



GBS/CIDP
*Foundation
International*

**Guillain-Barré Syndrome and
Chronic Inflammatory
Demyelinating Polyneuropathy**

*Serving patients of GBS, CIDP and Variants
with support, education and research*

***A Handbook
For Caregivers***

*A guide for
relatives & friends*

*A publication of the
GBS/CIDP Foundation International*

About The Author

Helen Rummelsburg, wife of the late Arnold Rummelsburg who recently passed away from an illness **not** related to GBS is a pianist and piano teacher. Arnold was a civil engineer by profession, GBS patient by luck. Her experience as a GBS caregiver led to the creation of this handbook in the hope that other caregivers and patients could benefit from her experiences and those of others.

Helen Rummelsburg lives in Bakersfield, California, has four grown children and (at latest count) four grandchildren.

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A HANDBOOK FOR CAREGIVERS

Guillain-Barré Syndrome

Guillain-Barré Syndrome is a bizarre and frightening illness, but in spite of the trauma which accompanies it, patients and families must keep in mind the fact that almost everyone recovers from it. The loss of control which patients experience, while terrifying, is temporary. It is necessary for patients and caregivers to see through the duration of the syndrome to the likelihood of eventual recovery, and for the caregiver to provide consistent support for the patient throughout his or her progress.

Every illness interrupts life; GBS is a severe interruption, often lengthy. The caregiver must somehow manage families, jobs and ordinary life activities while continuing the support of the patient during the illness and recovery. Caregivers should try to make life easier for themselves, putting some activities on hold, giving some responsibility to others. Friends and family are usually happy to do what they can to help.

Onset of GBS and Acute Care Hospitalization

This stage of GBS may seem like a whirlwind of trauma. It is important for you, the primary caregiver, to become as familiar as possible with the disease. The excellent booklet, *GBS, An Overview for the Layperson*, published by GBS/CIDP Foundation International in Narberth, PA, (610) 667-0131, is highly recommended.

A packet of useful and informative resource information concerning GBS and CIDP can be sent to the family upon your request to the GBS/CIDP Foundation International. GBS is rare and it is not uncommon to come in contact with medical personnel who are not that familiar with it.

The most commonly seen form of GBS is a paralysis beginning at the extremities (toes-feet and/or fingers-hands) and extending up the torso. It may reach only the knees or hips or it may go all the way to complete body paralysis. The length of time a patient is paralyzed also varies; a light case may last only a few weeks or months but a more severe case may last much longer.

GBS is a disorder of the peripheral nervous system, which

controls all body function of movement. (The central nervous system [brain and spinal column] are not involved.) The paralysis is caused by an attack by the body's immune system on the myelin sheath of the peripheral nervous system. The primary doctor treating this disease will be a neurologist, who will oversee the case and contact doctors who specialize in other areas should the need arise.

You as caregiver should make contact with a chapter of the GBS Foundation in the area of hospitalization and/or the area in which you live. You should request of someone in a support group that a former GBS patient come to visit the patient in the hospital. It is tremendously reassuring for an ill patient to communicate with someone who "has been there." Information concerning the location of support groups can be obtained from the GBS/CIDP Foundation International.

Especially during the acute or early phase, support from loved ones is very important. You, the caregiver, should stay with the patient as much as possible. Losing control of oneself is a frightening experience, and a steady source of encouragement and support is very helpful for a patient. You can take things to do: letters to write, Christmas cards, bills to pay, etc. Your simply being there is reassuring to the patient.

While you are at the hospital you can attend to some personal needs of the patient (grooming, etc.). Busy nurses and aides will usually welcome your assistance.

Start a daily record of activities concerning the patient: note which doctors visit, what procedures are done, who the nurses are for the day's shifts, changes in the patient's condition, etc. Such a record may prove invaluable to you later, and will certainly provide a perspective of the illness. Your record book may be in diary format, or it may just be a notebook. It could be kept in the patient's room.

Physical therapists and occupational therapists, as directed by the doctor, should be working with the patient on a regular schedule. These therapies are of the utmost importance; they will keep joints and tissues more pliable and make recovery easier and more complete. They should be started early in the disease and continued well into the recovery time.

You, as caregiver, should feel free to ask the therapists how you can help the patient by helping him do activities or exercises during your visits. They can show you which exercise you can do and how to do them without strain – injury to yourself. These will generally be range-of-motion exercises (to keep muscles stretched in order to avoid stiffness and atrophy from nonuse) rather than strengthening ones.

Caregiver Support of the Hospitalized Patient

If the patient is on a ventilator, he will not be able to speak and may not be able to make his needs known. Letter charts can be used for him to spell out his wishes. Some hospitals have these, but they are easy to make if you prefer. The GBS Foundation has available a set of "Communication Cards," designed by a GBS patient/doctor. They may help greatly in communication.

If the patient is unable to press a call button for a nurse, you can request a specially designed call sensor which can be activated by a movement of his head, or if that is not available, a sensor in the form of a tiny pillow which is activated by a light touch.

It is important for an immobilized patient to be turned in bed often. This is often uncomfortable for the patient. If there are not enough attendants to watch the turn, arms and legs may get caught in the bed-railings. The caregiver can assist here.

Many hospitals have computerized air-beds which can be inflated and deflated side-to-side, providing continual turning. If a severely ill patient is not provided with such a bed, one should be requested. (These beds usually do not work perfectly, but are still of good benefit to the patient.)

Bring newspaper articles or other news items of interest to the patient to keep him connected to the world to which he will return.

Friends and relatives are always concerned. Encourage them to visit if they wish, but to stay for a short time only, as long visits can be very tiring for the patient. Letters and cards are a real lift and can be displayed on a bulletin board or window sill or wall. You should keep in mind that some genuinely devoted friends may find a visit to a patient on a ventilator too traumatizing emotionally and simply may not be able to handle the situation. Encourage these friends to send cards or letters.

Children can react in different ways to a parent's illness. They must be allowed to verbalize their fears.

In the case that you as caregiver find it difficult to cope with the situation, the hospital's Social Services Department personnel may be of help. You will find social workers to be caring individuals trained to assist in family traumas. Personal support can also be given by friends, family, your minister or church group, etc. GBS presents a difficult time. You must work to accept the situation, and then carry on. Your job is an important one.

Stay in contact with friends and family. Progress bulletins may be

used, including the hospital address for cards and letters.

You can bring and display pictures of home and family in the patient's hospital room. Large poster-size prints can be made of photos meaningful to the patient (a favorite vacation spot, home, family, etc.) and taped to the walls of his room.

If possible, obtain access to a DVD player and watch, with the patient, light, escapist movies, or meaningful home videos, sports events, or TV shows. A CD player can be left in the patient's room and audio CD's of books, old radio shows, favorite music, etc. can be played for the patient.

Some GBS patients experience a great deal of pain; others have none at all. If pain is not in evidence, physical contact such as massaging may be very comforting to the patient.

Complications and Management

In severe cases of GBS, the doctor may choose to admit the patient to the ICU (Intensive Care Unit) or the DOU (Direct Observation Unit) of the hospital. In these units patients are monitored very closely by nurses and attendants. Give the attending physician, the one in charge, your phone numbers, so you can be reached at any time. Also, have a nurse put this information on the chart, in an obvious place.

In these severe cases of GBS, medical complications may arise as the paralysis spreads and affects other areas of the body. The lungs (pulmonary system) may become paralyzed, necessitating the ventilator, antibiotic-resistant infections may occur, often in the lungs but also in the urinary tract or the blood. GBS patients are prime targets for infections, as the paralysis of GBS can lower the body's natural resistance to infection.

Patients with antibiotic-resistant infections may be required to be in hospital isolation, in a closed door unit, with all attendants and visitors wearing protective gowns, masks and gloves so the infection will not spread to other patients in the hospital. (If this situation occurs when the patient is not in ICU or DOU where he is closely monitored, it may be a good idea for the caregiver to stay with the patient continually, especially if the paralysis still limits him severely).

Other complications may include blood clots, which can result from immobility; these can become dangerous if unattended. Blood-thinning medications (Heparin, Coumadin) are used in the prevention and treatment of blood clots.

Muscular contractures (rigidity) can result from immobility. Medications to aid muscle relaxation may be used. Physical and occupational therapists will work to avoid or lessen this.

Mental confusion is common. The caregiver can reassure the patient that he is being cared for. Hospital personnel can be introduced and their functions explained. Compassion and patience are in order.

Anger and depression frequently occur. The fury of helplessness and the seeming inattention of busy attendants fuel these emotions commonly experienced by patients. You must expect this and offer loving support as you can. It will take time for patients to work through their depression. Hospitals usually have psychiatrists, psychologists, social workers, and clergy who can help. Family, friends or church personnel may be of assistance here. It may help the patient for you to show your understanding of his feelings by verbalizing them. "You are really angry at this situation. I don't blame you; I would be angry too!"

Other complications may include abnormal heart beats, paralysis of the gastrointestinal tract or bowels, hypertension, blood pressure fluctuations or visual disturbances.

Some difficulties may arise from individual reactions to medications given.

If complications occur, don't panic. It is important to remember that they will be treated by the doctors (usually specialists – working as a team). GBS is a challenging disorder, but recovery usually follows treatment.

You should know the names of the doctors on the medical team and their specialties.

You must take good care of yourself. Eat well and get enough sleep. Recognize that this is a stressful situation for you and keep yourself strong. If you find you are getting overwhelmed by the situation, seek respite for yourself, and counseling from empathetic persons, such as close friends and clergy. Don't exhaust yourself to the point where you too become a patient.

During the acute hospitalization phase, especially in severe cases of GBS, the caregiver should become the patient's "Watch-person" and advocate. The patient will be temporarily helpless and unable to look after his own care and interests, so the caregiver can do this for him. Stay in contact with doctors, especially the primary doctor, with whom all specialists will communicate. You should know what

medications and treatments are being used, what they are for and what side effects they may have. Ask lots of questions. Occasionally you can ask for copies of med sheets (daily medication lists used by nurses) and observe the continuity of medications. You should take with your copies of current med sheets when the patient is being transferred to a different hospital (rehab or other), to ensure continuity of medication during transfer.

Some Treatments and Medications Commonly Used in the Treatment of GBS Patients

Treatments

Plasmapheresis (Plasma Exchange) is a blood-filtering procedure, done in a hospital, out-patient clinic or Doctor's office. Blood is removed from the patient's veins, centrifuged to separate the red and white blood cells from the plasma or liquid portion following which the cells are suspended in a salt and albumin solution and returned to the patient. The discarded liquid or plasma of patients with inflammatory neuropathies contains agents that contribute to the inflammation.

IVIG (Intravenous Immune Globulin) is a highly concentrated preparation of protein (antibodies, immunoglobulins) purified from the plasma of normal healthy adult humans. This protective protein is given to patients intravenously to modulate various inflammatory neuropathies.

Medications

Immuno suppressants

Steroids (Prednisone, corticosteroids) are used in treatment of some chronic inflammatory neuropathies to counteract the inflammation occurring in the peripheral nerves. Steroids must be discontinued gradually over a long period of time. A sudden stop from a high steroid dosage may trigger a worsening of the inflammatory neuropathy and lead to increased weakness and paralysis. Steroids are often used in conjunction with Fosamax.

Imuran®, (*azathioprine*) depresses the autoimmune system. Others include cyclosporin, cyclophosphamide, mycophenyl mofetil, and Rituximab®

Medication for complications of inflammatory neuropathy

Baclofen®, (*dantrrolene*) relaxes muscles, relieves muscle spasms, occasionally used for pain

Fosamax®, (*alendronate*) strengthens bone which has experienced thinning from immobility or from prolonged use of steroids. Many other newer medications are available including Evista, Boniva, Reclast etc and should be discussed with your doctor.

Coumadin®, *Heparin* blood-thinning medications, to avoid the formation of blood clots during acute hospitalization. Others include low molecular weight heparin and aspirin.

Dietary supplements: *Vitamins and minerals*, Vitamin D, calcium, potassium

Antibiotics, as prescribed by a doctor, to treat bacterial infections which may arise in the lung or kidneys.

Pain Medications,

Tegretol® (*Carbamazepine*), *Dilantin®* (*phenytoin*), *Neurontin®* (*gabapentin*)

Rehabilitation Hospitalization

The GBS patient should, as soon as the disorder stabilizes and he is not on a life-support system, be transferred to a rehabilitation hospital, where his recovery will be guided by a physiatrist (a doctor specializing in rehabilitation medicine) and physical and occupational therapists, plus the medical staff.

The transfer to rehab is a happy occurrence! It means the patient is getting better. Rehab hospitals are generally very supportive places. The staff is use to helping people ease back into their lives and the environment is much more upbeat than that in an acute-care hospital. There are also fewer dangerous germs for the patients to be exposed to.

At rehab, range-of-motion therapy is gradually replaced by strengthening exercises, but with great care, as relapses into the paralysis can be caused by over-exercising. Therapists are trained to balance therapy and exercise carefully in the treatment of GBS patients.

Rehab hospitals have their own schedules and activities. Many offer crafts, sing-alongs, programs, special events, barbecues, etc.

They have Program Activity or Recreational Directors who do a fine job of getting recovering patients interested in life again. You should get to know the rehab system, make good use of it and enjoy it with the patient.

It is still important to watch the continuity of medications, especially since a new team of medical personnel will be on the scene. Rehab hospitals have their own staff of doctors, nurses and aides, plus therapists. The acute-care doctors who attended the patient through the acute phase of GBS may be still seeing the patient as needed, but less and less as the patient improves.

In some rehab hospitals the only staff doctors are physiatrists, whose specialty is rehabilitation therapy rather than acute or health care. If this is the case, it is a good idea to request that the patient's medical doctor continue to see him periodically or as needed. You can call on him then if you feel the necessity.

Rehab hospitals are very busy places. Patients attend therapy sessions on rehab schedule as their stamina will allow. They are often busy until 3:00 or 4:00 in the afternoon.

Many rehab facilities have DVD's and allow videos to be played for the patients.

Relapses are rare. If this occurs, don't panic. Relapses may need treatment (Plasmapheresis, IVIG, may be used), and are often accompanied by depression. The patient may temporarily have to return to the acute-care hospital. You need to hold fast to the knowledge that this will be overcome and the recovery will resume. After the relapse is checked, rehab will be continued.

The Return Home

Returning home means the patient has progressed to the point where he no longer needs to live in the rehabilitation hospital, but can go home and continue his therapy as an out-patient. Improvement in functions will continue, often for years, while the patient has resumed his life activities.

Preparing for the return home should be directed by physical and occupational therapists. It is very helpful for these therapists to visit the home a patient will be returning to in order to suggest adjustments in the home.

Some Usual Adjustments

Bathroom

- An elevated toilet seat
- Support bars on both sides of the toilet
- Support bars in the shower
- Install a hand-held shower
- Get a shower chair

Remove glass shower door, replace with curtain, improvise hooks if necessary (short pieces of wire can be threaded through shower curtain grommets and around the top of glass door shower enclosures)

Chairs

Build up upholstered chairs by placing folded blankets under seat pillows. Unwanted egg-crate mattresses work well also; they can be cut with scissors and put inside a pillowcase.

Steps

If a wheelchair is involved, a ramp may be built, using one foot of length for one inch of height.

Kitchen

Special dinnerware with some high sided plates and thick handled silverware, easier for a handicapped person to handle may be purchased at medical supply stores or ordered through a mail-order catalog.

Physical and occupational therapists usually have access to these catalogs.

Wheelchair Accessibility

If it is not possible to have physical or occupational therapists visit the home before the patient's return, try to borrow a wheelchair for a "test run" to try doorways, hallways, possible furniture rearrangements.

The patient will need lots of extra help while he is adjusting to life at home. This is a time for patience and understanding, and for the sure knowledge that improvement in his functions will be steady and observable.

If the patient is still taking a lot of medicines, you should get several

large capacity divided pillboxes (the long ones with a section for each day of the week work well); use one whole pillbox for each day, relabeling the sections to fit the medicine schedule. Fill all pillboxes at one time; this saves a lot of time and makes it possible for the patient to take his own medications when he is able to handle them.

Soap can be slippery and hard to handle. Consider using liquid body soap in an easy to dispense pump bottle.

If clothes do not fit as they did before the illness (this may be temporary), Velcro can be used imaginatively to aid the fit.

Zippers can be difficult to work because the tiny pull-tabs are hard to hold when fingers don't work well. A small sturdy key ring can be worked into the little hole at the end of the pull-tab, so there is a larger handle to pull, or a hook-with-handle can be fashioned, using a wire clothes hanger. The hook will fit into the pull-tab hole.

Patients who have been on a ventilator may find their neck sizes larger (this is usually temporary, but may last for some time). Button extenders may be ordered for men's dress shirts.

It is important to do regular exercises, as directed by the therapists. Home exercises may be made more interesting if the caregiver does them along with the patient.

Food may not taste too good for a while, so make attractive meals of food the patient likes. Vitamins can fill in nutrition gaps. Check with the doctor.

Beware of falls. Remember that long-unused muscles are not strong, balance is not yet secure, bones have become temporarily weaker from immobility (and steroids, if they were used).

An electric shaver is easier to use than a razor, with less possibility of accidental cuts.

Sonic toothbrushes are expensive, but excellent for care of the teeth and gums, and especially helpful if hand control is not good. Electric toothbrushes are very good, if sonic is not possible.

In general, the support person should be an "enabler," helping the patient to resume life activities as he or she become able to do them. The caregiver needs to provide help as needed and to gently hold back help as the patient is able to do more.

Financial Management of a GBS Case by the Caregiver

Early in the case, you should familiarize yourself with all aspects of your health insurance. If you can, make contact with one case worker

from your insurance company to whom you can refer all claims.

You should stay current with doctor and hospital billings to your health insurance company. If claims are refused and you feel they should be paid, appeal them in writing. Contact your insurance company to find out the correct procedure for making a written appeal of non-payment. Delay paying bills if you feel they are the insurance company's responsibility. An appeal by the patient or by the caregiver on behalf of the patient carries weight. Remember that you are the customer!

You may need to contact doctors' billing offices to straighten out billing procedures. Sometimes diagnosis or procedure code numbers in the bills are wrong, in which case the insurance company will not pay. It is very helpful in this situation to be able to process all claims through one person in your insurance company. It is also very helpful, if documentation or explanation of a bill is needed, to be able to refer to a daily record which you have kept.

Hospital bills, especially in severe GBS cases, are gargantuan. You must keep in mind they are almost always discounted heavily by insurance companies who usually have prearranged agreements with the hospitals to pay certain amounts for specified care and procedures. Hospitals will, according to the prearranged agreement, accept the lesser payment as payment in full, excluding any co-payment requirement. The caregiver should know what the insurance payments will cover and what the patient's financial responsibility will be.

Too often treatment, including length of hospital stay, is dictated by the insurance coverage available. Insurance coverage is usually better for acute care hospitals than for rehabilitation hospitals. Both acute care and rehab hospitals have billing personnel who are familiar with different insurance plans, and who work together with the case supervisor and the primary care doctor to arrange the best care for the patient, as covered by the insurance plan. Occasionally, the doctor will disagree with the insurance company representative about a patient's readiness for discharge. Your direct contact with the company may help support the doctor in giving the patient the best care. Insurance companies don't want unhappy customers.

*T*HOUGHTS FROM FORMER GBS PATIENTS

On the day after my husband, “V” was admitted to the hospital with GBS, I started taking snapshots of him. First while he was paralyzed, then receiving the Plasmapheresis treatments, and at milestones during the recovery process. I placed copies of each picture in two albums with a sentence to explain each picture. One album was sent to our daughter two months or so later. She lives in Colorado and I gave her instructions to forward it to relatives in New York when she had finished with it. The pictures were reassuring to our relatives that “V” was indeed progressing. The other album was circulated among friends here in town, then kept at the rehab center so “V’s” visitors could see how he was improving.

“V” tried to wear his ordinary pants and shorts, but he didn’t have the strength to zip or unbutton them. The crotch also proved to be too high or tight for necessary functions. So I made several pairs of pants in wild prints. I made the crotch 3-1/2” lower and used Velcro for fasteners. I also sewed Velcro fasteners on pajamas and on the undershorts’ waistbands, which I’d cut apart. He found these comfortable and useful.

When “V” began to use the wheelchair I made a vinyl case for his Walkman with a neck strap and a vinyl holder with neck strap for his water bottle. Then he could use his hands to wheel himself around the facility and have the radio or water whenever he wanted them

After “V” had begun to walk with his hi-tech plastic AFO’s (braces), he started getting friction marks on his legs. I made footless socks out of cotton knit with elastic at the top. He puts on the “socks”, then his braces, and turns the elasticized “sock” top over the upper part of the braces. The “socks” cushion his legs adequately.

J. W., Torrance, CA

...from an ex-patient who was (at age 82) on a ventilator:

I hit on the idea of spelling out my concerns by printing out each letter with one active finger on a smoothed bedspread, pausing at the end of the word, then with a sideways motion indicating the end of the thought.

J.C., Rochester, NY

I had GBS last year. I was on a respirator five weeks. When I was able to move my hand, a nurse printed an alphabet on a cardboard and I used an aspirator as a pointer and was finally able to communicate.

A.T., Dunedin, FL

Things That are Nice in ICU

Silk flowers, since you can't have real ones.

A stuffed dog. Because I am so attached to my dog, who could not visit, my children brought me a stuffed one that looked like him and he would sit on by bed and keep me company.

Mail – the cards were great.

Pictures – my grandchildren drew for me and the nurse taped them up where I could see them.

Grooming – obviously with a ventilator down your throat and numerous tubes, you don't look very good! One of my daughters gave me a manicure and when I left ICU my nails had never looked better.

Another daughter made me some hospital gowns – attractive prints and much nicer than the standard issue. They had Velcro on the shoulders....

After You Come Home with GBS

Friends should visit, but not stay too long.

Long phone calls are tiring.

It is important to let the patient do what he/she can around the house. The first time I sat down and folded laundry was a major achievement!

A stationary bike is helpful for getting strength back in the legs.

It has been over six months now and I still have some leg pain. However, I have found that wearing support pantyhose helps this. Not the heavy type – Just Leggs or NoNonsense or whatever is available.

I think the main thing is to understand that the recovering GBS patient can get depressed, discouraged, panicky and run through a lot of emotional upheaval. You are tired, tired, tired!

Drive when you can; go with someone else at first and take short drives around the neighborhood.

You feel better if you look good. Get someone to take you for a manicure, get your hair done, buy some new clothes!

S.M.

...as a patient, the things which were most helpful to me were:

Family support – my wife visited me every day.

Prayers and get well cards – I averaged ten cards a week.

The most important thing to me is my own determination to get well. I am determined to walk...

L.A., Boonton, NJ

