



**The Leeds
Teaching Hospitals**
NHS Trust

Multiple System Atrophy (MSA)

Information for patients and carers



Leeds Centre for
Neurosciences

Multiple System Atrophy (MSA) is a progressive neurological condition, currently there is no cure but there is on-going research into the causes with a view to new treatments and finding a cure.

MSA causes damage to different areas of the brain, the damage occurs due to an accumulation of protein that causes the nerve cells to shrink and become less effective. The shrinkage of these cells occurs in different parts of the brain and lead to symptoms that include problems with movement, speech, balance and autonomic functions such as bladder control.

The name MSA represents:

Multiple: more than one

System: brain structures that control different functions

Atrophy: cell shrinkage and loss of function

What is MSA?

Early symptoms can present as Idiopathic Parkinson's disease and some patients may wait two to three years before your Neurologist reaches a differential diagnosis of MSA. This is very common and reflects the challenges of identifying and managing the disease. MSA may sometimes be referred to as Parkinson's plus syndrome or Parkinsonism. These are general terms which refer to a group of Neurological disorders that cause movement and non-motor problems similar to those seen in Parkinson's disease.

MSA usually occurs in adults between the ages of 50-60 years but can be seen in both younger and older adults. There is no evidence that suggests the condition is hereditary. There are approximately 3000 people in the UK affected by MSA, around five in every 100,000 people. The average life expectancy varies from person to person, in some rare cases people may live up to 15 years from diagnosis.

The three main areas of the brain affected by MSA are the basal ganglia, the cerebellum and the brain stem.

Damage to the basal ganglia causes parkinsonism demonstrated by:

- Muscle stiffness with or without tremor.
- Slowness of movement
- Lack of balance
- Noticeable handwriting changes

Damage to the cerebellum causes:

- Ataxia - poor coordination, clumsiness, unsteady walking and slurred speech.

Damage to the brain stem causes autonomic dysfunction:

- Feeling dizzy or fainting due to blood pressure
- Bladder problems
- Erectile dysfunction
- Pain around the neck and shoulders
- Respiratory changes
- Difficulty maintaining and regulating body temperature

The MSA Trust

This is a national charity providing excellent, detailed advice, support and information to people living with MSA, carers and associated health professionals. They provide educational resources, practical and emotional support and financial advice. The MSA Trust have four MSA Specialist Nurses across the UK, they offer support and advice to patients, carers and health care professionals.

Telephone: [0333 323 4591](tel:03333234591)

Email: support@msatrust.org.uk

Website: www.msatrust.org.uk

Driving and MSA

You are legally obliged to inform the Driver and Vehicle Licensing Agency (DVLA) and your insurance when you have received your diagnosis. You will be medically assessed as to whether you can continue to drive, this will be based on the severity of your symptoms.

Treatment

In some instances, you may start or continue with medication that is commonly used to treat Parkinson's disease. Some people with MSA notice a mild benefit from taking these types of medication, especially when treating symptoms of stiffness and slowness but may find the medication causes problems controlling blood pressure. Your specialist team and GP will advise you on medication.

Medications commonly used

Levodopa

Co-beneldopa (levodopa and benserazide) available as unbranded and branded formulations called Madopar, in standard and modified release capsules or dispersible tablets.

Co-careldopa (levodopa and carbidopa) available as unbranded or branded tablets called Sinemet.

Dopamine agonists

Ropinirole, pramipexole tablets, rotigotine patches. There are many branded names for these drugs including: Ipinnia, Requip, Ralnea, Repinex, Ropiqua, Spirocco, Ardatrel, Mirapexin, Oprynea, Pipexus and Neupro patches.

The role of the multi-disciplinary team

You will remain under the care of a Neurologist and the Movement Disorders Nurse Specialist team. This is to ensure your care is tailored to help manage your individual symptoms.

The multi-disciplinary team (MDT) offers the best approach for management of symptoms and works towards improving quality of life.

The MDT can comprise of:

Movement Disorders Nurse Specialist:

- A source of help, support and information for you, your carers and health professionals.
- To provide advice over the telephone or by email and to review you in either the clinic or at home.
- Work with your consultant, GP and other health professionals to optimise your treatment plan.
- Provide information about medication and prescribe or recommend medications for symptom management.
- Refer you to other health professionals such as Physiotherapists, the speech and swallowing team and community occupational therapists.

Physiotherapist

Provide advice, practical guidance and support for mobility issues, such as impaired gait, falls and balance.

Speech and swallowing therapist

Provide advice, practical guidance and support for communication and swallowing difficulties and provision of communication aids.

Occupational therapist

Provide advice, practical guidance and support with aids and adaptations equipment to use at home.

Palliative care team

Provide advice, practical guidance and support for pain control, counselling and psychological support and day therapies.

You may require support from other members of the multi-disciplinary team such as a social worker, mental health team, district nurses, community matron, continence service (CUCS) and dietician. These referrals are usually generated by your general Practitioner (GP) as advised by the Neurology specialist team.

Thinking ahead and Advanced Care Planning (ACP)

Early discussions regarding ACP are particularly important because of the communications difficulties people with MSA can experience. Although these conversations may be difficult, they are vital in seeking your views on treatment desires and wishes towards your future care.

These conversations can be held with your GP, your Specialist Nurse, Neurologist and or the Palliative care team. There are legal documents that can protect your wishes such as Advanced Decision to Refuse Treatment and Lasting Power of Attorney for Health and Welfare. For more information contact your specialist team.

Research and brain donation:

Research

As a regional Neurosciences centre, we are involved in clinical research trials for all movement disorders, you may be asked if you wish to take part. This is entirely voluntary and can withdraw at any time.

Brain donation

An individual's decision to donate their brain to MSA research after they die creates a long-lasting legacy, one brain can support multiple research projects over many years.

If you wish to discuss further, you can speak to your specialist team or to find out more information please go to the MSA trust website or contact Queen Square Brain Bank in London **0207 837 8370**.

Useful contact numbers and websites

Movement disorders Nurse Specialist team

Call: **0113 392 6689**

Email: pd.nurse@nhs.net

MSA Trust

Helpline and information service

Phone: **0333 323 4591**

Email: support@msatrust.org.uk

Website: <https://www.msatrust.org.uk>

Parkinson's UK

Helpline and information service **0808 800 0303**

Email: helpline@parkinsons.org.uk

Website: <https://parkinsons.org.uk>

Text relay: **18001 0808 800 0303** (textphone users only)

DVLA

Phone: **0300 790 6806**

Website: www.dvla.gov.uk

Carers UK

Phone: **0808 808 777**

Email: **advice@carersuk.org**

Website: **www.carersuk.org**

Carers Leeds

Phone: **0113 380 4300**

Email: **advice@carersleeds.org.uk**

Website: **www.carersleeds.org.uk**

Age UK

Phone: **0800 055 6112**

Website: **www.ageuk.org.uk**

National Hospice Information

Phone: **0207 520 8200**

Website: **www.hospiceuk.org**



What did you think of your care?

Scan the QR code or visit bit.ly/nhsleedsfft

Your views matter



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