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Relationships, Sex and multiple system atrophy

This factsheet addresses how MSA may impact upon relationships and how being aware of some of the issues can enable people to maintain happy and close relationships.

MSA causes autonomic dysfunction which occurs when the nerves that control involuntary bodily functions are damaged. This may affect blood pressure, temperature control, digestion, bladder function and sexual function.

However, it is important to note that MSA is a very individual condition, and your experience may be different to other people living with MSA.

Who is affected?

Sexual dysfunction can affect people of any age, although it is more common in people aged over 40 years old and is often associated with a decline in health, related to ageing. If you are concerned about how MSA is affecting your intimate and sexual function please do not feel embarrassed about talking to your GP, Consultant, Parkinson's Nurse or MSA Nurse Specialist about this. They are experienced in understanding that this can be difficult to talk about and can help you get appropriate support to address the issues sensitively.

In MSA, sexual dysfunction can be an early symptom. Often the first symptom of MSA for men is erectile dysfunction; signs of which are being unable to achieve or sustain an erection, and ejaculatory difficulties. We do not know whether women with MSA have comparable difficulties with sexual function. One report suggests that women with MSA might have reduced erotic genital sensitivity as an early symptom.

Sexual dysfunction can present in different ways; for men this can include erectile and ejaculation difficulties, impaired sex drive and reduced libido. In women it can include difficulties with reaching an orgasm, pain during sex, vaginal tightness, loss of lubrication and impaired sex drive and reduced libido.

Sexual dysfunction is much more common in MSA than in Parkinson's disease and may be associated with postural hypotension (a drop in blood pressure when standing).

A decrease in sex drive can be a normal sign of ageing and can vary from person to person. Some medications can also affect sex drive or sexual activity, so talk to your doctor about this. Other reasons for sexual dysfunction can be physical, hormonal, psychological and social in both men and women.

How does it affect people with MSA?

A diagnosis of MSA may affect your intimate relationship with your partner, if you have one. It can take time for both of you to come to terms with the changes that MSA can bring and how the future you may have planned together has taken a different direction.

Any long-term illness or disability is likely to have an impact on even the healthiest of relationships. Sex is an important part of life for many people, so any problems you experience may influence your life. However, sexual problems can be overcome, or other forms of intimacy and togetherness can be found.

For some people, the enormity of their diagnosis can affect their whole emotional life, including their sex life, whilst for others the sexual side of their relationship may become less important. Some people find other shared activities and time spent together becomes more rewarding.

Anxiety, fear, tiredness and depression can all affect how one is feeling generally, and other medical conditions such as diabetes, heart disease or the menopause can also affect sexual function. Some medications can have a detrimental effect on sexual desire, so it is important to discuss these with your GP.

Fatigue can have a big impact on sexual desire, and you might feel you simply do not have the energy. This can sometimes be misinterpreted by a partner who may come to think that you are no longer interested in sex or intimacy. It is important to discuss these feelings. If tiredness is an issue try being intimate or having sex at a different time of the day when you are less fatigued.

Physical intimacy is an important part of many relationships. Some symptoms may make it more difficult to be spontaneous, and as the condition progresses, the ability to maintain a sexual relationship may be affected, but touch is an essential part of being human and you can experience this, whatever your physical condition.

Changing Roles

When your partner is also your main care provider, they may find it difficult to shift between the roles of carer and partner. You might also find it difficult to switch from being 'cared for' to partner. Completely separating caring activities from sexual or romantic activities can help.

You may both have issues with tiredness and may need to consider some help from care agencies or social services. There may also be tasks of a highly personal nature that get in the way of your relationship as a couple and that you would perhaps prefer paid carers to carry out. The physical and emotional aspects of being a carer can also affect energy levels and libido. Our Carers Guide contains more information on how carers can look after themselves and the person they are caring for.

Communication

When one person in a relationship becomes unwell the dynamics of that partnership can change, leading sometimes to frustration, anger, guilt and blame. All these things can be softened by good communication and discussing each other's expectations.

Above all, it is important to talk to your partner as they may be worrying about what the future holds. The best relationships are built on honest, open communication. Allow time to talk through your worries together, when you are not overtired or likely to be disturbed.

Once you have discussed each other's needs, keep this going. MSA can affect all types of communication – verbal, written, and facial expression, but it's important to keep talking as much as possible so you know what the other is thinking and you can understand one another so much better.

Body image may also be a concern, particularly if someone has a urinary catheter or PEG (feeding) tube. Often people are worried about dislodging these, but this is rarely the case as they are usually well secured. Your MSA Nurse Specialist can reassure you regarding these issues so do contact them if you have any questions.

Fear of incontinence during sexual activity may also have a negative impact, not only on self-esteem, but also on personal relationships. If you experience urinary incontinence certain drug treatments may be helpful, so discuss this with your specialist.

When you have an appointment with your specialist you might find it helpful to write down the issues you've been having, or any questions you want to ask. That way, if you do get nervous, you won't forget what you wanted to discuss.

Management

Medication for problems with erectile functioning can be helpful for many people with MSA and can improve esteem and confidence and therefore quality of life.

Oral medications are taken by mouth as a tablet. There are four medications available, these are: sildenafil (Viagra), tadalafil (Cialis), vardenafil (Levitra) or avanafil (Spedra). They can be used to achieve and maintain an erection. Research has shown significant improvement in quality of sex life with these drugs. They work by increasing blood flow to the penis. However, they can reduce overall blood pressure so if you have postural hypotension you should make sure this is known before you are prescribed such medication. You and your partner can be advised on how to manage a drop in blood pressure if this happens.

Non-oral therapies include injections, urethral treatments (inserted into the tube in the penis) and topical creams (rubbed into the skin of the penis) as ways of delivering a pharmacological agent (medicine) into the penis to achieve an erection. These can be considered if taking a tablet doesn't work. A medication called alprostadil is available in various forms. Alprostadil can be given as a cream called Vitaros, as a urethral pellet called MUSE, or as injections called Caverject or Viridal. A specialist nurse or doctor can teach you and your partner how to use and administer these medications.

Finally, vacuum pumps can be used to encourage blood flow to the penis, causing an erection. These vacuum constriction devices consist of a cylinder and pump which are used to increase the size of the penis and a constriction ring is then placed around the base. Again, a specialist can advise on the use of a vacuum pump.

It is recommended that you see your GP or MSA Specialist for advice before starting on any treatment for sexual dysfunction. Your doctor will undertake an individual assessment and consider factors such as other medications, side-effects and most appropriate treatment. They may refer you to a specialist sexual dysfunction clinic. They should also advise on things to look out for and actions that you should take for safety reasons, for example what to do if there is a drop in blood pressure after taking medication.

Although treatment for erectile dysfunction can be bought on the internet, these are often fake drugs and can cause side-effects, we do not recommend doing this without speaking to your doctor first.

Women may also experience sexual dysfunction, although there is less research and understanding of these in relation to MSA. Loss of sex drive, vaginal dryness and the menopause may impact upon sexual relations. Addressing fatigue (see our factsheet on 'Fatigue in MSA'), effective lubrication and altering positions for sex may all help. The use of medications for sexual dysfunction e.g. Viagra have never been properly studied in women. It is not known if these are safe or effective for use with women and therefore no medication has been licenced to treat sexual dysfunction in women with MSA.

Specialists working in sexual dysfunction clinics and services are experienced in working with both individuals and couples and are sensitive to the needs of people from varying cultures, backgrounds, sexual orientation and genders. Referrals to local services can be made by your GP, or in some cases by the Consultant you see for MSA.

Talking therapies

Talking therapies is a term that covers psychological therapies that involve a person talking to a therapist about any problems or concerns they may be having. These include counselling, cognitive behavioural therapy (CBT), psychotherapy, family therapy, relationship counselling, and psychosexual therapy.

Many psychosexual therapists are also relationship therapists and can address both the practical problems you may be experiencing and help with any emotional or relationship difficulties. They can help people who are struggling to adapt to or communicate about their difficulties. Hospices also offer very good counselling services and are familiar with the types of issues that can affect people living with a long-term condition. Counselling on the NHS is often limited, but it is still worth asking your doctor to refer you.

Most health and care professionals understand sexual issues and will discuss these with you. But they might not wish to be intrusive, so they may expect you to raise your concerns with them rather than take the lead themselves. Similarly, Neurologists, Urologists and Nurse Specialists will be experienced at discussing sexual issues in an appropriate way and will put you at ease. Parkinson's Nurse Specialists provide expert advice and support to people with MSA and those who care for them. This includes dealing with anxieties about sex and relationships. They can also act as a liaison between other health and social care professionals to make sure your needs are addressed.

Further help and support

Living with MSA can be stressful and sometimes exhausting but making the time and space to maintain loving and caring relationships is important for everyone.

Being open, communicative and being prepared to explore intimacy in different ways can help support this. Overleaf are some organisations that you may find useful:

College of Sexual and Relationship Therapists
COSRT
PO Box 13686
London SW20 9ZH
Telephone:
020 8543 2707
Email: info@cosrt.org.uk
www.cosrt.org.uk

Relate/Relate NI/Relationships Scotland
(England and Wales)
Telephone 0300 100 1234
www.relate.org.uk
(Northern Ireland)
Telephone 028 9032 3454
www.relateni.org
Relationships Scotland
Telephone 0845 119 2020
www.relationships-scotland.org.uk

United Kingdom Council for
Psychotherapy (UKCP)
020 7014 9955
info@ukcp.org.uk
www.ukcp.org.uk

British Association for Counselling
and Psychotherapy (BACP)
01455 883 300
bacp@bacp.co.uk
www.bacp.co.uk

Institute of Psychosexual Medicine
(IPM)
020 7580 0631
admin@ipm.org.uk
www.ipm.org.uk

Further reading

Enabling romance: a guide to love, sex and relationships for people with disabilities (and the people who care about them) by Ken Kroll, Erica Levy Klein. Published by No Limits Communications (2001). ISBN: 0971284202.

The ultimate guide to sex and disability by Cory Silverburg, Miriam Kaufman and Fran Odette. Published by Cleis Press (2007). ISBN: 1573443042.

The sex book by Suzi Godson. Published by Cassell Illustrated (2003). ISBN: 1844035115.

The Trust's contact details

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB

T: 0333 323 4591

E: support@msatrust.org.uk

W: www.msatrust.org.uk

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References for this information sheet are available by contacting support@msatrust.org.uk.

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