

The MSA Trust

The Multiple System Atrophy Trust (previously the Sarah Matheson Trust), was created after the founder Sarah Matheson was diagnosed with MSA in 1993 and became aware there was little support for people living with MSA in the UK. The Trust became a registered charity in 1997 and was renamed in 2010. It is run today by a group of trustees, many of whom had a personal connection to Sarah, or who have experienced MSA with a family member. Sir Roger Bannister CBE and Professor Christopher Mathias are the Trust's Patrons.

The vision of the MSA Trust is a world free of MSA – in the hope that one day there will be a cure for this devastating disease. The Trust is committed to supporting people whose lives are affected by MSA, their carers, family and friends. Support is provided in many ways, including:

- Three Nurse Specialists working within the MSA community.
- A telephone and email support service supplemented by our website.
- A network of 35 volunteer-led support groups located around the UK.
- An online local hub to harness community knowledge and to offer support at local level.
- An online forum where members can connect with others with similar issues.
- Education and support for health and social care professionals to help them provide the best possible care and treatment for people with this rare and complex disease.
- A sense of community for people isolated by the challenges of MSA.

The MSA Trust has a five-year strategic plan which identifies five goals that reflect the views of our members. These five goals are:

- To develop a volunteer network
- To educate healthcare professionals
- To increase commitment to research
- To increase support for carers
- To develop a model for MSA centres

Research priorities for the MSA Trust

The funding of research grant projects with the aims of finding the cause of MSA and improving treatments for people with MSA, through drug discovery and translational studies including, for example, the treatment of important symptoms in MSA.

To seek collaborative partnerships with other organisations involved in neurodegenerative research, to increase research capacity, share resources and generally raise the profile of the disease.

To encourage engagement with the pharmaceutical industry, in particular around target identification and drug discovery, working in collaboration with the Trust-funded MSA UK Network. The Network will provide a biobank, enabling sharing of samples amongst the MSA research community and ultimately facilitate the participation of patients in clinical trials.

To develop interest amongst clinical and non-clinical scientists to undertake MSA research by

demonstrating the on-going commitment of the Trust to fund research, and by building links with existing research structures (e.g. the National Institute for Health Research and the Dementias and Neurodegeneration (DeNDRoN) Specialty), thereby organically growing the MSA scientists and clinicians of the future.

To support international scientific collaboration, enabling participation in European initiatives and considering overseas grant applications from researchers with a demonstrable link to a UK based Principal Investigator or institution.

The Role of the Nurse Specialists

The MSA Trust Nurse Specialist's primary role is information and support to those living with MSA, their carers, families and the professionals supporting them. They attend specialist MSA clinics across the UK by invitation from Neurologists with an interest in MSA, and offer education sessions to anyone supporting someone with MSA. The MSA Nurses also liaise closely with Parkinson's Disease Nurse Specialists, Community Matrons and Palliative Nurse Specialists.

Why is this role needed?

People's worlds fall apart. They don't know where to turn. They are frequently overwhelmed and unable to act. Often Health Professionals are not familiar with MSA. As people's experience of MSA is individual and symptoms and challenges are constantly changing, ongoing trusted support is vital.

What does the role involve?

- Answering (and initiating) calls and emails to people living with MSA and their carers and families, including Health and Social Care Professionals. Last year the nurses dealt with over 2500 telephone and 14000 email enquiries. Commonly asked questions are "How long have I got?", "Am I going to pass this onto my children?" and "How will I die?"
- Attending specialist MSA clinics. Last year the nurses attended 55 clinic sessions at 11 locations, reaching 345 patients.
- Providing advice and practical help at Support Groups: last year the nurses attended 34 support groups, with 177 attendees.
- Teaching – formally at conferences, and informally with local services. Thirty-seven training courses were given last year.
- Contributing to raising the profile of MSA and the Trust at meetings e.g. National Palliative Care and contributing to policy work e.g. NICE guidelines.
- Acting as a resource to the Trust, supporting colleagues in communications and fund-raising.

The Nurses are available by telephone or email Monday to Friday 9 to 5, and referrals can be made by telephone, email or post.

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