

Most people, whether they are affected by ataxia or not, find it difficult to talk about their sexual problems. Very little has been published on sexual function in ataxia. The information here is mainly based on personal information and suggestions from people with ataxia and their partners.

PEOPLE WHO ARE IN LONG TERM RELATIONSHIPS

This section has been written by people with ataxia and their partners who are affected by ataxia as adults.

By the time we are in our mid-twenties and upwards, we have formed an image of ourselves; who we are to our families with our roles as husbands, wives, mothers, fathers, lovers, providers, carers; and who we are to the world with our careers, our social status, our physical 'look'.

With the onset of ataxia, even in a mild form, this starts to change. You may have to give up your job if it involves physical activities. You may notice that other people's attitudes towards you change. They may not ever mention your difficulties because they find it embarrassing - so conversation becomes unnatural. Strangers may stare at you, and accuse you of being drunk. At home, your children may automatically start to ask your partner for anything they want. Your partner may start to take decisions which you previously took jointly. You may have to ask for help with things, and hate asking.

The result can be depression, fear, frustration and sometimes aggression. These feelings inevitably affect a couple's sex life. Partners are in a difficult situation. They are making their own adjustments and reassessing their sexual attitude and attraction to a person who is changing physically, and perhaps emotionally.

They may want to show love and concern but be unsure how to do it. They may experience a loss of sexual interest or attraction because of the disability, and feel guilty and harassed by sexual advances. All these feelings are quite natural. What's important is to discuss and deal with them.

A lot depends on your former relationship. If sex was good before, there will be a greater feeling of grief and loss, but a mutual determination to work it out. If it was unsatisfactory, it's harder to improve the situation.

Some couples will be able to work it out for themselves by talking honestly about their feelings and supporting each other through their depression and guilt. You may have to approach sexual relations very gently, emphasising affection and sensual pleasure.

If problems with sex continue, the whole relationship may start to suffer. Seek specialist advice. Specialist sex counsellors work on a psychotherapeutic or behavioural basis. Ask your GP for a referral or contact Relate.

Liz's story

Liz is 29 and has two little girls, and is currently pregnant with twins. She has been with her husband since she was 19.

I met Rob in 2001, and agreed to a date. When I told him about my condition, he was brilliant. 'We'll get through it together,' he promised. In September the following year we got married, and four months later we were over the moon to find out I was pregnant. I always feel good when I'm pregnant, and we were overjoyed when in 2007 I became pregnant with our second daughter. Two years on I'm pregnant with twins, and keep taking my vitamins to keep my bones healthy, and hoping that one day there will be a cure.

YOUNG PEOPLE

This section has been written by young people with ataxia and their parents.

You're young, attractive, a really interesting person, and attracted to boys/girls. You also have ataxia and are gradually becoming more disabled. Your existence as a sexual and social person seems to be at risk before you've had a chance.

Puberty, with its physiological and hormonal changes, is generally seen as the start of adult life, including sexual life. Sexual characteristics develop, and with them the intense preoccupation with physical appearance that is such a feature of adolescence. Ataxia is an awkward condition. With an early onset ataxia such as Friedreich's ataxia, the shift from childhood to adulthood is accompanied by a transition from 'normal' to 'disabled' status. This may make you very withdrawn and isolated. On a purely physical level, it's harder to join in activities: going to concerts, sleepovers at friends' houses, pubs, clubs, dances.

Because it was now so obvious to everyone that something was not right, I became very self-conscious. To cope with this, I started drinking a lot. I cut myself off from my friends, thinking that they wouldn't want to be seen with someone like me, so I spent a lot of time on my own. (Max)

Then there is the problem of where you live. If you remain at home, you may feel you have no privacy or control. Some parents cannot cope with the idea that their teenage son or daughter who has ataxia also has sexual feelings.

Difficulties with transport, access to public places, and work opportunities can help you to feel cut off from opportunities for social and potentially sexual interaction.

The sexual problems that young people with ataxia face are not different in kind from those of other young people. But ataxia does magnify and give a sharper edge to these 'normal' problems. There are extra problems in finding a partner who can see beyond the physical disability and recognise you as a person with potential for a sexual and emotional relationship. There are problems in getting out and about to meet people and have a social life.

The main issue, though, is psychological withdrawal and loneliness. Many young people with ataxia are determined not to be controlled by it. Their interesting, outgoing personalities and their belief in themselves as attractive people make them popular and wanted. Positive sexuality is about interaction, communication and personal engagement. It's about saying YES!

See *Further Information* for more suggestions

PHYSICAL AND PSYCHOLOGICAL FACTORS

Sex is not just about penetration but ways of both giving and receiving pleasure. For loving and sex to be at their best, partners must help each other, and tell each other what they like.

Physical and mental play is usually important in getting ready for intercourse. It can be especially important for disabled people. There are no positions specifically for disabled people, only lots to try. Some days you may prefer one, some days another. If you are trying something for the first time, take it slowly, see how you feel and check that your partner is OK. If you feel uncomfortable or find there is too much pressure on your body, switch position.

Find gentle ways of saying what you don't like. Suggest alternatives without discouraging your partner. Encourage your partner to feel able to look for their own pleasure. This will help both of you.

If you suggest new ways of having sex to your partner, wait until you are both feeling relaxed and sexy, then suggest "It's great when you do this..." or "I'd love to try that..." You may find your partner is more willing to try new things than you imagined.

Penetration is not essential to have a good time, and it doesn't have to be deep for both partners to find it enjoyable. If penetrative sex is your goal, be aware that many people do not orgasm from being penetrated, and need additional manual or oral stimulation. Everyone is different, so it's essential to ask, watch and learn.

Communicate Let your partner know what gives you pleasure, and be receptive to their needs. Conquer shyness between you, and remember that whatever gives you pleasure, is fun, and does not cause harm, is OK. However, if one of you does not wish to engage in a particular sexual activity, then the other should respect this.

SOME PRACTICAL SUGGESTIONS

Gentle sex, to avoid breathlessness or rapid heartbeat, may be better for some people with ataxia. You may find penetration difficult or just hard work, but that you can easily enjoy manual or oral stimulation. Many people prefer this. Avoid rushing or thinking too much about orgasm. Concentrate on the pleasurable feelings that you and your partner are experiencing.

Lubricants can make a big improvement to your sex life. Remember if you use condoms to buy a water based lubricant. Oil-based versions can damage rubber.

Continence can be helped by having a regular bowel and bladder programme. Go to the toilet immediately before you have sex to minimise any problems. Also empty your bladder again immediately after sex; this helps prevent urinary tract infection. If you have a **catheter** you can still have sex. Suprapubic catheters which go into the bladder through the abdominal wall may make sex easier, but you can still have sex with a normal bladder-outlet catheter. Your continence advisor may be able to teach you and your partner how to take it out and put it back in after sex, or you may have sex with it still in place.

Sex aids/toys

Their rather furtive image has changed significantly in recent years. 'Sex toys' are much more mainstream. Many people with and without a partner use sex aids to help them masturbate. If you are unable to visit your local sex shop for whatever reason, there are plenty of internet sites offering this service.

SEXUAL PROBLEMS

Sexual problems are quite common for couples who stop communicating, or who believe that sex is something that just happens magically. You may be able to overcome some issues by discussing them with your partner, perhaps referring to books. However, if you can't find a way through, your next step is to talk to your GP or sexual health clinic. They should know whether you need practical information, medical help or relationship therapy. They may, for example, be able to refer you to a disability-friendly sex therapist.

Emotional and sexual problems occur where people feel too shy to experiment or tell their partner what they want. Or where their situation changes, and partners avoid discussing these changes.

As well as affecting coordination, people with ataxia may get tired and sometimes be depressed. Disability obviously affects, and may limit, sexual techniques and positions, and sex drive may be lowered by fatigue or depression. Yet few people whether they have a disability or not can honestly claim to have a perfect sex life. A mutually satisfying sexual partnership needs time. Learning what you really want and what gives another person pleasure is a process. Sexual needs and activities vary from person to person, and change for each person during their life. The most important thing is to feel comfortable with your own image of your body and your desires.

PAID SEX

Paying for sex is a choice made by some people who are not looking for a relationship. If you want a relationship, be careful you don't come to rely on professional sex.

Even if they haven't had a client with ataxia before, good sex workers are probably experienced with disabled clients. Whatever your request, from learning how to chat someone up or please them sexually to exploring your fantasies, they have probably heard it before.

FURTHER INFORMATION

Outsiders (www.outsiders.org.uk) 16+

A nationwide, self-help, community “providing regular mailings, and unthreatening events for people to socialise”. The independent group is run by and for disabled people who may “**feel isolated, dejected or afraid to make that initial move to make new friends and perhaps find love and romance.**” **This organisation has thrived for 30 years.**

The website has a number of downloadable leaflets.

Sex and Disability Helpline 11am -7pm weekdays 0707 499 3527 sexdis@outsiders.org.uk

BCM Box Outsiders, London WC1N3XX (enclose sae)

Relate (www.relate.org.uk)

Offers counselling to adult couples with relationship difficulties.

Whether offices have wheelchair access is listed on the website.

Tel: 0845 4561310 enquiries@relate.org.uk

For the Relate Direct Counselling Service, book a session on 0845 1304016

REGARD (www.regard.org.uk)

Founded in 1989 “to address the absence of information and lack of understanding about the reality of disabled lesbians and gay men within the disability movement.”

Fax 08444 431277 secretary@regard.org.uk

BM REGARD, London WC1N 3XX

The Samaritans (www.samaritans.co.uk)

The Samaritans are there to speak to anyone in confidence about many different problems that people are experiencing.

Tel: 08457 909090

or correspond by email jo@samaritans.co.uk

or letter Chris, PO BOX 9090, Stirling, FK8 2SA

FOR YOUNG PEOPLE

Contact a Family (www.cafamily.org.uk/packs.html) downloadable booklet for young, disabled people ‘Growing Up, Sex and Relationships’. Free as pdf or order hard copy for £1.50.

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