

# GUIDE

## *Sexuality and GBS/CIDP*

*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](http://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.*

### **Introduction**

If Hollywood is to be believed, sexual intercourse is the most important part of life, ranking just below breathing in terms of necessity. And if you can't perform sexually, you might as well have no life. But in reality, not only is life more than a single biological function, but sex itself is much more than just the physical act of intercourse. That's good news for those of us with GBS, CIDP and related disorders.

Anyone who has had to deal with a long-term disability can tell you that it can create a great strain on any relationship. Where once partners were equals, sharing in all aspects of life and responsibility, suddenly one partner is partially or totally dependent upon the other. Even without the actual physical disability, the emotional upheaval can interfere with a couple's sex life. To complicate matters, many couples find talking about sex difficult. What once was a close, intimate relationship can become distant and stressful for both partners.

The information in this guide explores some of the issues that may arise in dealing with sex, provides a few tips on how to cope with problems, and gives suggestions of other sources of information and help. Recognising that the subject is delicate and difficult to discuss without upsetting the sensitivities of some, and the author has attempted to be frank and to the point, while discrete.

## **Communication**

Ask any counsellor (or any happy couple who've been together for a long time), and they will tell you the most important part of a relationship isn't sex, but instead is communication. The best sex is with someone with whom you are comfortable, with whom you can talk about all aspects of life, both good and bad. That's true not only for people with disabilities, but for everyone. So, start by reading this with your partner and talking about it.

People with GBS and its related disorders often have numerous physical problems with which they have to deal. But often these are exacerbated by the emotions that disabilities can bring. Some are afraid that talking about their problems may sound as if they are complaining or whining. Some fear that they are a burden to their partner, particularly if that partner has to take on the role of carer. Talk about it. Tell your partner how you feel, and get them to talk about their thoughts and emotions as well.

Communication is vital for the health of any relationship and it is important for both partners to accept that it may take time and a lot of effort on both parts before things improve. But all relationships have to go through hard times as well as good times, and most come through stronger than before. Bottling up your emotions, 'being strong' and holding it inside, will only lengthen the time needed for improvement and weaken the relationship as a whole. So talk.

Of course, for most of us, sex is not a topic of general conversation, and couples who can discuss just about anything else have trouble discussing sex. They can have sex, they just can't talk about it. But when something like GBS or CIDP invades their lives, it is imperative that they overcome this normal embarrassment and open up.

So talk to your partner. Talk about what your body is doing and what it's not doing. Talk about what feels bad, what feels good and what you can't feel at all, and get them to talk as well. Nothing is taboo here, nothing off-limits. Talk.

## **Physical Problems**

GBS, CIDP or any other peripheral neuropathy can bring on problems in any relationship; sexual relationships certainly aren't excluded. Weakness in the legs and arms, changes in physical sensations and discomfort because of 'pins and needles' are common; and vaginismus (a painful spasm of the vagina) and vaginal dryness in women and impotence in men are not unseen. Couple this with changes in your feelings about yourself and/or your partner, and it's understandable that the result could be a lack of libido. But all is not lost; people with all sorts of disorders carry on sexual relationships that are fully satisfying to both partners. If one organ of the body doesn't work well enough, others can provide satisfaction to both partners. If penis or vagina has problems, there are still hands and mouths; the only hindrance is lack of imagination.

## **Impotence**

Erection problems can, of course, have both physical and psychological sources; in neuropathies, damage to nerves in the pelvis can make erection difficult and can limit sensations. However, erection means that the penis has enough blood to sustain it throughout intercourse; orgasm and ejaculation can be achieved without an erection so impotence does not mean that men cannot have a sex life. In addition, there are now several ways of managing erection problems, such as Viagra, regarding which your GP, neurologist or urologist should be able to advise you. Normally, such treatments are not available on free NHS prescription for GBS or CIDP, but your doctor may be able to prescribe these drugs on the basis of the disorder having caused 'severe pelvic injury'.

## **Vaginal dryness and vaginismus**

Vaginal dryness is a problem faced not only by women with neuropathies but also by those in menopause, and occasionally by women in general. It can be remedied with one of the various water-based lubricants sold over the counter for this problem, and the application of the lubricant can actually be used as a part of foreplay.

In vaginismus, the muscles of the entrance to the vagina spasm, making sexual intercourse difficult or impossible. Often the cause is psychological: worry over some aspect of sex can itself cause the vagina to spasm. However, in those suffering from GBS and its related disorders, the cause can be the disruption of nerve impulses. Longer foreplay, particularly with more manipulation of the vaginal opening before attempting penetration, may help. Otherwise, it may be necessary, at least in the short term, to use other means to bring orgasm. More

important is loving gentleness and the assurance that intercourse isn't as important as the closeness and intimacy that sex brings.

## **Incontinence**

Some people, both those with these disorders and others in the general population, have problems with incontinence — as is seen from the number of adverts on television for special underwear. During sex, the fear of wetting can be a special problem, but protective bedding can be used. It should also be borne in mind that the sensation of wanting to pass urine can be a response and part of orgasm, and thus is not necessarily unusual in sex.

## **Strange sensations**

Few sufferers of neuropathies manage to avoid the odd sensations that demyelinated nerves bring. Burning, tingling, pain, the feeling of running water over your body or insects crawling across your legs — these don't stop for sex. Sensation can be increased to the point of painfulness, or decreased to the point of non-existence. First, talk about it with your partner. Tell them what feels good and what doesn't. Explore your body with your partner (and explore your partner's body, too) to discover what gives pleasure.

For sensations that are painful or cause burning and tingling, there are medications that can help. In addition, if you're finding that sensation is decreased, you might find a sex aid helpful. It isn't cheating to use a vibrator or other stimulation device, and when the partners use them together, they may well find both experience better sex. There are a great many sex aids available through mail order and over the Internet, or for the more courageous, in sex shops — and perhaps even your local chemist, since Boots is planning a range of sex aids.

## **Fatigue**

One of the biggest problems for people with GBS and its related disorders is fatigue. Even a little exercise can completely deplete what little energy the person has, and fatigue can be greatly exacerbated by weakness in the arms and legs. Physical disability can severely limit the physical exertion needed for sexual intercourse even though everything else is willing! As a consequence 'traditional' intercourse might be difficult or impossible. This does not mean that satisfying sex is impossible, though it may need a change of approach. Different positions are less tiring than others, and the couple may find it beneficial to arrange a 'date' that will allow the disabled person to get additional rest beforehand.

## **Psychological problems and lack of libido**

Impotence and vaginismus, numbness and tingling particularly in normally erogenous areas, severe illness where all dignity has been lost, disability in which the partner becomes a carer: it is hardly surprising that GBS and CIDP can interfere with a person's sex life, both physically and psychologically.

Those with these disorders may take a long time coming to terms with their disabilities and suffered indignities, and even longer rediscovering themselves as sexual beings. Their partners may be weary from their increased duties, or even fear complicating the recovery or course of the disorder. Others may be overly amorous, particularly if sex has been long delayed. Again, talk about it; if necessary, include your neurologist or GP in the discussion, since they may be able better to describe the effects of the disorder.

Some people find it hard to communicate any affection or physical love, particularly after going through a disabling illness. If the 'want' aspect of lovemaking has diminished, professional counselling or sex therapy may help you find ways through this.

## **Conclusion**

There are many ways to give and receive pleasure and there is more to lovemaking than penetration; finding alternatives can be fun. Some people find pleasing their partner satisfying enough when their own libido is diminished. It is important that you maintain your view of yourself as a whole person, including your sexuality, and focus more on what you can do, rather than what you cannot, as well as remembering that people love people for who they are. Social pressures can affect the way you feel and you may feel less attractive or desirable because your self-image has been dented. But with a little love, communication and experimentation, you may end up having a better sex life than you had previously.

All those things your mother warned you about: forget them. There are many books on the market, sold openly by major book retailers, that discuss everything from emotions to lubricants to positions to sex toys to problems in sex. There are sex aids and medicines. Sex is not the be-all of Hollywood lore, but the intimacy and oneness it provides is important, particularly in a relationship that has to endure the results of one of these disorders. Let go of your preconceptions of what should and should not happen in a sexual relationship and experiment. Who does what to whom does not matter; mutual enjoyment is what counts.

And keep a sense of humour: sex is supposed to be fun, not an agonising performance. Things will go right, and things will also go wrong. Learn to laugh together.

One GBSer said that while he was still in hospital, his doctor told him that he needed to be adventurous in bed. Not bad advice!

## **Tips on coping**

Generally:

- Be open with your friends and family about aspects of the disorder. Do not assume that people understand the condition; discuss it with them.
- If you suffer mood swings, do not push your family away.
- If you have disabilities or loss of sensations, it does not mean you have less to offer. You may have more.
- Try to keep a sense of humour in your relationships.

Sexually:

- Give your partner individual attention when able and needed.
- Try to understand each other verbally and non-verbally and ask your partner to explain when you do not understand.
- If you have a broad mind, try an Internet search on the keywords 'sex' and 'disability'. Amongst the dross may be some gems. In addition, try searching Amazon.co.uk using the same keywords. There is a huge amount of printed material available.

## **Contacts**

Sexual Dysfunction Association (formerly Impotence Association)  
Windmill Place Business Centre  
2-4 Windmill Lane  
Southall UB2 4NJ  
Helpline: 0870 7743571  
[www.impotence.org.uk](http://www.impotence.org.uk)

Relate  
Central Office  
Herbert Gray College  
Little Church Street  
Rugby CV21 3AP  
(lo-call) 0845 456 1310  
[www.relate.org.uk](http://www.relate.org.uk)

Wellbeing  
27 Sussex Place  
Regent's Park  
London NW1 4SP  
020 772 6400  
www.wellbeing.org.uk

Unfortunately, the charity SPOD (Sexual and Personal Relationships of People with Disabilities) has folded. If you would like to talk with the author of this document or another of our experienced contacts, please get in touch with our office. Your confidentiality will be respected.

*If after reading this guide you still have anxieties and unanswered questions, telephone our helpline on 0800 374803 (UK) or 0044 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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21/7/05