Multiple System Atrophy Trust

www.msatrust.org.uk

The Multiple System Atrophy Needs Surveys

Multiple System Atrophy is a rare progressive neurological condition affecting adults. With a prevalence of around 4.5 people per 100,000 it causes significant problems with movement, speech, balance and autonomic body functions such as bladder and blood pressure control.

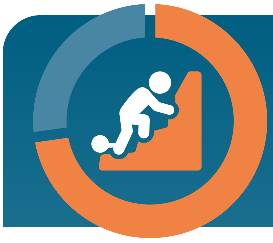
It leads to premature death and there is currently no cure. The MSA Trust is the only organisation covering the UK and Ireland specifically focussed on supporting people affected by MSA.

Our MSA Needs Survey 2022 was completed by a total of 520 people.*

215	people living with MSA
214	current carers
91	people had previously cared for someone with MSA

Headlines

The vast majority of people say that MSA **severely** impacts their quality of life with only 5% saying they were independent.



73% of respondents stated that MSA impacts **severely** on their quality of life.

Support with physical needs is often lacking, compounded by a lack of knowledge about MSA amongst health and care professionals.

44% of respondents felt help for their physical needs was **poor** or **very poor.**

Similarly, support with emotional aspects of MSA diagnosis is also viewed as limited.

> *“It affects every aspect of my life, from the second I wake up I constantly think about it. I can’t ever forget about it as it affects everything, my speech, my swallowing, my walking, my balance and coordination and it has made me incontinent.”*

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*All percentages and statistics given relate to those that responded to that specific question.

Over 70% of people with MSA reported feeling **depressed** or **anxious.**

But **63%** of respondents rated their emotional help for this as **poor** or **very poor.**

> *I went through what can only be described as a grieving process. For the life we would never have. I was lucky I was able to talk friends and come to terms with it.*

This lack of support impacts both people living with MSA and their carers.

76% of people living with MSA had thought to some extent about what they wanted to happen towards the end of their lives.

38% of respondents had discussed end-of-life care options with a health care professional.

Of those who had this discussion, **over 81%** found the conversation helpful.

MSA Trust services are highly regarded with our MSA Nurse Specialists, information materials and Support Groups providing a vital role in filling in current gaps and reducing isolation.

MSA and the UK Rare Disease Framework

In this second iteration of our Needs Survey (following our 2019 survey), we looked more specifically at the four issues identified as crucial in the new UK Rare Disease Framework. This will help us in providing future evidence through tracking progress of the four issues, as well as targeting our own work in these areas.

1 | Helping patients get a final diagnosis faster

49% of people living with MSA said it took between **two to four years** after experiencing symptoms to get their diagnosis. Some reported even longer.

Parkinson's Disease and Ataxia were the most commonly reported initial diagnoses.

The top 3 symptoms that prompted people to initially seek medical help were:

1. Balance issues
2. Difficulty walking
3. Dizziness/blood pressure issues

2 | Increasing awareness of rare diseases amongst healthcare professionals

56%

of people with MSA responded that they thought their GP and practice **did not understand** MSA.

41%

of respondents were **not** given any information about what to expect from living with the condition on the day they were diagnosed.

> *“No support about what to expect and limited advice on all aspects.”*

> *“Every time we talk/see the doctor we have to explain again about MSA symptoms and the disease, it is very frustrating.”*

Only

20%

of carers reported that their needs were considered at clinic appointments, despite their role being so vital.

3 | Better co-ordination of care

Over three quarters of respondents with MSA stated that no-one coordinates their care locally.

89%

of carers experience fatigue and tiredness.

Over 60% of carers said that they had never received a carers assessment despite the significant and complex needs people with MSA experience.

34%

of people had **not** been referred to any specialist palliative care or hospice support.

However, of those that had, **82%** reported that the services had knowledge of MSA.

Only 1 in 10

had been offered social work help despite MSA impacting severely on quality of life, with **66%** of people needing help with at least half of daily activities.

> *“I feel that more timely discussions need to be held between health professionals and families about palliative care and end of life care. I planned these and discussed my wife’s wishes. I feel that health officials stay clear of such discussions for their own emotional well-being.”*

4 | Improving access to specialist care, treatment and drugs

Where available, specialist support was highly valued, with Specialist Consultants and our MSA Nurse Specialists receiving positive mentions.

> *"I think that it would be better if we saw the same person regularly instead of being a person who helped the doctor understand what MSA is."*

85% of people with MSA said they had **never** been offered Multi-Disciplinary Team support. Given the complexity of needs arising from MSA this is very worrying.

38% of people with MSA found it fairly or very difficult to get to their healthcare appointments.

There were varied preferences when asked about face to face or 'virtual' appointments, with a common view that it all depended on what the appointment was for.

The MSA Trust

82% of people living with MSA felt the MSA Nurse Specialists provide them with valuable support.

86% of respondents rated the information provided by the MSA Trust as **good** or **excellent.**

> *"Having the Trust to help is very reassuring, knowing you have always got a nurse specialist who will be able to help you and advise, and the Zoom calls are excellent."*

> *"MSA Trust is the only reliable source of holistic information."*

The results of the 2022 MSA Needs Survey will directly influence the Trusts organisational strategy for the next four years. This will include service development, new project work and impact on policy work in the wider charity and health and social care sectors. We want to continue to work with people affected by MSA and those who support them. If you feel you can contribute somehow, please contact us.

The full technical report is available on the MSA Trust website now.

www.msatrust.org.uk