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GBS|CIDP

Caring for a Child with GBS or CIDP



A PUBLICATION OF THE GBS/CIDP
FOUNDATION INTERNATIONAL

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BY PATRICIA SCHARDT



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ABOUT THE AUTHOR

Patricia Schardt has worked as a school administrator, teacher, private tutor and homemaker. She received her Bachelor of Science degree in special education and Master of Science degree in educational administration from the University of Nebraska. Patricia is the mother of a daughter with Chronic Inflammatory Demyelinating Polyneuropathy.

The Schardts live in Deshler, a town of 900 people, in rural southeast Nebraska. They have four adult children, a son and three daughters. Melissa, one of a set of identical twins, has been challenged with CIDP.

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This pamphlet is provided as a service of the GBS/CIDP Foundation International.

Caring for a Child with Guillain-Barré Syndrome or Chronic Demyelinating Inflammatory Polyneuropathy

INTRODUCTION

Few life events impact a family as forcefully as a child's serious illness. Guillain-Barré Syndrome and chronic inflammatory demyelinating polyneuropathy seem to come out of nowhere and turn the lives of healthy children upside down. Suddenly, the predictable routine, the accepted roles, and the health we took for granted, change families forever. GBS and CIDP bring with them a profound loss of control. The healthy body now behaves in a puzzling way. The family's schedule and routine becomes punctuated by one appointment after another. Family roles can be reversed overnight.

A child with GBS or CIDP suddenly or slowly must live with a body that does not function correctly. The family also must live with this body. The child who skipped and ran, walks with difficulty or cannot walk at all. Adults must dress them, help them lift a spoon, accompany them to the bathroom and drive them where they previously could walk. Adults are making the choices that used to be theirs. Parents decide what help they need and how much. Physical therapists decide on a routine of appointments and an exercise schedule. Teachers expect missed work to be made up. Physicians are scheduling frequent appointments, hospitalizations, tests and more tests. The child's previous autonomy has been seriously compromised. Parents, too, face daily dilemmas. It is difficult to plan around GBS and CIDP. Normal childhood is full of active play; now activity is subdued. Daily plans might be changed to accommodate a low level of energy. Children remain ambitious, but their schedules are restrained. When families look to the future they are cautious and skeptical. When will our child feel well and full of energy again? Will this outing end in compromise because GBS or its after effects made the decision? Can we travel as a family or will it simply be too much trouble? Will fatigue cut short one more school day, one more party, one more evening of fun?

Healthy siblings of a seriously ill child live in two worlds. They have the familiar world of school and friends, and a family completely changed by GBS or CIDP. Brothers and sisters sincerely want to help and be part of the recovery; but they also want their family to be like everyone else. They usually feel empathy and compassion, but may also feel guilt and resentment – sometimes all in the same day!

My daughter's CIDP from age seven to the present presented a special challenge. She went from a state of health to a state of illness and back again. The exacerbations and remissions were very stressful. Making short term and long term plans was very difficult. Will she feel well in June or not? Should we plan a family trip or put it off – again? There was always the constant fear during an exacerbation that she might not get well again. What if this is permanent? If her disability is permanent, that would require yet another set of adjustments. Health ambiguity was tougher to handle than outright illness. We could manage when we knew what adjustments were needed. Uncertainty kept us constantly off balance.

FAMILY COPING STRATEGIES

Parents set the tone and attitude for the whole family. If the parents decide that the illness is overwhelming and life as they know it is over; the children will accept this as a roadmap. If the parents adopt an attitude of problem-solving and competence, the child will approach his or her illness with confidence and a can-do attitude.

It is important to remember that children will absorb what they hear said about them and Guillain-Barré Syndrome. I cringed when I heard a mother say tearfully (in front of her ten year old son with GBS) "He can't do anything. His life is over. His friends don't want to come over. He will never play sports again. We don't know what to do." Think very carefully about what is said to others about your child and this disease – especially when your child is listening.

The family's general routine should be maintained as much as possible when impacted by serious illness. Every member will benefit from a continuation of "normal.". The disease is change enough for anyone. The ill child certainly needs doctor appointments, therapy appointments and adjustments with school work; but siblings need to know that one child's illness will not become the central axis for the family structure. Their needs and concerns are equally as important as that of the ill child. It becomes very easy for parents to become so focused on the one child's illness that all other needs and concerns are treated with secondary importance. Resentment can creep into relationships, despite the parents' best efforts. My daughter's twin sister (and her strongest ally) grumbled, "When you can't walk, you get to stay home from school, and you get presents and everyone likes you better."

Rules and responsibilities in the home need to remain as consistent as GBS will allow. It becomes easy to excuse the child with GBS or CIDP from courteous behavior or her usual

chores because parents are tired, it is easier to do the job yourself, or you feel guilty that she is suffering. It is imperative, however, to insist on some contributions to the household during the recovery period. Our daughter could fold laundry from a wheelchair while her sister cared for both girls' pets. This builds dignity during a period of disability and keeps resentment to a minimum. Since fatigue is such a prominent factor in GBS, these decisions can be quite a challenge for parents.

Brothers and sisters should feel free to ask parents any questions they have – no matter how extreme. Parents should answer as completely and empathetically as they can. Siblings need to know that they have the right to feel all kinds of feelings about this puzzling disease and how it has impacted their family. Siblings can be a very real part of recovery. They can help with therapy or homework, visit in the hospital and assist in managing the household. Conversely, most children also want their family to be like others families. They may not always want to push the wheelchair in public or do all of their brother's chores.

GBS and CIDP can be long, complicated illnesses. Keep all of the tests, medications, and appointment information organized in a three-ring binder. Bring it to every medical appointment and therapy session. This prevents physicians from ordering unnecessary tests and procedures if you have not had all the records transferred from one physician to the next, and physicians do not have access to all of the medical history.

Most parents feel that the more choices that can be safely made by the child with GBS the better. Making choices allows the child to feel in control (something the disease takes away), lessens helplessness, and minimizes victim mentality. Choices help family members return to normalcy. It also teaches the child to manage his own body and his own health. Children (especially older children), who have a voice in their own health management cooperate with physician directives more consistently.

CHOICES A CHILD CAN PARTICIPATE IN:

- **Conditions for receiving IVIG.** Speed of infusion, needle size, the procedure for inserting the IV. After several infusions, children may have very specific requests about the procedure. There are creams and local painkillers that can make needle sticks less painful.
- **Health scheduling.** Physical therapy scheduling, doctor's appointments, home exercise, IVIG infusion schedule, and rest breaks. Can we move my physical therapy appointment so I can attend the birthday party?
- **Social dilemmas.** Will I take a wheelchair on the field trip or not? What will I do when everyone is riding bicycles?
- **Appearance.** What clothes and shoes feel comfortable and look stylish? Can I comb my own hair or are my arms too weak and I need help? Who do I want to help me?
- **Family responsibilities.** How can I help my family? If some household tasks too difficult, what can I substitute? I can't stand long enough to vacuum, could I bake or cook while seated instead?

- **Athletics.** How can I participate in sports if I am too weak to run and jump? Could I be the scorekeeper or student manager? Could I write sports reports for the school paper? Could I still wear a uniform and travel with the team?
- **Communication.** When others asked why I am using a wheelchair, what will I say? Memorize a two sentence summary to the illness's most common questions.
- **Unsolicited advice.** People whose children have rare neuromuscular illnesses soon become accustomed to an avalanche of advice from others. Even children can begin to discern what should be thoughtfully considered and what should be politely ignored. There is a life lesson in diplomacy here.

EDUCATION

The home and the school are partners in the education of your child. Both want the same outcome – a healthy, educated student. Most schools will work willingly to adapt to your child's special needs if given adequate information and treated with respect.

The first step is to schedule a conference with your child's teachers and administrator. Bring along a letter signed by your physician that states a diagnosis and the educational changes that will be needed. It is also helpful to bring a letter with directives from any physical or occupational therapists that have evaluated your child.

Parents need to do their homework. It is important to thoroughly understand Guillain-Barré Syndrome or chronic inflammatory demyelinating polyneuropathy. Be familiar with the illness in general and the aspects specific to your child. Be prepared to explain the illness concisely and how it has impacted your child's education. You may want to hand out literature that summarizes the disease. GBS is very rare and most adults are not familiar with it. Inform the bus driver, lunchroom staff and anyone who works with your child.

The rarity of the disease, coupled with the fact that your child looks normal makes it imperative that the parent present himself as calm and professional. The conference must convey that this child has real educational needs that you expect to be met. It is important not to present oneself as a dramatic, overprotective parent latching on to a fringe medical ideology.

Parents need to familiarize themselves with the educational laws of their state as well as those of the federal government. Public Law 94-142 mandates a "free and appropriate education for every child in the least restrictive environment." This education must include any related services that your child needs consistent with the Americans with Disabilities Act.

Most schools are working with tight budgets and some are reluctant to supply services to a seriously ill child because the extra equipment or manpower adds to their expenses. A 504

plan or an Individual Educational Plan (IEP) is a legal contract that can be written for your child's specific needs. It should define your child's needs in very specific terms. It should list who will provide the service, when and how often. It should include specific long and short term goals and prioritize them. This plan can be changed as your child's needs change and stopped when your child fully recovers. Ask politely and firmly for what your child needs, but advocate for your child and insist that the law be followed.

Schools are required to be accessible to all students. The law addresses both classroom instruction and extracurricular activities. Students cannot be left out of field trips, drama performances, or music programs because they need a wheelchair, have difficulty walking, or have hand weakness. Physical education classes must be modified to include frequent rest breaks or alternate activities. Often physical and occupational therapy activities can be substituted for physical education class and still meet state educational requirements.

It is important to adopt an attitude of problem solving to the educational dilemmas posed by GBS and CIDP. The quality of a child's life will be decidedly different when adults say, "Mary can't be in marching band, because she can't walk very far," as opposed to "Mary is going to be in the marching band this year. What changes do we need to make so that can happen?"

Parents can play a major role in identifying the specific changes needed to make school a successful experience even with compromised health. When a child's hands are weak, there needs to be a plan in place to compensate. Tests can be given orally or on the computer when a child cannot write legibly. Answers can be circled instead of writing out complete sentences. A math assignment could be trimmed to ten problems instead of thirty if the student demonstrates that he can master the concept. A thirty item assignment could also be broken down into six assignments of five problems each and completed with a rest break after each section.

There needs to be a plan in place for needs outside the classroom as well. Who will carry the lunch tray? I can only carry one heavy book to class, how will I carry three? Does a backpack on wheels work better than one I have to carry? Do I need more time to travel from classroom to classroom? Make sure each desk and chair is comfortable and the correct height. Improperly fitting chairs and desks can give any student a backache.

Teachers and administrators may also be uncomfortable with a child who has frequent absences and long hospitalizations due to GBS or CIDP. Again, the law specifies how this is to be handled. A hospital social worker or special education teacher should be able to address this issue so there is little reason to force a child with a serious illness to repeat a grade. State laws specify that extended absence qualifies a child to receive homebound instruction. Part of the Individual Education Plan can also make arrangements for rest during the school day. We arranged for a two hour lunch break for our daughter for two months. She could sleep for one and one half hours and then return to class.

If you cannot agree with the school on what services your child needs or you are unhappy with the delivery of these services, voice your concerns and resolve disagreements by respecting the educational chain of command. Start by voicing your concerns to the classroom teacher, then the special education teacher, the principal, special education

supervisor, and finally the superintendent. Try to solve problems at the classroom level whenever possible. The school board, state board of education courts are institutions of last resort. At these levels, conflict is very costly in terms of emotion and public relations.

The bottom line is that the child needs to master the objectives set for his grade level. He needs to be able to demonstrate that he knows the material. Parents, however, have the right to insist that needed modifications be made in the teaching process. There are many ways to teach the same material. With all of the mandates and services available to schools today, there are few reasons for any child to be denied promotion or credit because of an extended illness.

SOCIAL SITUATIONS

Social situations can pose additional problems for the child recovering from GBS or CIDP. Residual symptoms can cause awkward dilemmas because they are not obvious to others. Communication and education can make a big difference. We gave a brief explanation of the disease to our child's third grade class. We explained the illness in language they could understand, built empathy by explaining the symptoms and what they feel like. We finished with a list of practical suggestions as to how they could assist her and thanked them for all the efforts that had already been kind and helpful. A brief friendly note summarizing the same information and a treat were sent home with each child. Occasionally, we invited our daughter's friends to an IVIG party. Melissa received her infusion, several friends shared pizza and soft drinks with her. They played games or watched the latest movie together. This also worked well for teen friends. She sometimes invited a friend to join her at doctor's appointments or physical therapy sessions. When combined with a shopping trip to the mall, an obligation turned into a fun event.

Some families feel that one on one play dates are ideal when a child is temporarily disabled as often happens with GBS or CIDP. They have experienced the child with illness as left out when two or more healthy children are present. It becomes very easy for two healthy children to run off and leave the non-ambulatory child alone. Sometimes bullying or name calling can be a difficult social dilemma. Again, it is ideal if the child can handle the situation herself with confidence and poise. Sometimes, however, bullying is more severe. If the child's efforts are not effective, then it is imperative that parents and other adults intervene.

Children can also role play awkward questions and social situations. Our daughter explained to others how she had "jello legs". She said she felt that everything was heavy and a giant magnet was pulling her to the ground. She explained that it felt like her legs were going to sleep or the same feeling as hitting her elbow on the "funny bone."

Sometimes a child with GBS or CIDP will refuse a social activity because it is too difficult or uncomfortable. Friends were usually not offended if the child offers an alternate activity. In this case, the activity is being refused; not the friend. "I would love to go rollerblading, but

it hurts my feet too much. Would you like to come to my house instead?” Fatigue is also a frequent social obstacle. Children need to plan their activity schedule and set priorities for leisure activities. “I can stay awake at the sleepover until midnight; then I will ask to go into another room and sleep.” “I can play soccer or ride bicycles; I can’t handle two strenuous activities in one day.” “I need to do my homework after school. I am always too tired in the evening.”

Children suffering from neuromuscular illness need to problem solve, not withdraw when faced with difficult social situations. How can I participate in Halloween? How can I be part of the sports program? How can I attend the party, and handle the standing involved? Social experiences are as essential to children’s development as their education. Parents need to communicate that social dilemmas are simply situations that require problem solving; then, their lives can continue with an attitude of competence and optimism.

RELATIVES, FRIENDS AND STRANGERS

Family, acquaintances and even strangers feel free to pass judgment and give unsolicited advice, as often as they ask honest questions and seek genuine understanding.

Children, more than any other group, are accused of “pretending to be sick” because they look normal. Even teachers and medical professionals sometimes have trouble accepting the reality of symptoms that they can’t see, that are difficult to measure, and are so poorly understood. Children with borderline difficulties and incomplete recovery often have the hardest time and leave others confused. This disease has no wounds, no rashes, and no heavy casts. The child looks just fine. While parents are grateful that the child looks so normal, it becomes an added burden to explain to others why they need handicapped parking, why their child cannot take a long walk, or why she needs to sit down and rest so often. It is frustrating to deal with the skepticism of others. Parents do not always want to have to prove the legitimacy of their child’s disability. Advice for parents with a sick child is as rampant as the common cold. Everyone seems to know what caused the child’s sickness and how to cure it. “My second cousin had the same thing. She started using herbs and is completely cured.” “Physical therapy is a waste of time, what you really need is a vegetarian diet.” “Stress is what caused it, she’s under too much stress.” Parents are advised to keep their emotions under control even when it is very difficult. They would be wise to use the opportunity to educate and restate their position on treatments. “Thank you for the information. We plan to continue with IVIG and physical therapy.” “I appreciate your concern. We believe it is wise to respect our child’s need to rest when she requests it.” “Yes, she can use a pencil; but her hands are too weak to carry her books.” “Yes, she was walking this morning and tonight she needs a wheelchair.” “We have researched this disease very carefully. We do not believe our child is crazy or that we are in denial.”

Grandparents deserve special comment. Parents may not realize that when a child is seriously ill, grandparents suffer on two levels. They hurt for the child who is suffering, but also for their adult child who is suffering, as well. It is very difficult when people you love are enduring a medical crisis like GBS or CIDP. Strangers in public places, especially children, often comment about a child who seems different. Their questions can be honest curiosity or intrusive and rude. “Why do you use a wheelchair?” “Do your legs hurt?” “Why can’t you walk very far.?” Other parents often discourage questions from their children, but such questions can help with general understanding and education. Practice with your child how you will answer the most common questions you receive. Review which questions you will answer and how you will respond to those that you do not wish to answer. Memorize a short, accurate response of two or three sentences. Strangers do not want a neurology lecture, politically correct commentary on disability, or your life story.

CAREGIVERS AND COMPASSION FATIGUE

Parents and other family members often become so concerned about the ill child in their family, that they often forget their own very legitimate needs. It is easy to give and give; but giving long term can lead to mental and physical exhaustion.

One of my daughter’s nurses cautioned me on lifting her. Melissa did not walk for weeks at a time. She mentioned that if I continued carrying a seven-year-old several times a day, I was going to end up with serious back injury because I was not carrying her correctly. Caregivers need to also need eight hours of sleep, regular and nutritious meals, time alone and time with others.

A seriously ill child usually brings in many offers of help. This is the time to say yes to everyone who wants you to “call if you need anything.” Let other people drive your other children to activities, host play dates, bring meals, or babysit. One of my dear friends offered to color Easter eggs with my other children while I was in the hospital with Melissa. They didn’t miss an annual tradition because of her thoughtfulness. This is an appropriate time to let others help you. Your time is precious and a crisis like GBS is certainly the time to accept assistance.

There are a million reasons why parents do not have time for themselves. However, taking care of oneself is not a luxury, but a necessity. Martyrs and those who feel chronically guilty putting their own needs first, do not benefit themselves, their marriages, or their sick and healthy children.

Live in the present. While this is easier said than done; forming small attainable goals for the day makes dealing with a serious disease easier. It is overwhelming to visualize all the

doctor appointments, all the therapy sessions (I stopped counting when we reached 300 physical therapy sessions for CIDP) and all of the “what ifs” that might present themselves in the future. Focus on what is needed today. List five things you are thankful for (if these don’t easily come to mind, think harder). At the end of the day, list five things you are proud of. Examples might be: I answered my friend’s questions effectively. I was patient when I went through my child’s PT regimen. I took a walk with my spouse.

Meeting with a friend, social worker, counselor, clergyman, or parent group can be very healing when faced with a child’s serious illness. Sometimes family members simply don’t want to hear the story one more time, even though you need to tell it again. A parent needs to have a safe place to say what they are feeling and also to learn to listen to what others are saying.

Time becomes very precious, however, adults need at least one activity per week with their spouse, each healthy child, and one activity for themselves. Try to also schedule at least thirty minutes a day for time for yourself. Parents who do not take care of themselves and their relationships cannot adequately care for their ill child. Taking care of oneself is not selfish, it is smart.

CLOTHES, SHOES AND WEIRD FEELINGS

Sensory distortion is a common symptom with Guillain-Barré Syndrome and CIDP. While the weakness and paralysis of the motor involvement is easier to understand, the sensory damage can be very perplexing.

Some children have trouble with pain and unusual sensations for a long time. I don’t know how many hours we spent trying to find dress shoes that my daughter was comfortable in. Custom made insoles, however, made a big difference in managing the neuropathy in her feet. She still prefers high top basketball shoes. In fact, she wore them under her formal ball gown at her wedding!

Some children have a heightened sense of touch either during the acute form of the disease or even permanently. Socks, certain fibers, and seams in clothing might be irritating. Some children fight wearing shoes of any kind.

The sense of taste can be affected by neurological damage as well. Some individuals have difficulty with swallowing. Experimenting with spices or flavorings, temperature of food, and texture may help children get appropriate nutrition.

Temperature perception may be extreme. Our daughter wanted to walk outside barefoot in the snow to “cool off” more than once. Some individuals, however, cannot feel cold or heat. Parents may have to be especially careful that bathwater does not scald if a child cannot

perceive heat accurately. Some children need to be very careful not to get frostbite on hands and feet.

Neuropathic pain can be a very challenging symptom of GBS and CIDP. While there are few complete solutions for such a pain, your neurologist or even a pain specialist should be able to offer possible remedies. It is important for families and professionals to be aware of unusual sensory perceptions and take them seriously. Even though treatment remains very individual, acceptance of the reality of such symptoms goes a long way towards management of them.

It has been twenty years since CIDP came into our lives. Our family has never been the same. Our daughter is grown up now. She graduated from college, is married and the mother of two young children. CIDP is still a part of her life, but she and her husband have built a family of strength, love, and laughter we could all learn from. Caring for a child with GBS or CIDP can tap one’s deepest emotions. Some days will be incredibly difficult – nothing will go right. Others will be intensely delightful when a child takes her first step after months of paralysis. This illness has given me a new respect for the human body and the God that created it. I will never see my children in quite the same way again!

PATRICIA SCHARDT

Mother of a child with CIDP

References & Appendix

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APPENDIX

Here is a copy of the note that was sent home to classmates of our child. At the time she had been diagnosed with GBS. Later, the diagnosis was changed to CIDP.

Dear Parents and Students,

Thank you to everyone for all of times you have helped Melissa since she became ill. Many people have asked questions about this illness. Guillain-Barré Syndrome is a very rare illness. Most people don't know anyone else who has had it. Maybe this will answer some of those questions.

Melissa has Guillain-Barré Syndrome. It is an autoimmune disease that attacks the peripheral nervous system. These are the nerves near the skin that help move our muscles and help us feel things. Scientists are still not sure how or why people get this disease, or why one person gets it and not another; but they know it is not contagious.

Most of the time, GBS starts in the feet and moves up to the ankles, knees, hips and so on. The legs get very weak and won't hold the body up or let the patient walk or stand. Sometimes they also have trouble keeping their balance. Sometimes their back, arms and neck get weak, as well.

Many patients also have feet that ache and burn. You may have had those feelings when your foot "goes to sleep" or when you hit your elbow on the "funny bone." The weakness and funny feelings may stop at the hips or the waist. Some people are totally paralyzed and have trouble breathing.

Melissa says she has "jello legs." She says they feel like rubber and she can't make them move where she wants them to go. She also says that she feels like a giant magnet is pulling her to the ground. If you ever tried to stand when you were dizzy or when your feet were "asleep", you have some idea of what it is like.

Standing can be harder than walking for many patients. A person may be able to walk easily, but have trouble standing for even a few minutes. This is because gravity puts pressure on your feet all the time you are standing. When you walk, one foot always gets a brief rest.

If the arms and hands are affected, a glass of milk may feel like it weighs ten pounds. A hamburger may feel too heavy to lift. The patient may be able to pick up an object for a short time, but drop it if he has to hold it more than a

few seconds.

People with GBS get tired fast, too. Most kids can easily walk a mile. A kid with GBS can walk maybe three steps, or across the room, or two blocks before he has to sit down.

It all depends on the severity of the disease.

Almost all patients need physical therapy to get strong again. A physical therapist plans special exercises that strengthen certain muscles. He also helps patients use a walker, crutches, or a wheelchair if they need one. Even after they learn to walk again, the child may need more physical therapy to be as strong as other children. The additional training is necessary to be able to ride a bike, roller blade, or hang on tightly to the playground equipment. Stamina needs to be built up so the child can play games or walk without being totally exhausted.

Most people recover over a period of weeks or months. Sometimes it takes a couple of years. The good part of Guillain-Barré Syndrome is that nearly all the patients get completely well again.

Melissa is getting stronger every day. We appreciate your prayers and concern. We thank you for all the times you carried her books or her lunch tray, opened the door when it was too heavy, and waited so she could rest a few moments.

Thank you again.

Ron and Pat Schardt

For more information, please contact:

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A close-up photograph of a wheelchair wheel, showing the spokes and the hub. A semi-transparent green rectangular box is overlaid on the upper portion of the wheel, containing white text. The background is a light, neutral color.

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