

- Introduction
- Who is affected?
- How does it affect people with MSA?
- Changing roles
- Communication
- Management
- Further help and support

## Relationships, Sex and multiple system atrophy

### Introduction

This leaflet 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 what is called autonomic dysfunction and 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?

The first symptom of MSA for men is often erectile dysfunction (being unable to achieve or sustain an erection). However, sexual dysfunction can affect people of any age, although it is more common in the 40-65 year range and is often associated with a decline in health, related to ageing.

We do not know whether ejaculation and erectile dysfunction are equally affected, or whether women have comparable difficulties with sexual function. One report suggests that women with multiple system atrophy might have reduced erotic genital sensitivity as an early symptom.

Sexual dysfunction is much more common in MSA than in Parkinson's disease and may or may not be associated with postural hypotension (a drop in blood pressure when standing).

## **How does it affect people with MSA?**

A diagnosis of MSA may affect your intimate relationship with your partner. 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 have a big effect on 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, sex life included, 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 affect 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 more alert.

**Physical intimacy is an important part of many relationships. Some symptoms may make it more difficult to be spontaneous, 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 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.

## **Communication**

When one person in a relationship becomes unwell or disabled, the dynamics of that partnership can change, leading sometimes to frustration, anger, guilt and blame. All of 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 had a discussion about 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 Nurse Specialist can reassure you regarding these issues, 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 particular 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, confidence and therefore quality of life.

**Oral medications** such as Sildenafil (Viagra), Tadalafil (Cialis), or Vardenafil (Levitra) 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 and so if you have postural hypotension you should make sure this is known before you are prescribed such medication.

Even if this is the case another option could be to use the shorter acting Tadalafil. The person with MSA and their partner can be advised on how to manage a drop in blood pressure if this happens.

**Non-oral therapies** include vacuum constriction devices which 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. It would be best to attend an Erectile Dysfunction Clinic to be told more about this and how to work the device.

Intracavernosal injections and intraurethral plugs (a way of delivering pharmaceutical agent without injection which allows a drug to be inserted into the urethra and massaged into the penis) are less used nowadays following the introduction of oral agents. Anyway these are probably less useful in neurological conditions.

Penile implants are rarely used and are not recommended for people with MSA.

Women may also experience particular issues, 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) effective lubrication and altering positions for sex may all help.

Again, speak to your Nurse Specialist or your consultant for advice.

## Talking therapies

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 these 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 care professionals understand sexual issues and will discuss them 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 your 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 met.

## 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 aim.

Here 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](mailto:info@cosrt.org.uk)

[www.cosrt.org.uk](http://www.cosrt.org.uk)

The Sexual Advice Association

Suite 301, Emblem House, London Bridge Hospital,

27 Tooley Street London SE1 2PR

Telephone 020 7486 7262

[info@sexualadviceassociation.co.uk](mailto:info@sexualadviceassociation.co.uk)

[www.sexualadviceassociation.co.uk](http://www.sexualadviceassociation.co.uk)

Relate/Relate NI/Relationships Scotland

(England and Wales)

Telephone 0300 100 1234

[www.relate.org.uk](http://www.relate.org.uk)

(Northern Ireland)

Telephone 028 9032 3454

[www.relateni.org](http://www.relateni.org)

Relationships Scotland

Telephone 0845 119 2020

[www.relationships-scotland.org.uk](http://www.relationships-scotland.org.uk)

Sexual Advice Association  
Information about sexual difficulties.  
Helpline 020 7486 7262  
[www.sexualadviceassociation.co.uk](http://www.sexualadviceassociation.co.uk)

United Kingdom Council for  
Psychotherapy (UKCP)  
020 7014 9955  
[info@ukcp.org.uk](mailto:info@ukcp.org.uk)  
[www.ukcp.org.uk](http://www.ukcp.org.uk)

British Association for Counselling  
and Psychotherapy (BACP)  
01455 883 300  
[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)  
[www.bacp.co.uk](http://www.bacp.co.uk)

Institute of Psychosexual Medicine  
(IPM)  
020 7580 0631  
[admin@ipm.org.uk](mailto:admin@ipm.org.uk)  
[www.ipm.org.uk](http://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:

MSA Trust, 51 St Olav's Court, City Business Centre, Lower Road, London SE16 2XB  
T: 0333 323 4591 | E: [support@msatrust.org.uk](mailto:support@msatrust.org.uk) | W: [www.msatrust.org.uk](http://www.msatrust.org.uk)

MSA Trust Nurse Specialists:

Samantha Pavey (South East & East England): T: 0203 371 0003 |

E: [samantha.pavey@msatrust.org.uk](mailto:samantha.pavey@msatrust.org.uk)

Katie Rigg (Scotland, Ireland and North England): T: 01434 381 932 |

E: [katie.rigg@msatrust.org.uk](mailto:katie.rigg@msatrust.org.uk)

Jill Lyons (Wales & South West England): T: 01934 316 119 |

E: [jill.lyons@msatrust.org.uk](mailto:jill.lyons@msatrust.org.uk)



#### Disclaimer

We have taken every care to ensure the accuracy of the information contained in this publication. It is produced independently, is not influenced by sponsors and is free from endorsement. The information should not be used as a substitute for the advice of appropriately qualified professionals, if in any doubt please seek advice from your doctor or legal professional.

References for this information sheet are available by contacting [support@msatrust.org.uk](mailto:support@msatrust.org.uk).

#### Feedback

Your feedback helps us ensure we are delivering information to the highest standard. If you have any comments or suggestions please complete a short survey at: <http://svy.mk/OZHzsU> or contact us at [support@msatrust.org.uk](mailto:support@msatrust.org.uk).