

GUIDE

After GBS — Children

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

First published in *After GBS*, edited by Jane Tempest-Roe, Administrator GBS Support Group.

Going home

Before children are discharged from hospital, key members of staff should provide contact telephone numbers. Occupational therapists will discuss the suitability of the home environment and any specialised equipment needs. Children's walking frames on wheels are sometimes available and can be very useful. If considered necessary, arrangements are made for physiotherapy to continue, and advice given on daily and recreational exercise programmes. Parents who are not completely satisfied with the arrangements should make their reservations known.

Hydrotherapy and swimming are very helpful. Cycling is also a good form of exercise. Horse riding helps with balance (contact 'Riding for the Disabled', tel: 024 7669 6510). Any exercise is beneficial as long as children are willing. Since they are usually very active and move around without thinking, this is a good indicator of their capabilities.

Nerve-endings can become extremely sensitive and the slightest pressure can result in pain or discomfort. Recovery can be a drawn-out process and some symptoms can linger for many months. However, there are ways of helping children to cope. Doctors can prescribe medication to counter pain. Rest, relaxation, massage and physiotherapy are all helpful.

Tiredness is an obvious symptom. Children listen to their bodies as adults do and may prefer to sit and watch endless television. If this is how they relax and cope with exhaustion, then so be it. Children will feel miserable if forced to be active when not feeling up to it. Children are often affected by temperature changes. Cold weather can sometimes bring on muscle aches or stiffness, whereas warm weather can ease them. Colds and bugs are more common in the wintertime and GBS symptoms such as tingling may recur if children are under the weather. This does not indicate a recurrence or relapse, though this is an outside possibility.

If regaining weight is a problem, build-up drinks may be prescribed. Alternatively, they are available from chemists and health food shops. Consult your child's GP about vitamin supplements if a normal diet cannot be achieved. If children lose their appetites when they are not feeling well, it is less stressful all round if they are given a small portion of something they like. Bartering can work wonders. The 'finish your peas for one chocolate and the rest for two' method can be used. This turns meal times into fun times, especially if brothers and sisters join in the game. Star charts can be a useful incentive for any activity, including meal times, bedtimes and exercises.

The trauma of GBS may have had a temporary affect on children's overall behaviour. They may become frustrated, angry and upset at not being able to do everything that their friends can. Some children become clingy, whilst others may appear to be more independent than they were before their illness. Embarrassment, self-consciousness and loss of confidence may also be evident. It is best for you not to make too much of these mood swings and to treat these times as normally as possible, as well as to try not to give too much preferential treatment over siblings. Lots of hugs, reassurance and understanding are required, without over-fussing. Children should be listened-to. Beneath the mixed-up emotions they are the same people inside. Keep in mind that these problems are temporary and will improve in due course. Supply your child's GP with GBS literature to file away for future reference.

It is very important, if you are at home with a sick child, to take breaks and to ask for help from family and friends. Respite periods, however short, can be extremely beneficial. If you feel calm and in control you will be better equipped to help your child. Parents should also try to spend time out alone with each other, for they are both experiencing similar emotions.

Jenny's Story is a book describing the illness from a child's perspective, and is available from the GBS office. It can be also seen on the Group's Web site along with other pages about GBS specially written for children. If the school is linked to the Internet, give the teacher the address of the Web site.

School

Returning to school on a part-time basis is one approach that might be considered. If the time off school has been considerable, then it may be necessary to miss a year. Expecting a child to work extra hard at this time to catch up with the rest of the class would be, in many cases, unreasonable.

If you are concerned about your child missing school, ask the teacher to send some work home. There are also a wide variety of work books available in shops and libraries. It can be beneficial, both academically and socially, to take children to school for as little as an hour at a time during recovery. Even a social visit is helpful as they can miss their friends and the whole atmosphere of school life.

School facilities should be checked that they are suitable for your child's needs. Depending on the speed of recovery and/or the amount of residual disability, it may be necessary for your child to return to school in a wheelchair. If this applies it is important to check there is access to the toilets and that there is sufficient space. Chairs and desks need to be comfortable and of the right height to prevent back pain. Writing and eating difficulties can be facilitated by attaching insulation pipe (foam) around pencils, pens and cutlery. 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 the teacher and headmaster. Provide them with literature about the illness and to discuss your child's needs. Emphasize that whilst your child may appear to have recovered well, children after GBS typically have some residual weakness and general discomfort, particularly in the extremities.

If tiredness is an issue, your child may need rest breaks throughout the day. Strict bed and rest times are beneficial as a week at school can be exhausting. Control out-of-school activities to avoid overwhelming your son/daughter. A busy weekend can take its toll on Monday morning.

Physical limitations may temporarily prevent your child from participating in physical activities. If splints have been provided, make sure they are used exactly as instructed. It is most important that they are worn.

It is helpful if the teacher can explain about the illness to the class and to mention the limitations your child may be facing at that time. Teachers should try to ease your child gently back into the classroom environment with a minimum of fuss and should be aware of the difficulties that young children may face in being labelled 'different' from their peers.

Keep in regular contact with the teachers, without worrying about being a nuisance. Locums and new teachers should be told about your child's illness at the beginning of each new term. Should problems arise, ask to see the school's special needs policy and remember that you have rights.

Contact the office if you would like to be put in touch with a 'child/parent contact', whose own child has suffered from GBS.

Contact a Family

0808 808 3555, www.cafamily.org.uk

Parentline Plus

0808 800 2222, www.parentlineplus.org.uk

Association of Wheelchair Children
0870 121 0050, wheelchairchildren.org.uk

Whizz-kidz
020 7233 6600, www.whizz-kidz.org.uk

JABS (health problem after vaccinations)
01942 713565. www.jabs.org.uk

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.

giftaid it

GBS Support Group, LCC Offices, Eastgate, Sleaford, Lincs, NG34 7EB

Tel: 01529 304615 E-mail: admin@gbs.org.uk Web site: www.gbs.org.uk

© GBS Support Group



January 2005