



The Multiple System Atrophy Needs Surveys

Multiple System Atrophy is a rare progressive neurological condition. It causes 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.

Previous research has demonstrated that MSA has a severe impact on quality of life.¹

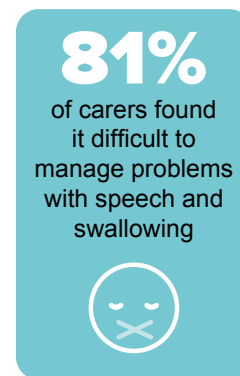
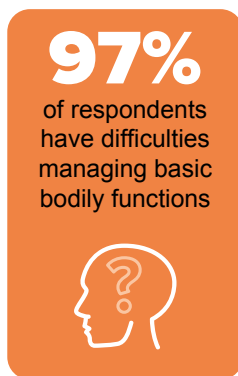
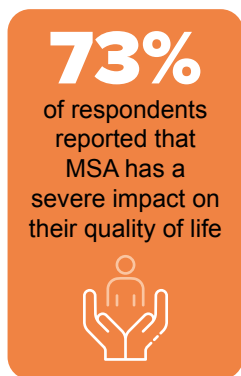
Our research looked at both people living with MSA and people who previously cared for somebody with MSA (this group are referred to as 'carers' in this document) making it the largest ever study of people affected by the condition. It covered the UK and Ireland.

Fieldwork took place in 2019 using hard copy and online questionnaires.

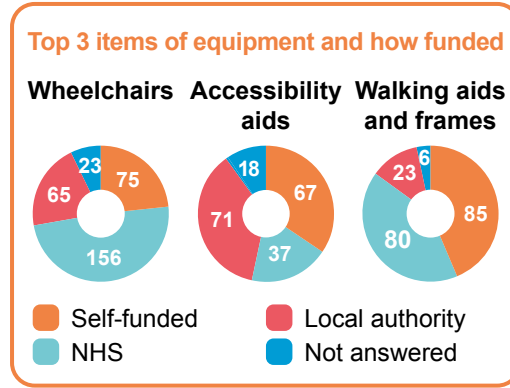
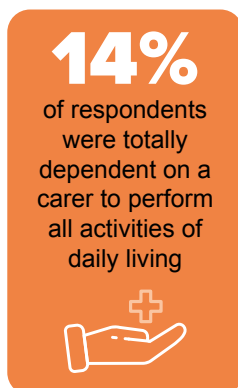
The summary of results here serve to emphasise the huge impact that living with MSA has on those affected.



Physical impact of living with MSA



“One symptom would not be so bad, but it is very difficult dealing with them all at the same time and very tiring.”



“Frustrated that I cannot do the things I used to do. Also, there is a lack of understanding about the reality of trying to get about outside the home and live as normal as is possible using a big electric wheelchair.”

¹ www.neural.org.uk/news-neuropatience-updated

² All percentages and statistics given relate to those that responded to that specific question.

Emotional impact of living with MSA

“I have found that I am becoming more isolated as I prefer to stay at home more.”

“Physical sex ended some years ago as pain and restriction in movement progressed. Kissing remains a lifeline.”

96%

of respondents living with MSA and

80%

of carers

experienced fatigue or tiredness



80%

of respondents living with MSA and

96%

of carers

experienced depression and low mood



86%

of respondents reported that their sex life has been affected by living with MSA* – of these, just 7% were receiving any form of treatment



*of those who answered this question (n.189)

82%

of respondents reported that their social lives have been negatively affected



Coordination of care



Under half

of respondents currently living with MSA had a care plan despite their severe physical and emotional needs

91%

of respondents that have a care plan felt it helps improve quality of life



Views on advanced MSA

81%

of respondents report positively on palliative care support*



*of those who answered this question (n.75)

Three quarters

of respondents living with MSA had thought about what they wanted to happen at their end of their life



85%

of respondents felt that more choice and control should be available at end of life and felt Assisted Dying, with safeguards, should be made legal by Parliament

Benefits and entitlements

78%

of respondents received some kind of benefit or welfare support to help with living costs



“We are not sure about what we can claim as we put in for something then something else gets taken away.”

The MSA Trust

Three quarters

of respondents report positively on the care and support provided by the four MSA Trust Nurse Specialists



“The MSA nurses are knowledgeable, understanding and supportive. The factsheets are helpful and clear. The support group is good for meeting others who understand the disease and sharing information and support.”

The MSA Trust magazine

is the key link people have with the Trust from both groups surveyed



The MSA Trust will be conducting a number of follow-up projects to further explore key themes in order to make recommendations for service development and improvement, for both ourselves and other support organisations. The full technical report is available on the MSA Trust website.

www.msatrust.org.uk
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