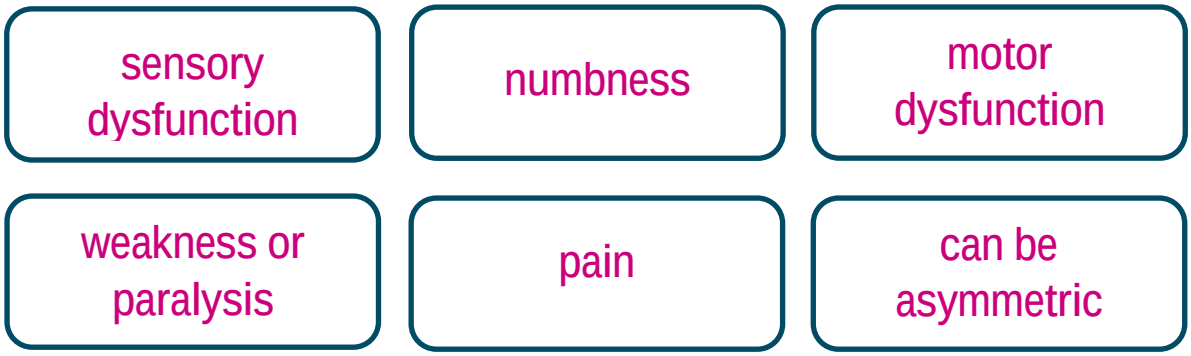
Vasculitic Neuropathy

Vasculitis is a disease causing inflammation of blood vessels. This may block the flow of blood which carries oxygen, leading to damage. It can affect any organ in the body,

often the kidneys, lungs, heart, bowel, skin, and sometimes the peripheral nerves, called vasculitic neuropathy. This may happen with or without vasculitis in other organs.

What are the symptoms of vasculitic neuropathy?

Vasculitic neuropathy develops more slowly than GBS and is usually less severe. Classically there is pain, numbness and weakness in one hand or foot, which starts suddenly and persists. Then over the next few weeks or months a similar problem happens in other parts of the body, known as 'mononeuritis multiplex'. These areas can merge so it affects both feet and hands. It may cause a floppy foot ('footdrop'). Symptoms are variable but often include:



Unlike most other peripheral neuropathies, vasculitic neuropathy can be very asymmetric and affect one limb more than the others. Over time, the main problems are usually unsteadiness walking, pain and clumsy hands.

How is vasculitic neuropathy diagnosed?

Blood tests usually show markers of inflammation or antibodies. Vasculitis may be diagnosed in another part of the body. Nerve conduction tests (EMG) can show neuropathy. Some people need a biopsy of nerve or muscle.

Treatment

The inflammation is usually suppressed by a combination of corticosteroids and strong immunosuppressive treatment such as cyclophosphamide, methotrexate and/or azathioprine. Treatment may be led by a rheumatologist, or kidney specialist. Nerve pain can be treated with medications such as amitriptyline, gabapentin, duloxetine or other medications originally developed for treating depression or epilepsy.

Sources of support

For more information about vasculitis contact one of the following charities:

Vasculitis UK	www.vasculitis.org.uk
Versus Arthritis	www.versusarthritis.org
British Lung Foundation	www.blf.org

Possible triggers

About two thirds of people who develop GBS had an infection within the preceding six weeks. Usually this is a fever, chest infection, or flu-like illness without detecting a specific infecting organism.

If a specific infection is found, the most common is Campylobacter bacteria which causes severe diarrhoea, typically caught by food poisoning such as from eating under-cooked chicken. Other specific infections that are proven sometimes to trigger GBS include: influenza, Haemophilus influenzae, mycoplasma pneumoniae, hepatitis A, hepatitis E, cytomegalovirus (CMV), glandular fever (Epstein-Barr virus), and Zika. Most of these just cause mild flu-like symptoms or a chest infection.

Most people who catch these infections don't develop GBS. GBS only happens rarely if the infection triggers a sort of allergic reaction of the immune system against a person's nerves. After Campylobacter infection the risk of developing GBS is under 1 in 1,000.

GBS is sometimes trigged by major surgery including transplant surgery. Rarely GBS is triggered by certain biological drugs used for treating cancer or other diseases. Sometimes, no trigger or infection can be identified.

How is GBS diagnosed?

GBS can be difficult to diagnose because several other conditions can cause similar symptoms. Your GP will refer you to hospital if they think you might have it or they are not sure what is causing your symptoms.

Examination

A GP or specialist may

- ask about your symptoms, such as when they started and whether they're getting worse.
- examine your hands, feet or limbs to check for weakness or numbness
- ask if you've recently been ill, as GBS may follow an infection
- ask about risk factors or symptoms of other conditions such as toxins, alcohol, tick bites, diabetes, family history, etc.
- check your reflexes, such as whether your leg twitches when your knee is tapped, as people with GBS usually have absent or reduced reflexes.

Nerve Tests (EMG, neurophysiology)

To measure how your nerves are working, a specialist clinical neurophysiologist usually does these two tests at the same time.

- nerve conduction studies (NCS) – mild electric shocks are given through the skin to activate the nerves and measure the signals travelling along your arms and legs.
- electromyogram (EMG) – tiny needles are inserted into several muscles to record their electrical activity. This can show if there is damage to the axons.

Lumbar Puncture

A lumbar puncture is a procedure to remove some fluid from around the spinal cord (the nerves running up the spine), known as cerebro-spinal fluid (CSF). It involves lying on one side and having a needle inserted into the base of the spine under local anesthetic.

The CSF usually has a raised protein level in GBS. The CSF may also show signs of other conditions with similar symptoms to GBS, such as an infection.

Occasionally the diagnosis may not be clear even after the tests, or it may take time to arrange the tests. The diagnosis usually becomes more obvious with time.

Treatment

Treatment for GBS can help improve the symptoms and speed up recovery. Most people need to stay in hospital for a few weeks to a few months. Usually either intravenous immunoglobulin (IVIg) or plasma exchange is given if the person cannot walk unaided, or if symptoms are worsening rapidly. Milder cases of GBS usually improve without these treatments.

Intravenous immunoglobulin (IVIg)

The most commonly used treatment for Guillain-Barré syndrome is intravenous immunoglobulin (IVIg). Immunoglobulin is made from donated blood that contains healthy antibodies which can help stop the harmful antibodies damaging your nerves. IVIg is given intravenously, which means directly into a vein, over a period of five days, and is most effective if given in the first two weeks following onset.

Plasma exchange (plasmapheresis)

Plasma exchange, also called plasmapheresis, is sometimes used instead of IVIg. This involves being attached to a machine that removes blood from a vein and filters out the harmful antibodies that are attacking your nerves before returning the blood to your body. This is also usually delivered over a period of five days, and is considered most effective during the first four weeks following onset.

Both IVIg and plasma exchange are considered to be equally effective and on average lead to earlier recovery than if left untreated. Unfortunately these treatments do not work for everyone. There are currently no other treatments with proven efficacy for GBS.

Specific patient groups

Patients with pure MFS tend to be more mildly affected than GBS, and most recover completely without treatment within a few months. Therefore, in pure MFS treatment is generally not recommended, but patients should be monitored and a subgroup may need treatment if they develop significant weakness (considered to be GBS-MFS overlap) or BBE.

Pregnant women

Either IVIg or plasma exchange may be given during pregnancy if required. IVIg may be preferred.

Other treatments

While in hospital, you'll be closely monitored to check for any problems with your lungs, heart or other body functions. You may also be given treatment to relieve your symptoms and reduce the risk of further problems. This may include:

- a ventilator if you're having difficulty breathing
- a feeding tube through your nose if you have swallowing problems
- painkillers if you're in pain
- being gently moved around on a regular basis to avoid bed sores and keep your joints healthy
- a thin tube called a catheter in your urethra (the tube that carries urine out of the body) if you have difficulty peeing
- laxatives if you have constipation
- heparin injections to prevent blood clots
- physiotherapy to help you learn to move again and build up your strength

Intensive Care Unit (ICU)

Advice for friends and family

Intensive care is a unit within hospitals, staffed by medical support personnel who are specially trained in the high levels of care required. This is also known as ITU (Intensive Therapy Unit). Patients are constantly monitored, day and night, and everything is done to ensure that they receive the highest level of care possible. The amount of equipment may seem a bit daunting at first, but you will soon become familiar with all the machinery.

Admission to ICU is particularly recommended for patients who are experiencing problems with their breathing, swallowing or coughing muscles. Around 20% of GBS patients are admitted to ICU.

Equipment that may be used on an ICU includes:

- ventilator – a machine that helps with breathing by pumping air in and out while they are temporarily unable to breath unaided.
- breathing tube - placed in the mouth, nose, or through a small cut in the throat (tracheostomy) which makes it more comfortable if ventilation is likely to be needed for longer than a week. This cut will heal up when the person can breathe again for themselves. The inflatable cuff around the bottom of this tube stops fluid and secretions from slipping down the throat into the lung and causing infection.

- monitoring equipment – used to measure important bodily functions, such as heart rate (ECG), blood pressure and the level of oxygen in the blood.
- IV lines and pumps – tubes inserted into a vein (intravenously, iv) to provide fluids, nutrition and medication
- feeding tube, placed through the nose down into the stomach (nasogastric tube, NGT) or sometimes through a small cut made in the tummy (gastrostomy, PEG) if a person is unable to eat normally
- catheter – a think tube to drain urine from the bladder
- drain - tube used to remove any build-up of blood or fluid from the body

Airways and lungs will be kept clear by suctioning when required. This makes the person feel much more comfortable, but is noisy, and visitors may prefer to leave until it is completed.

If this all sounds a bit frightening, just remember that these procedures are all regularly used in ICUs and are essential for the person's wellbeing. These tubes and procedures will stop as soon as they are no longer needed.

How does a ventilated GBS patient feel?

Some patients in ICU are fully awake, others are awake but partially sedated with medication to help them relax, and others are kept asleep. If awake, they may be alarmed at the new situation and surroundings, so talk to them calmly and explain what is going on.

Senses

They may have reduced or absent sense of taste and smell, and some patients experience visual disturbance. Hearing is unlikely to be affected, and GBS does not affect the brain, so the patient is usually aware of what is going on around them. However, this may be dampened by sedative or painkilling drugs which are often used to make GBS patients more comfortable.

Some patients do experience an increase in skin sensitivity so although contact is important, be aware that rarely even a light touch may cause severe pain which the patient cannot easily communicate to you.

During the severe phase of the illness, GBS patients can feel very hot or cold and might frequently request a fan to be turned on and off.

Movement

GBS is a paralysing condition. The paralysis is temporary but may be extensive, which can be frightening and hard for the patient to accept. Because of the lack of movement, there may be muscle wasting, possibly leading to weight loss. Gentle

physiotherapy, even at the early stages, will help to minimise stiffness of joints and muscles. The nurses will regularly turn the patient to prevent bed sores.

Pain

Pain is common in GBS and may be experienced to a greater or lesser degree at various sites around the body, for which appropriate medication will be given. Pain levels must always be considered when moving the patient and care taken to ensure that all movements are as gentle as possible.

Hallucinations

Hallucinations, unusually vivid daydreams or nightmares are not uncommon for GBS patients when very weak. They may be worsened by sedative or painkilling drugs but can also arise in patients without any drug effects. They are not necessarily frightening, but hallucinations can seem very real, and they may be convinced that these are actual events. Talk to them calmly, using their name, and ask them what is happening, and whether they feel afraid or confused. Explain that they are having a hallucination and that you don't see or hear what they do, but acknowledge their feelings. Tell them you are there, and everything is ok. Gentle patting may help bring them back, and you could try to turn their attention to something they enjoy, by talking about favourite music or a TV programme they like to watch.

Locked-in and feeling vulnerable

Many GBS patients are alert and acutely aware of what is going on. They feel vulnerable, isolated and locked-up inside their own body. They are likely to feel anxious and frustrated and may exhibit irrational or uncharacteristic behaviour. It will be difficult to come to terms with what has happened, so do not be surprised if they are tearful, bad tempered or panicky.

Mentally and emotionally, loss of movement and inability to speak makes a person feel fragile and vulnerable, so be sympathetic and caring whenever you are with them.

What family and friends can do to help

Communication

Understand as much as you can about this condition. If you are the person visiting most frequently, introduce yourself to the doctor in charge of the case and don't be afraid to ask questions. Some doctors are better than others at explaining things, so let them know if you don't understand. Get to know the regular nursing staff and ask for a daily update on progress.

Physiotherapy can start while the patient is still paralysed. Get to know the physio and keep yourself updated on procedure and progress. They can tell you how you can help with exercises between physio sessions.

Talk to the speech therapist about communication aids. If facial muscles aren't paralysed, then lip reading could help. Some people retain finger movement and can write letters in the air or on the palm of the hand. A common method of communication with a patient whose movements are restricted to the eyes and eyelids, is to use a question and answer technique with the patient answering with one blink for 'yes' and two for 'no'. Pointing to the letters on an alphabet board and asking 'Is it on this line? Is this the letter?', will help. If the patient is strong enough, they may be able to point at an alphabet board with a finger or pointer attached to a headband.

A hospital communication book contains lots of words and images useful in a hospital setting and can pre-empt many questions or comments a ventilated patient is likely to make. **GAIN** will send you a free copy on request, that you can leave at the bedside for staff and visitors to use.

Another useful tool is an app developed by David Muir, who was ventilated due to muscular dystrophy and became non-verbal as a result.

The app is called Passy Muir Trachtools and is free to download in your app store for Apple and android devices.

It has several pre-recorded phrases, and allows you to record your own customized words and messages. When you find a communication method that works, make sure you share this with staff and other visitors so they can adopt the same practice.

Mental stimulation

Remember they are socially isolated and will need to be stimulated. Tell them what day it is and talk about what is happening in the outside world. Read extracts from the news and encourage friends and family to send cards and texts about what they are up to. Remember to include them in all conversations, even if they can't respond verbally.

Make use of your tech! Read to them or offer to play an audio book on their smartphone or tablet. Download films, favourite TV shows and music onto their device and watch or listen together if you can, with one earbud each.

Financial worries

Financial concerns may be causing anxiety, especially if the patient is the main wage-earner. Get in touch with the Social Worker at the hospital who will advise on benefits. Alternatively, Citizens' Advice offers free expert advice which you access online, or by phoning your local office. Stay in regular contact with employers and make sure you understand the absence and returning to work processes. There is more information about returning to work later in the booklet.

GAIN may be able to help through our Personal Grants Scheme with travel costs for frequent journeys visiting a family member in hospital.

Comfort

The little things you can do will mean a lot. Do they need a hair wash or a shave? Do nails need manicuring? Can you help by massaging their hands or feet? Eating and drinking while you're visiting might have a negative impact, if they are unable to swallow anything, so make sure you have something before you arrive.

Some patients have pain in the acute stage, others as recovery kicks in, and some have no pain at all. Try to understand what pain they have, if any, and the frequency and type of medication being given to alleviate it.

GBS patients tire easily, may be on sedative drugs and may nap quite frequently. They might not want visitors over and above one or two close family members, especially in the early stages following diagnosis and the start of recovery.

At the end of your visit, make sure you leave them in the best possible frame of mind. Turn off any device that might cause irritation or disturbance and make sure they have what they need or can attract attention if required.

Coming off the ventilator

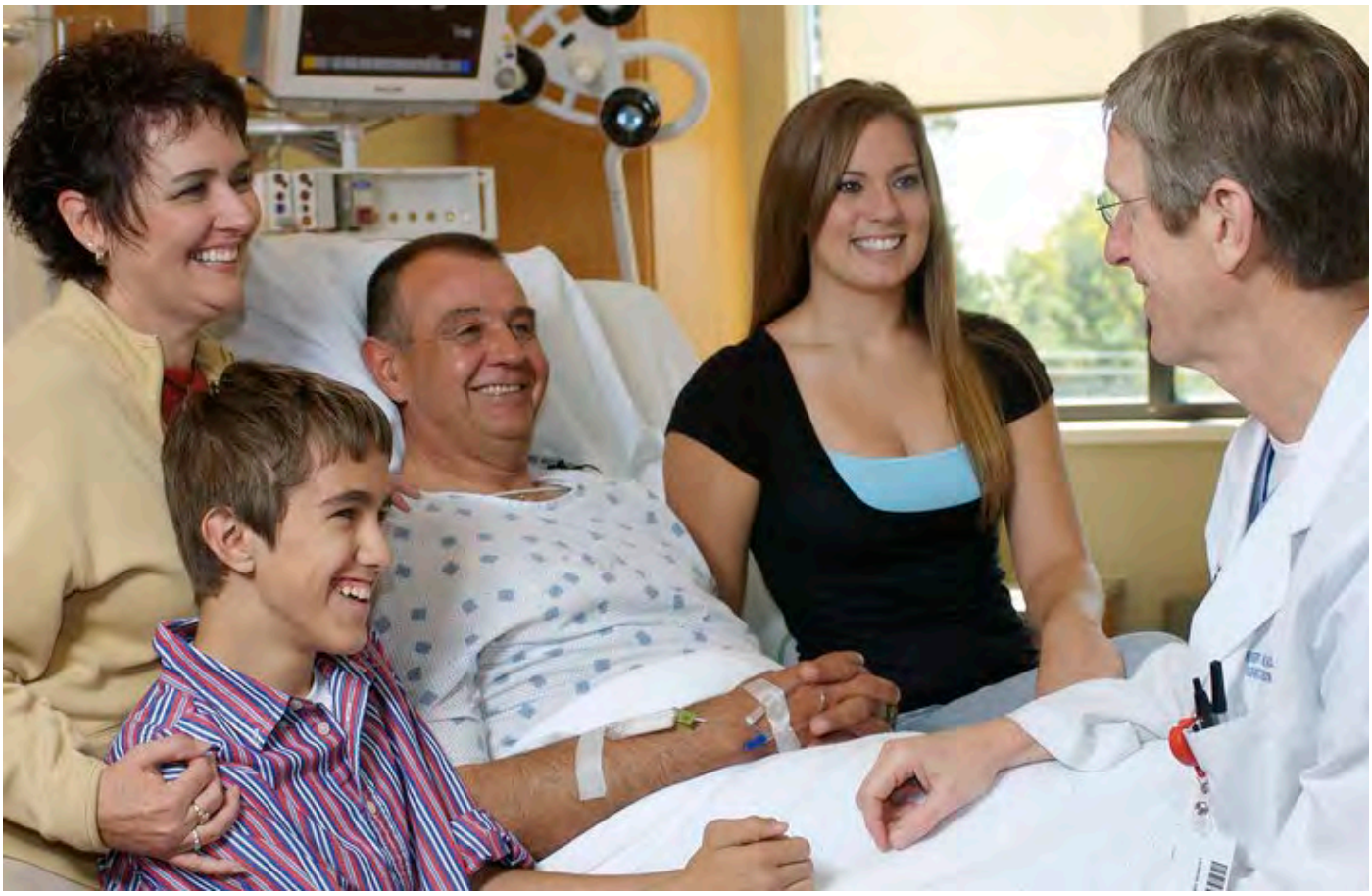
As things improve, they will be taken off the ventilator, often starting with just a few minutes and building up gradually. Patients can get quite panicky at the beginning of this procedure as they have become reliant on the ventilator and might not believe

that they can breathe again without it. Reassure them that their natural ability to breathe is returning and that this is the start of getting well.

Once off the ventilator, it is likely that they will soon be transferred to a general ward for a time before moving into a rehab unit or being discharged home. Moving out of ICU, where patients are monitored continuously, can be stressful in itself, but it's all part of recovery, and no one will be moved until the medical team is satisfied that they are ready.

Stay positive

Your role is to offer love, comfort and reassurance during this difficult period. Try to remain calm and positive and give lots of encouragement on progress. Keep yourself well informed by the medical staff. Writing a few lines each day in a journal will help you keep a perspective on progress. You can share this over the coming weeks to show how far they've come since those early days. For close family, this period of the illness can be an exhausting time of stress, uncertainty and disruption, as you struggle to maintain other commitments alongside frequent hospital visits, so don't forget to look after yourself and stay well. If it is difficult for you to visit as frequently as you would like, we might be able to help you keep in touch with a smart tablet. Contact **GAIN** for further details.



Introduce yourself to the doctor in charge of the case and don't be afraid to ask questions.

What happens next

Support and rehabilitation

60-80% of GBS patients can walk independently at 6 months, and the vast majority recover within a year. Of these, some will be discharged straight home without spending time in a rehabilitation unit, but if you need it, support is available to help you recover and adapt to any long-term issues.

Specialists who might support you through rehab:

physiotherapist	will help you with movement issues, re-building muscle, and learning to walk
occupational therapist (OT)	will identify potential problem areas, and work out some solutions
speech and language therapist	will help with communication and swallowing problems
counsellor or psychologist	someone you can discuss your problems with and help you find ways to cope emotionally

Going home

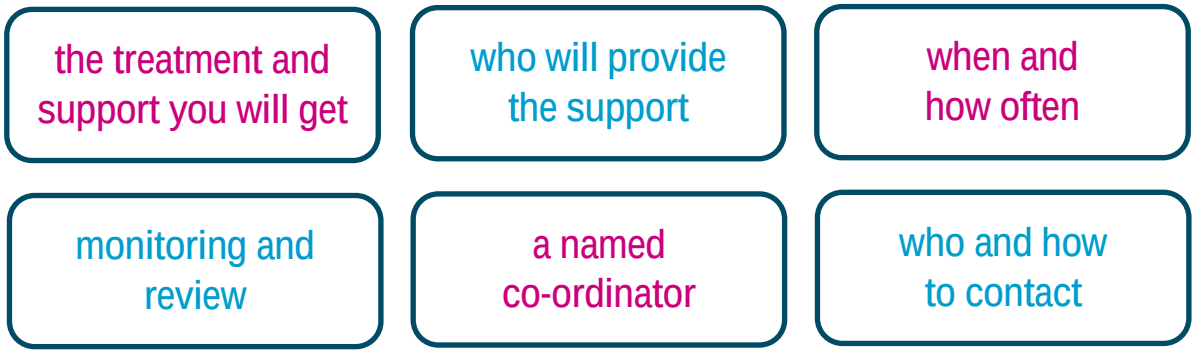
Leaving hospital or a rehabilitation centre and heading home can be daunting and takes a while to arrange. You may need equipment to help with everyday tasks, your home may need adaptations, or you may need a care package in place. There are many people and organisations that can help with this, starting with the occupational therapist and your care team. Your family can also be a great help in getting the information together and speaking to organisations that have in-depth knowledge of what help is available.

Assessment & care plan

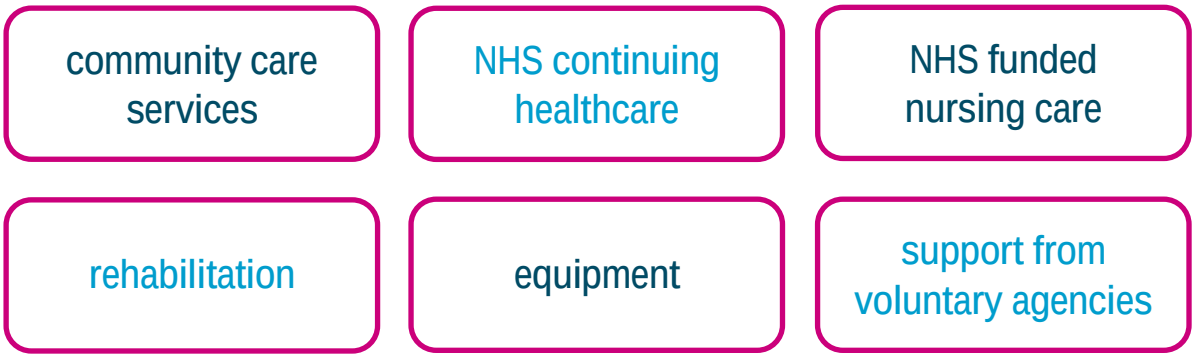
If you are likely to have ongoing health and social care needs you should have an assessment carried out by a multidisciplinary team of health or social care professionals such as a social worker, physiotherapist, occupational therapist,

psychologist or dietician. You, and a family member if appropriate should be involved in this process.

A care plan should include details of:



The type of support that might be in a care plan:



Residual symptoms

It is normal to experience persistent symptoms over the weeks and months after discharge from hospital following GBS. These symptoms vary from patient to patient and include weakness, tingling, aching in the limbs, nerve pain, cramps and extreme tiredness. Balance and co-ordination problems are also not uncommon. It is normal for these symptoms to fluctuate a bit, being worse when you are particularly tired, stressed or affected by illness, such as a cold, sore throat or flu. For most people, they gradually decrease over time, but you may feel some of them coming back in a milder form at periods like that for a year or two. It is very unlikely that this indicates a recurrence of GBS, which is very rare. Unfortunately, around 15% of people will not make a good recovery, and will experience permanent mobility and dexterity problems, perhaps remaining dependent on a wheelchair or other mobility aid. Persistent pain and fatigue may also be an ongoing issue that needs to be managed.

Preventative measures

Nothing can be done to alter the very small risk of a recurrence of GBS. Since GBS can be triggered by an infection, you might think it desirable to avoid all possible exposure to infections. As observed during the COVID-19 lockdown in 2020, this may

be possible, but involves sacrificing normal life to a degree that is neither practical nor desirable. Having had GBS does not increase the probability that you will get it again.

Hospital follow-up

There is a wide range of different practice regarding hospital follow-up visits. Unless you are taking medicines for other conditions, or unless you are being prescribed medicines for pain or complications, it is unlikely you will need to attend hospital as an outpatient following discharge. The person you are likely to need to see is a community physiotherapist, rather than a neurologist. Some neurologists may ask you back for a follow-up appointment to see how your recovery is going, but most do not, because you no longer have an ongoing neurological condition and their role in your treatment has come to an end.

Physiotherapy after discharge

If you have difficulty accessing physiotherapy, but feel it would benefit you, or if you find yourself on a lengthy waiting list, please contact **GAIN** for access to our online physio videos free of charge.

Hygiene and cleanliness

Personal cleanliness for those who are unable to attend themselves fully can be a problem. Many returning home from hospital may have reduced use of their hands, usually temporarily, but sometimes permanently. Many will be unable to wash themselves, brush their hair, use the toilet independently, brush their teeth, cut their nails etc. It is important for both hygiene and self-esteem that these matters are attended to by a carer.

Teeth

Through no fault of their own, many people's teeth are neglected during periods of serious illness. Once you have returned home, arrange an appointment with your dentist as soon as possible. If you have difficulty attending a dental practice, enquire about community dental services. Using an electric toothbrush can be helpful if you have residual weakness in your hands. More advice can be found on the British Society for Disability and Oral Health website; https://www.bsdh.org/index.php/how-to-find-a-special-care-dentist

Financial help

Once you leave hospital, you could be entitled to benefits to help you support yourself. The benefits system is complex and subject to change, but Citizen's Advice has up-to-date information on their website and they can even help you make an application for benefits such as Personal Independence Payment (PIP) or Universal Credit: https://www.citizensadvice.org.uk/

Further information on benefits can be found at https://www.gov.uk/browse/benefits

If adaptations to your home are needed, such as installing a ramp or downstairs bathroom for example, it is worth contacting your local council to see if you are entitled to help via a Disabled Facilities Grant:

England and Wales:
https://www.gov.uk/apply-disabled-facilities-grant
Scotland:
http://www.disabilityscot.org.uk/info-guides/disabled-home-adaptations-1/
Northern Ireland:
https://www.nidirect.gov.uk/articles/disabled-facilities-grants-0
Republic of Ireland:
https://www.citizensinformation.ie/en/housing/housing_grants_and_schemes/housing_adaptation_grant_for_people_with_disability.html

If you are on a low income, or someone in your household is severely and permanently disabled, you may be entitled to a reduction in Council Tax. Further information is available in the Carers UK Council Tax factsheet:
https://www.carersuk.org/images//Factsheets/2020-21_factsheets/Council_Tax_April_2020-21.pdf

Diet

During illness, nutritional needs are at their peak, but it is not unusual for patients to lose their appetites or taste for food. Worry and fear often accompany illness and can also contribute to loss of appetite. Good nutrition can be a powerful ally in the process of recovery, so if you need advice, ask to speak to a nutritionist. If taste has been affected, this will usually improve with time. Plastic utensils can be used if bitter or metallic tastes are experienced whilst eating. Sometimes taste changes can be related to medications, but drugs should not be discontinued without first consulting your GP. Try to eat a healthy, balanced diet and keep consumption of sugary and processed foods, and drinks that are high in caffeine or alcohol to a minimum. There is some excellent advice on nutrition on the NHS website; https://www.nhs.uk/live-well/eat-well/

Your immune system

Although caused by your immune system malfunctioning, GBS does not weaken or damage your immune system, and having had GBS does not mean that your immune system is compromised. However, many people feel a bit rundown when they're recovering from a lengthy illness, and you may be more prone to pick up colds and other bugs until you're back to full fitness. Regular exercise and maintaining a healthy diet and sleep regime will all help during recovery. There is anecdotal evidence, and lots of hype surrounding supplements and alternative remedies, but very few are

known to have real benefits. Most people are able to get the vitamins they need from their diet, but if you wish to take dietary supplements, your doctor (rather than Google!) will be able to advise you on anything that may help you during recovery.

Exercise and rest

During the recovery stages, physiotherapy, occupational therapy (OT) and speech and language therapy play a vital role in the rehabilitation process as well as maximizing functional ability. At some point during rehabilitation the rate of recovery will plateau, and it is often at this point that patients will be discharged from all the support services on which they may have relied. It is also possible that patients may be placed 'on review'. This means that you may be followed up at regular intervals and can telephone for advice in-between but don't attend the clinic as often as you did before.

The role of exercise in the ongoing rehabilitation for patients with GBS is still to some extent unclear and clinical trials are being carried out to improve our understanding. However, there is evidence that where weakness and fatigue are problems, participation in regular graded exercise can be beneficial.

Exercise can help to improve your muscle strength and reduce your overall sense of fatigue. It can also aid sleep and support mood through the production of endorphins. Other benefits include helping your heart and lungs remain healthy and making you feel more positive about yourself. However, it may take weeks or even months before you feel some of the benefits, so it is important to pace yourself. You will find lots of exercises online, including seated exercises, or you could ask your GP or physiotherapist about how to start regular exercise and what exercises might be right for you. Recovery from GBS is not a race, and you also need to get plenty of rest, but try to avoid napping and develop instead a regular sleep pattern.

Visit the NHS website for advice on exercise: https://www.nhs.uk/live-well/exercise/ and also for advice on sleep: https://www.nhs.uk/live-well/sleep-and-tiredness/

Pain

Some people do not experience pain, but even if they had none during the active phase of the syndrome, it may occur during the recovery phase. The problem tends to resolve as recovery proceeds, but it can become an ongoing issue.

Being in pain naturally impacts on mood and the ability to cope with everyday situations. Your family and friends might expect you to be 'back to normal' once you are discharged from hospital, not realising that in many cases, there is still a very long way to go in terms of recovery. It is important to talk to your family and friends about this, so that they understand what you are going through and why you might be irritable and difficult to live with at times. Some other sources of support are shown overleaf.

Other sources of support	PAIN
Pain Concern	https://painconcern.org.uk/
British Pain Society	https://www.britishpainsociety.org/
Pain Association Scotland	https://painassociation.co.uk/
Welsh Pain Society	https://www.welshpainsociety.org.uk/
Pain Relief Foundation	https://painrelieffoundation.org.uk/
Pain Management NI	https://www.myni.life/pain-management
Pain Relief Ireland	https://painreliefireland.ie/

Mental health & wellbeing

With all the changes in your health it is not uncommon to feel anxious or angry. An acute stress reaction is recognised as being a normal part of the process of adjusting to a life change, and it can often help to talk things through with a partner or close friend. However, please seek advice and help from your GP if you are finding it difficult to cope or to sleep, or if you are feeling overwhelmed emotionally.

The impact of being severely affected by a sudden, frightening and potentially life-changing condition such as GBS can leave people with symptoms of PTSD (post-traumatic stress disorder). It can develop immediately, or many months or even years after a traumatic event.

If you are concerned about low mood, irritability, panic attacks, anxiety, flashbacks, physical sensations such as trembling or sweating, poor concentration or sleeping problems, please talk to your GP about getting some counselling.

Some other sources of support are shown overleaf.

Other sources of support	MENTAL HEALTH
5 steps to mental wellbeing	https://www.nhs.uk/conditions/stress-anxiety-depression/improve-mental-wellbeing/
Mindfulness	https://bemindful.co.uk/
Post-Traumatic Stress Disorder	https://www.nhs.uk/conditions/post-traumatic-stress-disorder-ptsd/
Mental health and wellbeing	https://www.nhs.uk/conditions/stress-anxiety-depression/
MIND	http://www.mind.org.uk/
Young Minds	https://youngminds.org.uk/

Sexual relationships

GBS, CIDP and associated inflammatory neuropathies can bring on problems in any relationship, and sexual relationships are not excluded. Dealing with a long-term illness or disability can put a great strain on a relationship, particularly when one partner is partially or totally dependent on the other. Even without the actual physical disability, the emotional upheaval can interfere with a couple's sex life and this can be difficult to talk about. This can mean that the once close, intimate relationship can become distant and stressful for both partners. Help is available so speak to your GP or a relationship counsellor.

Seasonal flu & COVID19 vaccine

Other sources of support	RELATIONSHIPS
Relate	https://www.relate.org.uk/
Sexual Advice Association	https://sexualadviceassociation.co.uk/

Immunisation

Professor Michael Lunn MA MBBS FRCP PhD, Consultant Neurologist and Professor of Clinical Neurology, National Hospital for Neurology and Neurosurgery, Queen Square, London advises: "One vaccine is not the same as another. The only reason that one advises against flu vaccine in someone with GBS is if they actually had GBS in the 6 week window after a flu vaccine and then only out of an abundance of caution which is not based on any real science. The rate of GBS after flu vaccine in all assessed years after 1976 has been about 1 per million and no study has linked vaccination to recurrence of GBS or CIDP. COVID vaccine is nothing like flu vaccine. COVID doesn't cause GBS in any significant number if at all and there is no reason to suspect the vaccine would cause it."

Most vaccinations do not cause GBS.

The influenza ('flu) vaccine changes every year. In some years this has caused a few cases of GBS, most notably in 1976. The risk remains extremely small. For every one million people who receive an influenza vaccine, only about one case of GBS is caused. In most years, influenza vaccine does not cause GBS at all.

Although some neurologists advise people to avoid vaccinations for 6-12 months after onset of GBS, this is purely precautionary. Several scientific studies have shown very little or no causal link between vaccinations and GBS, concluding that vaccinations do not trigger a recurrence and are as safe for people who have had GBS as for anyone else.

GBS is a one-off condition that is unlikely to happen again. After recovering from GBS, the risk of ever developing GBS again (many years later) is about 1 in 30 (2 – 5%).

If you developed GBS within 6 weeks after a vaccination, you may prefer to avoid **that particular** vaccine in the future, but don't have to avoid other vaccinations.

The risk of triggering GBS from the annual seasonal flu vaccine is far lower than the risk from flu infection.

Most people don't need a flu jab. However, if you are in an at-risk group, or you live or work closely with people for whom flu might be severe or life-threatening, then you should be vaccinated, to protect yourself and others.

Public Health England states in The national influenza immunisation programme 2020 to 2021 that

> *'Previous GBS is not a contraindication to influenza vaccination. A UK study found no association between GBS and influenza vaccines although there was a strong association between GBS and influenza-like illness. A causal relationship between immunisation with influenza vaccine and GBS has not been established.'*

This is further supported by the Medicines & Healthcare products Regulatory Agency (MHRA) which states:

> *'The balance of epidemiological evidence is not sufficient to confirm that currently used influenza vaccines are causally associated with the development of GBS. As GBS also occurs naturally in the vaccinated population, and particularly because flu-like illness is a known risk factor for GBS, a number of cases are reported each year in temporal association with vaccination. This does not mean the vaccine was the cause.*
>
> *Recent data supports the findings made in previous studies that an influenza vaccination may trigger GBS in fewer than 1 in 1,000,000 people vaccinated. There were approximately 14,000,000 people vaccinated in the UK during 2019/20 and there were 11 reports submitted through the yellow card scheme for the same period.*
>
> *These may be true side-effects, or they may be due to concurrent diagnosed or undiagnosed illness, other medicines or they may be purely co-incidental events that would have occurred anyway in the absence of therapy. Based on current evidence, the MHRA findings are that these reports do not indicate a causal relationship between influenza vaccine and GBS.'*

GAIN adds that this is supported by independent research showing colds and flu-like illnesses are triggers for GBS. The seasonal flu vaccination is a very low risk trigger, with approximately 1 case of GBS triggered per 1,000,000 vaccinations compared with 1 case of GBS per 60,000 cases of flu[1].

A large retrospective study[2] entitled *Vaccines and the risk of Guillain-Barré syndrome* was published in 2020. In comparing 1,056 cases of GBS with 4,312 controls, Chen et al found no increased risk of GBS or its recurrence among either children or adults within 180 days following vaccinations of any kind, including influenza vaccination. Therefore, previous case reports of GBS shortly after receiving several other vaccines were probably merely coincidental.

On vaccinations in general, our Medical Advisory Board advises:

- DON'T have a vaccine again which you received within 6 weeks before your GBS started.
- DON'T have unnecessary vaccines for travel but DO have all travel vaccines that are recommended for the particular area you are travelling to.
- DO have all vaccines that are 'necessary'. This includes the flu vaccine (if you are in an at risk group), MMR, DTP, pneumovax, HIF, COVID-19, etc. T**here are monitoring programmes ongoing so a link would be picked up if it occurred. No new links have been detected since the 1970s.**

- COVID-19 is a more serious disease than influenza and more easily caught. Most people with GBS or CIDP should receive any of the COVID-19 vaccines, except perhaps people with a history of severe allergy requiring an Epipen.

Vaccines currently in use are amongst the safest medicines available. However, there is no simple 'yes or no' answer, and each person must weigh up the risks of not having a vaccination against the very small possible risk from having it.

Having relatively mild side effects such as numbness and tingling is quite common following a vaccination, and is almost certainly nothing to be concerned about. If you have had GBS in the past, or if you have an associated chronic neuropathy such as CIDP, a vaccination might cause a slight 'flare-up' of symptoms due to your immune system being stimulated. Most will only last a few days, but if they last longer than this, or if symptoms get worse or start spreading, then I would suggest contacting your GP. There have been no serious neurological side effects reported on the Yellow Card Scheme so far, and no reports of GBS or CIDP have been causally associated with any of the COVID-19 vaccines. Anyone can report side effects of medication or vaccines, regardless of severity, and if you would like to do so, please follow this link; https://coronavirus-yellowcard.mhra.gov.uk/

[1]*Jeffrey C. Kwong, Priya P. Vasa, Michael A. Campitelli, Steven Hawken, Kumanan Wilson, Laura C. Rosella, Therese A. Stukel, Natasha S. Crowcroft, Allison J. McGeer, Lorne Zinman and Shelley L. Deeks The risk of Guillain-Barré Syndrome following seasonal influenza vaccination and influenza healthcare encounters, a self-controlled study. The Lancet Infectious Diseases, Vol. 13, No. 9, p730–731 Published: June 28, 2013*
[2]*Chen, Y., Zhang, J., Chu, X. et al. Vaccines and the risk of Guillain-Barré syndrome. Eur J Epidemiol* ***35,*** *363–370 (2020). https://doi.org/10.1007/s10654-019-00596-1*

Getting back to work

When someone is ready to return to work after an absence, the employer should have a procedure they follow. You can check your workplace's absence policy for this. Your workplace might have a policy for meeting with employees after absences.

After long-term absence

If there's been a long absence or the employee has an ongoing health condition, it's a good idea for the employer and employee to meet and:

- make sure the employee is ready to return to work
- talk about any work updates that happened while they were off
- look at any recommendations from the employee's doctor
- see if they need any support
- if the employee has a disability, see if changes are needed in the workplace to remove or reduce any disadvantages ('reasonable adjustments')
- consider a referral to a medical service such as occupational health
- discuss an employee assistance programme (EAP) if it's available
- agree on a plan that suits you both, for example a phased return to work

Making reasonable adjustments

If an employee has a disability, by law their employer must consider making 'reasonable adjustments' if needed to help them return to work.

Reasonable adjustments could include making changes to the employee's:

- workstation or working equipment
- working hours
- duties or tasks

This can help:

- get people back to work quicker
- prevent any further problems

For the best course of action, the employer should take advice from:

- the employee themself
- the employee's doctor
- their occupational health adviser

Phased return to work

A 'phased return to work' is when someone who's been absent might need to come back to work on:

- reduced hours
- lighter duties
- different duties

For example, after a:

- long-term illness
- serious injury
- bereavement

The employer or their HR manager and the employee should agree on a plan for how long this will be for.

For example, they could agree to review how things are going after a month and then decide to increase the working hours or duties, or they might decide they need to stay reduced for longer.

The employer or HR manager should continue to regularly review the employee's health and wellbeing in the workplace and make new adjustments if necessary.

Pay during a phased return to work

If the employee returns to their normal duties but on reduced hours, they should get their normal rate of pay for those hours they work.

For the time they're not able to work, they should get sick pay if they're entitled to it.

If the employee is doing lighter duties, it's up to the employer and employee to agree on a rate of pay. It’s a good idea to make sure this agreement is put in writing.

This information is provided by ACAS (the Advisory, Conciliation and Arbitration Service).

Further information regarding absence and returning to work is available on the ACAS website:

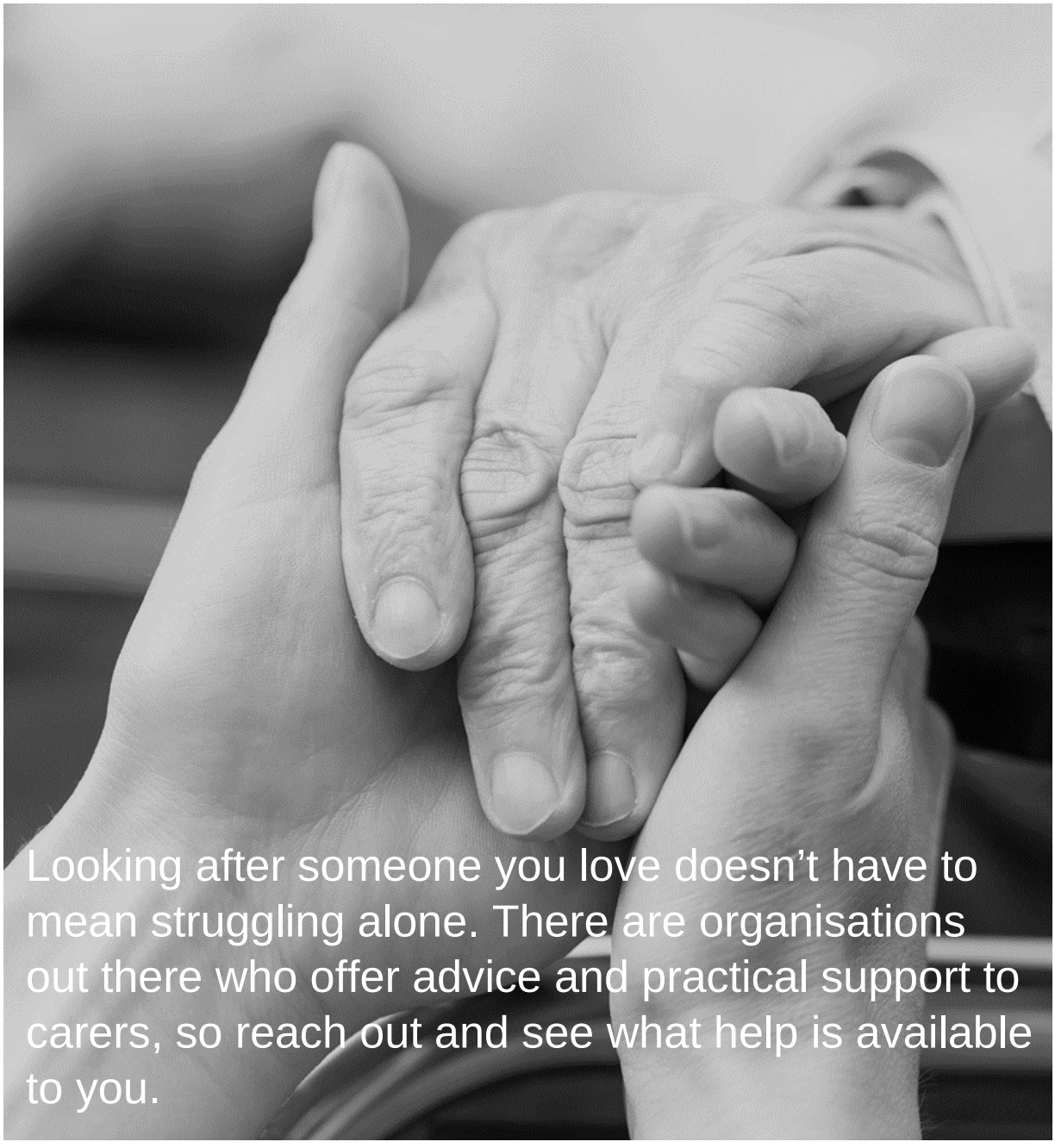
https://www.acas.org.uk/absence-from-work

Advice for carers

Hospital discharge can bring mixed emotions. Of course you’re glad to have your family member home, but it is quite normal to feel a bit daunted by what lies ahead, especially if you are now the main carer. Here are a few practical suggestions that can help you in your new role. Other sources of support are listed overleaf.

Ask for a needs assessment for the person you’re caring for	You need this before the council can recommend services such as equipment, home adaptations, help from a paid carer, etc (see table overleaf)
Get a carer’s assessment	This can be requested at the same time as a needs assessment, via social services at your local council (see table overleaf)
Don’t be afraid to ask for help	Ask family and friends (shopping, respite, etc), and contact carers’ organisations or Citizens Advice for benefits advice and other support (see table overleaf)
Look after yourself	Eat a healthy diet, maintain a regular sleep pattern and make time for exercise, preferably in the fresh air or at your local gym or pool, away from the care setting
Remember to rest	Put some activities on hold. Take some time for yourself by arranging respite care from a friend or relative, or through social services
Recognise limitations	Both those of the person you’re caring for and your own. Let them try to do things for themselves if they are able, but bear in mind their safety and yours
Look after your mental health	Talk to each other about your experiences and frustrations during illness and recovery. Talk to your GP if either of you is struggling

Be mindful of risks	Be aware of temperature (cooker, iron, hot bath water, hot drinks), risk of falls due to poor balance, and dropping or spilling things due to weakness
Diet & exercise	If appetite and taste are affected, ask about vitamin supplements to help maintain dietary needs. Ask the community physio about exercises to do between visits
Don't lose sight of your relationship	Whatever your relationship is to the person you're caring for, make time for it. Do things together that you both enjoy and that feel 'normal'
Get in touch with GAIN	We provide information and support, organise peer support via phone or video link, virtual group chats, and run an active and supportive Facebook group



Other sources of support	CARERS
NHS advice	https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/
Carers UK	https://www.carersuk.org/
Carers Scotland	https://www.carersuk.org/scotland
Carers Wales	https://www.carersuk.org/wales
Carers Northern Ireland	https://www.carersuk.org/northernireland
Family Carers Ireland	https://familycarers.ie/
Carers Trust	https://carers.org/
Help for young carers	https://youngminds.org.uk/find-help/looking-after-yourself/young-carers/
Citizens Advice UK	https://www.citizensadvice.org.uk/
Citizens Information RoI	https://www.citizensinformation.ie/en/
Find your local social services	England https://www.nhs.uk/service-search/other-services/ Scotland https://www.mygov.scot/find-your-local-council/ Wales https://111.wales.nhs.uk/localservices/ Northern Ireland http://online.hscni.net/social-services/ Republic of Ireland https://www.hse.ie/eng/services/list/4/

My child has been diagnosed with Guillain-Barré syndrome

Although more common in adults, Guillain-Barré syndrome can affect anyone of any age. The encouraging news is that children tend to be less severely affected than adults, and in most cases make a very good recovery. Even so, it is distressing for any parent to see their child debilitated by illness, and we hope that knowing a little bit about what to expect may help, especially in the early stages following diagnosis. Don't forget your child needs to be told what is happening and will be reassured by familiar faces and voices.

If you would like to talk to another parent of a child affected by GBS, please contact **GAIN**, and we will arrange contact with one of our support volunteers.

How is your child's condition managed?

Diagnosis, treatment and recovery will follow a similar path for children as for adults, and are covered elsewhere in this booklet. Paediatric services tend to be very self-contained, and you will have access to support that you would not experience in an adult setting. The following information is specific to differences between adult and paediatric services.

It is important your child is treated in a centre familiar with GBS and with intensive care facilities should they be required, so they 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.

People likely to be involved in your child's care:

- you, your child and your family
- paediatric nurses and nurse practitioners, doctors and neurologists
- paediatric intensive care nurses and doctors
- neurophysiologist, who does the nerve 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

Other staff you may meet could include dietician, health care assistants, family liaison nurses, play specialists, chaplains and interpreters.

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

Even if they can't respond verbally, your child will be conscious (unless placed in an induced coma for a time to reduce stress and anxiety) and can hear what is being said. Talk about things that matter to your child (a pet, the football results, family events, messages from friends, etc). Bring a favourite soft toy for them to cuddle. Your child may become extremely frustrated especially if he or she cannot speak. Try to work out ways of communicating, such as picture cards that they can respond to by touch, blinking or pointing with their eyes or pointer on a headband. Ask the paediatric team for support in communicating with your child if they are non-verbal.

Rehabilitation and outcome

The majority of children make a full recovery from Guillain-Barré syndrome without any lasting signs of having had the condition, but a small number may have some persisting problems, such as weakness of the hand and foot muscles. Most recovery is seen in the first six to twelve months, but gradual improvements can continue for five years and beyond.

Keep in touch with school, and once your child is on the road to recovery, ask their teachers for any resources they can access to help them catch up with what they would have been doing at school.

Going home

Although recovery can be a long and drawn-out process, 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 tell you how to access any specialised equipment that might be needed.

Hydrotherapy and swimming can be very beneficial, as the water is weight-bearing allowing freer movement. Consider going for a family bike ride once your child is strong enough, and even look at an activity such as horse-riding, as this can help with balance as well as the psychological benefits associated with being around animals (contact 'Riding for the Disabled', https://www.rda.org.uk/). Exercise is much easier when children are engaged, so it helps a lot if it is something fun and enjoyable. Since children are usually very active and move around without thinking, observing what they do naturally is a good indicator of their capabilities.

Your child may feel the cold and get tired more easily, or they may lose their appetite or complain of things tasting different. The trauma of GBS may also have an effect on their mood or behaviour. They may become frustrated, angry and upset at not being able to do everything that their friends can, and that they could do before. All of this is normal. It is important to listen to them, understand what they are feeling, and try to find things that will help. Be patient. These problems are temporary and will improve with time, but talk to your GP if you are concerned and feel further support is needed.

Back to school

Thousands of children live with health issues that involve long periods of absence from school. At some stage, these children will face the unenviable task of going back to school and reintegrating into their former class and its usual daily routines. Catching up with work and friendships can often be difficult, but a good school will do all it can to ease your child's passage back into school life.

Returning to school: catching up with work

When your child is ready to return to school, the thought of catching up on weeks of missed work can be daunting. But, says Lesley Black, special educational needs (SEN) advisor at the charity Contact a Family, 'no school will want to overwhelm a child who has been unwell or dealing with difficult circumstances by expecting them to do extra homework or catch up on work during playtimes.'

Schools may prioritise catching up with work in maths and English – the core subjects – over other subjects. It's quite common for schools to have small groups of children who need support with numeracy or literacy, and children who've been away from school will often slot into one of these. They may be given extra one-to-one help by a teaching assistant (TA) to help them catch up.

If you want to give your child a boost at home, speak to their teacher about how you can best help, such as games-based learning activities online that consolidate maths and English skills, or practical things you can do like reading aloud and cooking together. However, be aware that if your child has been ill they might find the school day very tiring, and may not be up to doing much homework.

Returning to school: fitting back in

Despite the fact that schools are under increasing pressure to ensure children achieve, your child's school is likely to be far more concerned about their wellbeing as they return to school. Your school should help your child to keep in touch with their classmates while they're absent, for example through visits, emails, letters or video calls. They also have a duty to help your child reintegrate once they're well enough for school.

Your child may feel awkward if they're bombarded with questions about why they've been away. Sometimes, they're so reluctant to draw attention to themselves that they put up with discomfort or distress rather than asking a teacher for help. Some children, however, are happier with everything out in the open and even like to stand up in front of the class to explain what's been happening. If your child has a specialist nurse or a social worker, they may be happy to visit the class, either with or without your child, to answer their classmates' questions.

‘It’s important that schools are sensitive about your child’s needs when they’re considering what information to share with their classmates and the wider school community, and that they make sure your child has someone they can ask for help,’ Lesley says. ‘This could be a school counsellor or the special educational needs co-ordinator (SENCO) rather than their class teacher.’

Returning to school: the Individual Healthcare Plan

A key part of your child’s return to school after illness may be the creation of an Individual Healthcare Plan. This is a formal document that sets out things like:

- What their condition is
- What medication they take
- Who, in the school community, can administer their medication
- What to do in an emergency
- Arrangements that need to be made to enable your child to attend school, such as a quiet rest area

‘You and your child should be central in drawing up the individual healthcare plan,’ says Lesley. Other people involved in your child’s care may also be involved, such as their GP, paediatrician or specialist nurse. The plan will identify if anyone needs to be given special training to administer medication or otherwise help care for your child at school. If so, someone from your child’s medical team is likely to arrange this.The plan should be reviewed regularly, and at least once a year.

Depending on the level of recovery or any residual disability, it may be necessary for your child to return to school in a wheelchair, and school facilities should be checked to make they are suitable for your child’s needs. 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.

This information has been adapted from TheSchoolRun: an online resource for parents of children at primary school:
https://www.theschoolrun.com/catching-up-at-school-after-absence

More detailed information is published online by Contact a Family:
https://contact.org.uk/advice-and-support/education-learning/attendance-absence-medical-needs/help-at-school-if-your-child-has-medical-needs/

CIDP

CIDP, or chronic inflammatory demyelinating poly-radiculo-neuropathy, causes similar inflammation in the nerves to GBS, but is milder and longer-lasting. ‘Chronic’ means ‘lasting a long time’. Although fewer people are newly diagnosed with CIDP each year (around 3 people per 1,000,000) than with GBS, the prevalence, or number of people living with the condition at any one time, is around 5-7 per 100,000. Like GBS, CIDP is an autoimmune disease of the peripheral nerves, and symptoms experienced by patients with both conditions can be similar, usually the symptoms of CIDP start more slowly.

CIDP is distinguished from GBS by timing. In GBS the worst point is reached within four weeks although may happen within a few days. By definition, CIDP continues to worsen more than eight weeks after onset. CIDP usually develops slowly over months, but sometimes a person initially diagnosed as GBS is later reclassified as ‘acute-onset CIDP’, because deterioration continues over an extended period, or several relapses occur after a period of improvement. In a large research study of patients initially diagnosed as GBS, 5% developed CIDP, and another 9% had a brief early relapse of GBS (‘treatment-related fluctuation’) but did not develop CIDP.

Occasionally, a patient who has recovered from GBS may develop GBS again many years later. This ‘recurrent GBS’ happens to around 3% of people with GBS. Sometimes a suspected recurrence of GBS is actually a relapsing-remitting form of CIDP.

If you wish to know more about CIDP and the chronic variants, please visit our website or see our information booklet of the same name.

Contact GAIN if you or a member of your family has received a diagnosis of:

ACUTE

GBS Guillain-Barré syndrome, also known as

AIDP Acute Inflammatory Demyelinating Polyneuropathy

MFS Miller Fisher syndrome

AMAN Acute Motor Axonal Neuropathy also known as **Axonal GBS**

AMSAN Acute Motor Sensory Axonal Neuropathy

BBE Bickerstaff's Brainstem Encephalitis

Brachial Neuritis also known as **Neuralgic Amyotrophy**

SIDP Sub-acute Inflammatory Demyelinating Polyneuropathy

CHRONIC

CIDP Chronic Inflammatory Demyelinating Polyneuropathy

A-CIDP Acute-onset CIDP

CMFS Chronic Miller Fisher syndrome

CANOMAD Chronic Ataxic Neuropathy with Ophthalmoplegia, IgM Monoclonal gammopathy, cold Agglutinins and Disialoganglioside antibodies

DADS Distal Acquired Demyelinating Symmetric neuropathy

MMN/CB Multifocal Motor Neuropathy/with conduction block

MADSAM Multifocal Acquired Demyelinating Sensory and Motorneuropathy also known as **Lewis-Sumner syndrome**

PDN IgM Paraproteinaenemic Demyelinating Neuropathy

sometimes described as CIDP with **Paraproteinemia**

POEMS Polyneuropathy, Organomegaly, Edema/Endocrinopathy, Monoclonal gammopathy and Skin changes syndrome

Sensory Neuronopathy also known as **Sensory Ganglionopathy**