

GUIDE

The Guillain-Barré Syndrome Patient in Intensive Care

This series of guides is produced by the Guillain-Barré Syndrome Support Group. We are a registered charity that supports those affected by the Guillain-Barré syndrome (GBS) and related conditions in the United Kingdom and the Republic of Ireland. The related conditions include chronic inflammatory demyelinating polyradiculoneuropathy (CIDP) and Miller Fisher syndrome (MFS).

Our guides are easily downloaded from our Web site at www.gbs.org.uk in PDF format and may be both read and printed using free Adobe Reader software. Alternatively, you can request printed copies from our office.

For information and support, ring our helpline on 0800 374 803

In the Republic of Ireland, call 0044 1529 415278

Introduction

Around a quarter of GBS sufferers are admitted to intensive care units (ICUs, sometimes called intensive therapy units or ITUs) for special care if their illness is judged severe or moderately severe. Admission to ICU is particularly recommended for patients with weakness of their breathing, swallowing or coughing muscles. A machine called a ventilator will be introduced to take over their breathing function and to stop fluid and secretions from slipping down the throat into the lungs where infection and lung damage may arise. It is principally for the family and friends of this category of GBS patient that this information guide has been produced.

It is important that you read this guide in conjunction with the GBS Support Group's guide *Guillain-Barré Syndrome*. This explains the illness in easily understood language. It will do much to relieve your worries. If no copy of the publication is available to you, please contact the Group by the Helpline number above or visit our Web site at www.gbs.org.uk.

What is an intensive care unit?

This is a special unit within hospitals, staffed by medical support personnel who are specially trained in the high levels of care required by each patient.

There is nothing sinister or depressing about these units. On the contrary, they are busy and cheerful places where patients are under constant watch, day and night, and everything is done to ensure that the patient receives the highest level of care possible. At first sight, there appears to be a daunting amount of equipment at the bedside, but you will be surprised how soon you and your affected relative or friend can come to understand the function of each piece of machinery

Why has the GBS patient been admitted to the ICU?

The patient's breathing needs to be supported. This is done by attachment to a ventilator: a sophisticated machine which will simulate the patient's own breathing requirement while he/she is temporarily unable to breath unaided. This may be done via the nose or mouth in the shorter term, or for those patients who are likely to require ventilation for more than a short period, then via a small incision in the neck (tracheostomy). This small opening is quite comfortable and will be closed up as soon as the patient is able to breathe again without assistance from a ventilator. The patient's immediate reaction to being put on a ventilator is frequently one of relief that the struggle to breathe normally is now over.

The patient's heart will be monitored on a screen to watch for any irregularities. A thin tube (catheter) may be used to drain urine from the bladder.

In order to feed the patient whose swallowing ability is impaired by the GBS or made impossible by the plastic breathing tube, a special tube called a nasogastric tube will be passed through the nose and down the throat and oesophagus into the stomach so that liquid food may be taken in.

Pulse, blood pressure, temperature and other vital signs will be regularly monitored.

Airways and lungs will be kept clear by a method of suctioning, as and when required. This is an essential procedure which, when completed, gives the patient considerable relief. However, it is noisy and if visitors find this distressing or unpleasant they should quietly leave the unit until it is over.

This all sounds a bit frightening, but remember that these procedures are all regularly used in ICUs and are essential for the patient's well being. Each support mechanism will be discarded as the GBS sufferer improves.

How does the ventilated GBS patient feel?

At first, patients are very alarmed at the new situation and surroundings in which they find themselves. However, they soon become familiar with what is going on and begin to understand the routine. A simple but careful explanation is essential to put the patient's mind at rest.

The first thing to note is that the GBS patient cannot speak and may also have a reduced or absent sense of taste and smell. Some patients will also experience visual disturbance. Hearing is rarely impeded, so the patient can generally understand and acknowledge all that is going on. However, appreciation of the surroundings may also 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 touch is important, care must be taken. In some rare cases even a light touch may cause very severe pain which the patient

cannot easily communicate to you.

GBS is a paralysing illness. Paralysis is temporary but can be quite extensive and the patient is fully aware of the lack of movement. This can be both perplexing and hard to accept.

The GBS sufferer, although receiving the requisite amount of nourishment, may lose weight. This is the result of wasting of the muscles and cannot be avoided.

Pain may be experienced to a greater or lesser degree at various sites around the body, for which appropriate medication will be given. The level of any pain must always be borne in mind when moving the patient and utmost care taken to ensure that all movements are carried out as gently as possible.

During the severe phase of the illness, GBS patients can go through hot and cold spells and will frequently request a fan to be turned on and off.

Hallucinations, unusually vivid daydreams or nightmares, are not uncommon for ventilated GBS patients. 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 the patient may be convinced of their reality.

Many GBS patients are alert and acutely aware of what is going on. They feel vulnerable, isolated and locked-up inside their illness. Considerable frustration occurs because they are unable to talk whilst on the ventilator, and you may encounter some irrational or uncharacteristic behaviour. It is never easy for them to come to terms with what has happened, so do not be surprised if they are variously tearful, bad tempered or panicky.

Everyone coming into contact with the ventilated GBS patient should remember at all times that the patient is quite aware of their reliance upon the machinery to which they are attached. Remember too that from a mental and emotional standpoint, loss of movement and inability to speak makes patients feel fragile and vulnerable. A less than caring action or unsympathetic attitude can set the alarm bells ringing inside the silent patient.

What can you do to help?

A great deal!

Your first task is to understand, at least in outline, what this illness means. Speak to the doctor in charge of the case as soon as you can to get yourself into the picture. Some doctors are better than others at explanations. Don't hesitate to ask questions. Have you read the guide published by the GBS Support Group? Does the hospital know that there is a national Support Group?

Secondly, familiarise yourself as soon as you can with the ICU. Get to know the regular nursing staff who will give you a daily update on progress.

If a patient is to receive a new treatment or procedure, make sure he/she knows about this in advance and understands why it is being undertaken.

A physiotherapist may begin passive movement of the limbs whilst the patient is bed-bound. Get to know the physio and keep yourself updated on procedure and progress. There is a lot he/she

can tell you.

The patient cannot talk but is anxious to communicate. Make sure the speech therapist is involved in advising on communication aids. If good facial strength has been retained then lip reading will be effective. Some patients 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 eyelids, is to use a question and answer technique with the patient answering with one blink for 'yes' and two for 'no', sometimes running through the alphabet until the correct letter is found. This can be improved upon by pointing to the letters on an alphabet board and asking 'Is it on this line? Is this the letter?', responding as before. If the patient is strong enough, he/she may be able to point at an alphabet board with a finger or pointer attached with a headband. A very useful method of communication is by the use of communication cards which pre-empt many questions or comments the ventilated patient is likely to make. ICUs should possess a copy of the Group's own cards, if not, copies are available from the Group.

The GBS patient puts a lot of effort in trying to communicate and you soon find a method that works and you will become quite expert. Encourage others to understand too.

The GBS patient is socially isolated and needs to be stimulated. Make sure he/she knows the day of the week and the date. Encourage friends and family to send cards and write letters about what they are up to. If the patient cannot see TV, relate what is going on in the outside world. Read extracts from a national or local newspaper. Would the patient like a cassette storybook played? Always include the patient in bedside conversation.

Financial worries may be bothering the patient, especially if he/she is a breadwinner. Get in touch with the Social Worker at the hospital who will advise on State benefits and claims. Alternatively, your local Citizens' Advice Bureau dispenses free and expert advice on benefits. Early action is essential as many benefits cannot be claimed retrospectively. Inform the patient's employers about GBS and confirm the situation on job security. Patients worry a good deal about such matters.

It is advisable not to eat or drink (or refer to such things) in front of the patient as this can be deeply intimidating for someone who can do neither.

The patient's view of the world may be very dull, so it helps if you wear bright cheerful colours and ensure that flowers (if they are allowed) and 'get well' cards can be seen.

GBS patients tire easily, so do not encourage lengthy visits. At the end of each day, as evening approaches, make sure you leave the patient in the best possible frame of mind, ready for the night. Have you turned off or turned down the radio? Has the patient all he/she needs for the night, such as the fitting of night splints (if required)? Can the patient easily attract the nurse's attention? Paralysed patients are especially afraid of the night, so ensure they are in a calm mental state before you depart.

Because patients have a small span of attention and may be on sedative drugs, they tend to drop off to sleep quite frequently, though perhaps only for a nap. Alternatively, they may appear to be half awake but inattentive. This could be because they are hallucinating. This is nothing to worry about and you should continue to talk to the patient and try to regain their attention.

Try to understand the patient's pain and the frequency and type of medication being given to

alleviate it. Some GBS patients experience very little pain, but if it is a factor then it is a comfort to know that it will decrease alongside the patient's general improvement.

Remember too that the patient's morale is at a low point. The little things you can do will mean a lot. Does the patient need a hair wash? Do nails need manicuring? Can you help by massaging the patient's hands or feet? Is the patient having problems causing any anxiety over his/her relationship with the medical staff? If so, you must resolve such difficulties speedily.

As the patient's breathing improves, he or she will be gradually taken off the ventilator, starting with just a few minutes and building up from there. Patients can get quite panicky at the beginning of this procedure as they have become reliant on the ventilator and do not believe, initially, 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.

In summary

It is impossible to cover every single aspect of the GBS patient in the ICU. This is a very personal illness and each patient has his or her particular set of problems and worries to cope with. Your role is to offer love, comfort and reassurance during this difficult period. To do this effectively, you must remain calm and resolute and give constant encouragement on progress. Patients easily lose sight of how they are doing so keep yourself well informed by the medical staff. Writing a diary of daily events will help you keep a perspective on progress. You can relate this to the patient who may not realise how he/she is getting on.

Some days are better than others for GBS patients and it is hard to be a hero every day, but you must keep up a constant flow of encouragement.

For the close family, this period of the illness is quite stressful, so don't forget to look after yourself and stay well.

If after reading this guide you still have anxieties and unanswered questions, telephone our helpline on 0800 374803 (UK) or 0033 1529 415278 (RoI). Alternatively, you can e-mail us or register for support on-line

The GBS Support Group is a registered charity and receives neither government nor Lottery funding. If you have found this guide helpful and would like to help us to continue publishing copies for others affected by GBS and its related conditions, please consider making a donation to the Support Group. Secure donations may be made on line. Alternatively you can request a form from our office.

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