Multiple System Atrophy Trust

People with MSA Needs Survey 2019: Technical report

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Quality Health

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1. Introduction

Multiple system atrophy (MSA) is a progressive neurological disorder that affects adult men and women. It is caused by degeneration or atrophy (shrinking) of nerve cells in several (or multiple) areas of the brain. This can result in problems with multiple bodily functions such as speech, movement, balance and blood pressure control.

It is important to remember that no two people are the same and every person's experience of MSA will be different. The MSA Trust aims to support each person affected by MSA throughout their journey.

Until recently MSA was thought to be a very rare disease. As we learn more about the disease, it has become easier to recognise and diagnose, although for many people it can still take several years to diagnose. Recent research suggests it affects about 5 people per 100,000 so that at any one time there are almost 3,500 people living with MSA in the UK and Ireland. Parkinson's Disease is about 40 times more common, affecting about 200 people per 100,000.

MSA usually starts between the ages of 50-60 years, but it can affect people younger and older. It affects men and women. MSA does not appear to be hereditary although current research is examining whether or not there is a genetic predisposition to develop the disease. The importance of environmental factors is not clear and there is still much to understand about MSA. We do know it is not infectious or contagious and has no connection with the much more common neurological disease, multiple sclerosis (MS).

With no dedicated study in the UK examining the experiences of people living with MSA, the MSA Trust commissioned Quality Health to work with them on the largest study of its kind in the world.

The 2019 National MSA Needs Survey presents a comprehensive picture of the experiences of people living with Multiple System Atrophy. It is the largest MSA study ever carried out which explores a wide range of issues for people living with MSA, and their families and carers.

Through gathering data on a wide range of topics - from diagnosis and information, to physical and emotional impact of MSA, to impact on relationships and home life, to the support offered to those living with MSA– the survey findings present a comprehensive picture of people's experiences of living with MSA. In the absence of nationally collected MSA patient outcome measures, or social care data that is related to MSA, this approach provides intelligence about how well health and care services are performing for people living with Multiple System Atrophy.

This technical report, authored by Quality Health on behalf of The MSA Trust, provides details of the background to the survey, the methodology, and data results tables. It accompanies a summary document[1], which presents a thematic discussion of the results in relation to the policy context, draws conclusions, and makes recommendations for

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[1] MSA Trust Needs Surveys www.msatrust.org.uk/cause-and-cure/msa-needs-surveys

system change accordingly. In addition, MSA Trust surveyed former carers of people living with MSA. There is a full technical report and summary report available.[2]

Overall, based on analysis of all the survey data, MSA Trust's key messages are that:

1. There continue to be challenges around diagnosis. MSA is most commonly initially diagnosed as Parkinson's Disease.

2. Impact on quality of life is severe – almost the most severe of all neurological conditions. The National Neurology Patient Experience Survey 2018 listed MSA as the 2nd most severe neurological condition[3]. MSA impacts severely on the ability to carry out day to day activities and levels of independence.

3. Due to the nature of MSA, and its effect on autonomic functions of the body, multiple symptoms are likely to be experienced and at different stages in its progression.

4. There is a significant gap around access to assistive equipment and the associated cost for people living with MSA.

5. Living with MSA has a serious and damaging effect on the individual's mental health and wellbeing along with their relationships. There is a clear gap in mental health provision.

6. The need for personalised care and care planning appears to be a significant issue.

7. Experiences with health and care professionals (HCP's) are varied. GPs generally fare poorly – which can be expected with rarer conditions. There appears to be a need for wider increased HCP education.

8. Impact on employment is severe and can be damaging both financially and emotionally due to the rapid progression of the disease.

9. Individuals living with MSA need additional support for end of life planning.

10. The majority of respondents feel assisted dying (with adequate safeguards) should be made legal by Parliament, however, slightly less would want this choice for themselves.

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[2] www.msatrust.org.uk/cause-and-cure/msa-needs-surveys

[3] https://www.neural.org.uk/resource_library/neuro-patience/

2. Background and methodology

2.1 Background

- This is the first ever MSA Trust Needs survey.
- MSA Trust engaged survey company Quality Health to undertake the survey. MSA Trust and Quality Health worked in close partnership to develop and test the methodology and survey questions, as well as to analyse and report on the data.
- In addition to the survey, a range of in-depth interviews were carried out with people living with MSA to better understand the responses given. With participant consent, some of these interviews were filmed.
- Data was collected between June and August 2019. The survey received 284 responses.

2.2 Objectives

The survey had four main objectives, to gather data about the experience of people with MSA in order to:

1. Enhance nationally collected data and intelligence about MSA, by providing evidence about the experience of people who are living with the condition.
2. Provide the health sector with evidence about patient experience in order to influence national policy.
3. Provide intelligence about the experiences of people with MSA to inform MSA Trust's strategic priorities and longer-term work. This supported a specific focus on identifying where there are gaps in provision for those living with the condition.
4. Produce a report about people living with MSA.

2.3 Methodology

The methodology for the survey was a dual method of data collection: to collect feedback from respondents via an anonymous online link (predominantly promoted via MSA Trust's social media channels), and by sending addressed copies of the questionnaire to individuals living with a diagnosis of MSA and whose details were held on MSA Trust's database. This method was chosen as many individuals did not have email addresses and due to the nature of the condition would prefer to complete the survey on paper. Paper copies did also have a link to complete the survey online if that was the preference of the respondent. Doing so would also offer the possibility of increasing the overall number of responses in order to improve the reliability of the data.

A summary of the methodology is below:

- A new questionnaire was developed from scratch but using some of the Neurological Alliance 2018/19 survey[4] for benchmarking. The aim was also to draw on Quality Health's extensive experience in running other national survey programmes including the Neurological Alliance 2018/19 survey and the National Cancer Patient Experience Survey (CPES).

- The questionnaire was developed alongside a project steering group, comprising MSA Trust representatives which included MSA Trust Nurse Specialists and Neurologists with direct experience of MSA.

- Cognitive testing was carried out with 10 people who were living with MSA to ensure the final questionnaire could capture the information required in the most straightforward and effective way.

- A final questionnaire was produced in May 2019 in preparation for full rollout. This was produced as a paper copy.

- During this time a replica of the paper survey was produced as an online survey. Quality Health carried out User Acceptance Testing (UAT). UAT is the last phase of the software testing process. During UAT, actual software users test the software to make sure it can handle required tasks in real-world scenarios, according to specifications. In this instance, it involved several test submissions using the online tool, to check all functionality.

- Both the online survey and paper survey were launched in June 2019 and ran until August 2019. The online survey was promoted to people via MSA Trust's social media channels and other forms of communication. A link to complete the survey online was also included in all paper packs.

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[4] https://www.neural.org.uk/resource_library/neuro-patience/

2.3.1 Questionnaire design and development

The questionnaire was designed and developed between January and May 2019. This involved a detailed process of drafting, reviewing, testing and revising the questions. Quality Health worked closely with MSA Trust on designing and agreeing the final question set. In addition, Quality Health worked alongside MSA Trust representatives including MSA Trust Nurse Specialists and Neurologists with direct experience of MSA.

As a part of the process, cognitive testing was carried out with 10 volunteers all of whom were living with a diagnosis of MSA: their time and input into the process is greatly appreciated. The volunteers completed the draft questionnaire and were then invited to share their answers to the questions, and to comment on the wording, the response options, any omissions; and any comments on the layout and length of the survey. After these interviews a report was provided to MSA Trust. A number of changes and improvements were made, and a revised questionnaire was then produced.

2.3.2 Scoring

A scoring methodology was developed so that one score per question could be reported, instead of the frequencies of individual response options. This enabled easier comparison when looking at breakdowns of the data (see section 4). A binary scoring system such as is used on national NHS survey programmes was developed. The full scoring methodology is attached to this report as Appendix A.

2.3.3 Sampling and data

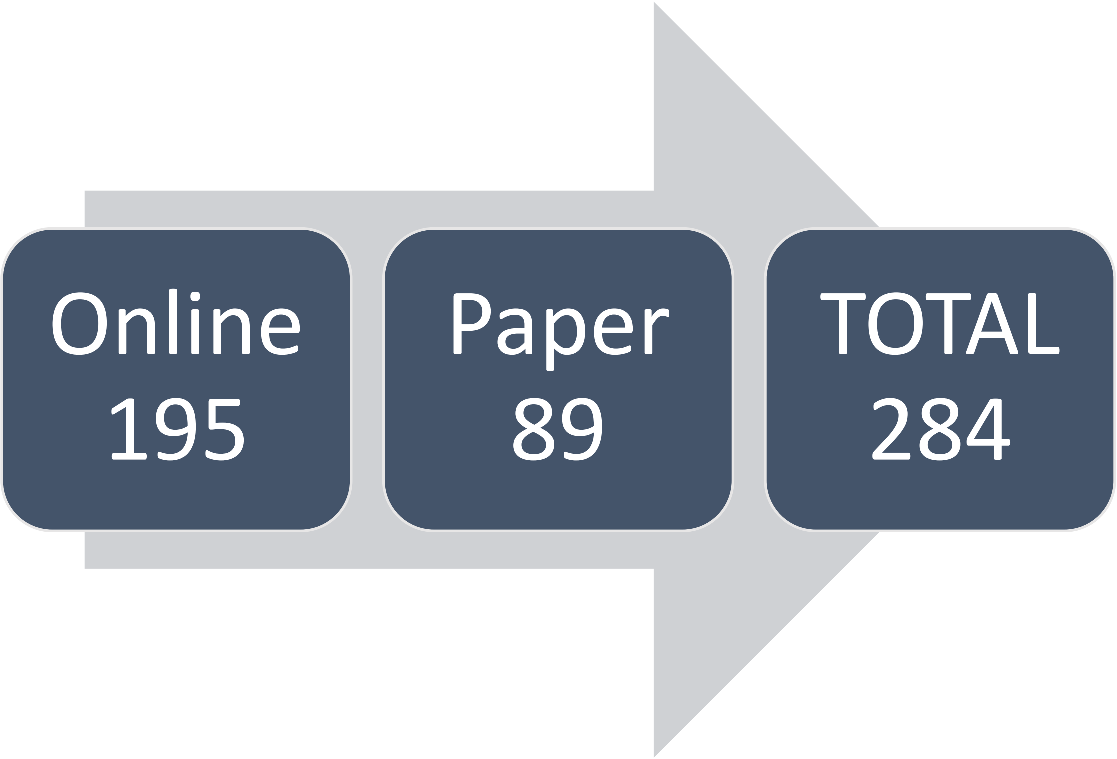
The online survey was promoted via MSA Trust members. There was also an anonymous link which was available to all respondents. Paper copies were sent to named individuals. In keeping with the MSA Trust's stringent procedures regarding data protection personal data was not sent between Quality Health and MSA Trust. Quality Health therefore sent paper packs to MSA Trust, who managed send out themselves. There was a system for anonymously tracking responses.

2.4 Timescales and fieldwork

The timescales were as follows:

- **Development of question set:**
    - Steering group meetings and development of questions: January – May 2019
    - Cognitive testing of questionnaire: April/May 2019
    - Further refinements to questionnaire: May 2019
    - Questionnaire ready: May 2019
- **Full rollout:**
    - Survey START: 24 June 2019
    - Survey CLOSE: 23 August 2019

2.5 Response rate



Based on a final sample size of 1,213[5], this represents a response rate of 22%.

Given the demographic and nature of the condition, this should be considered a success and means we can consider the results robust, which allow us to make meaningful conclusions.

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[5] The sample was drawn from the MSA Trust database and included those known to the Trust who were living with a diagnosis of MSA and had consented for further contact. There were also 21 patient responses and 27 carer responses which were anonymous rather than linked to the sample and these were all online.

3. Results of the questionnaires

3.1 Respondent characteristics

3.1.1 Age

There were no respondents under the age of 45. Given MSA is very uncommon in younger people, this is unsurprising. Just 6% were aged between 45 and 54. Almost three quarters (72%) were aged between 55 and 74. Just under a quarter of respondents were aged over 74. The chart below breaks this down in more detail.

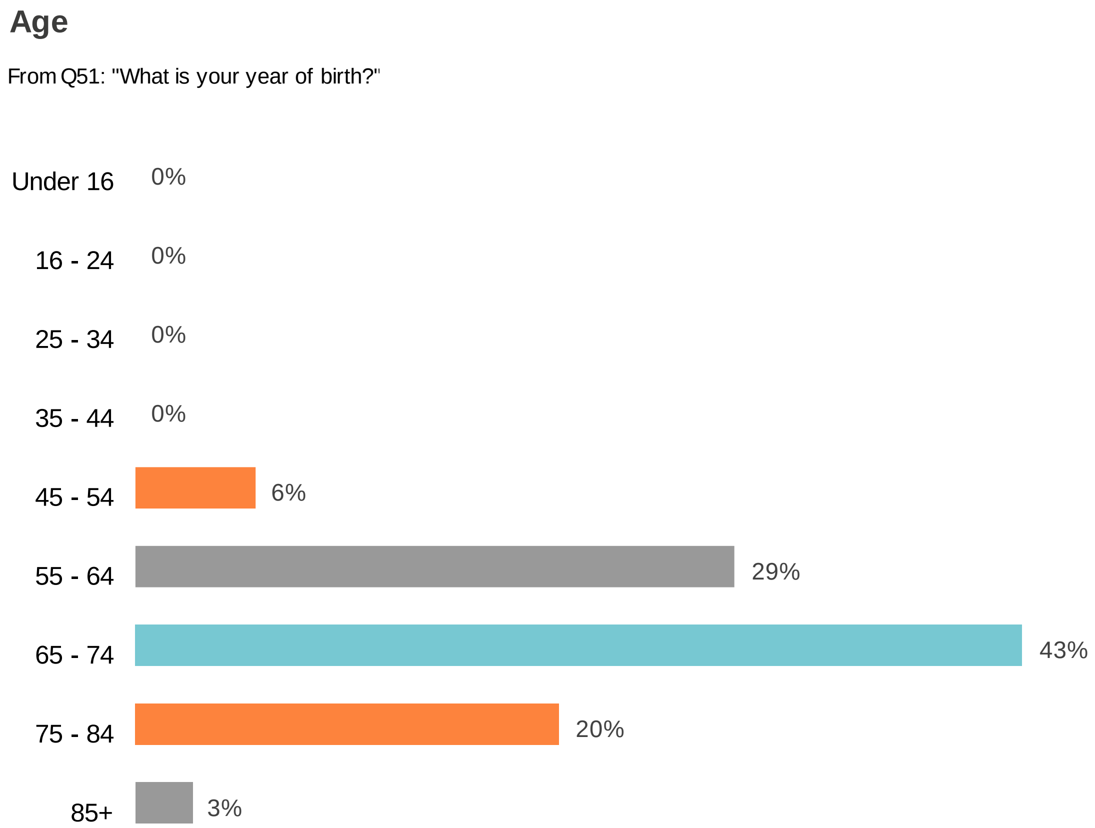

Fig 1. Age range of respondents

3.1.2 Ethnicity

Almost all respondents (98%) identified themselves as ‘White’ - either English / Welsh / Scottish / Northern Irish / British – or Irish / other White background.

The numbers of those identifying themselves as Black (including African, Caribbean and other Black background), Asian (including Bangladeshi, Indian, Chinese and other Asian background), Mixed Heritage (including White & Asian, White & Black African, White & Black Caribbean and other Mixed background), Arab or any other ethnicity except White, is very low (just 2%). This compares to 14% of the population in England and Wales (*2011 Census, Office for National Statistics*)[6]. It is important to point out that there are different ethnic profiles of the population when looking at older age groups who are more likely to be living with MSA. More details are contained in the footnote. When it comes to looking at the data broken down by ethnicity, the conclusions drawn should be used with extreme caution without further empirical investigation.

3.1.3 Gender

There was an almost equal split between genders, with slightly more male respondents. This is entirely typical of other national survey programmes.

122 respondents (47% overall) identified themselves as female. Just over half (53% or 138) identified themselves as male. Just one individual preferred to use their own term to describe their gender.

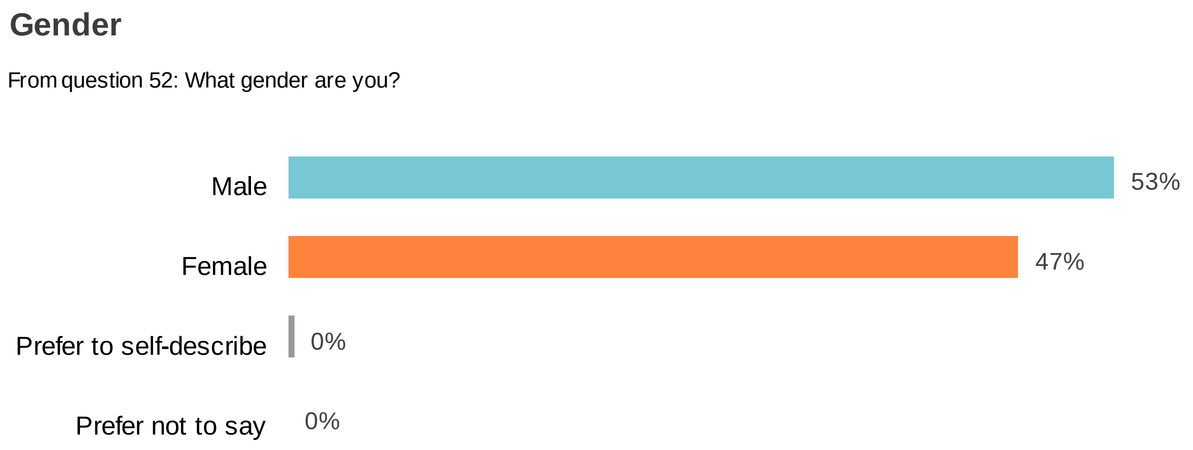

Fig 2. Gender breakdown

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[6] There is a different ethnic profile however of those aged older who are more likely to be living with MSA. The results remain unrepresentative of this group. More detailed ethnic breakdowns can be found at: https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/age-groups/latest

3.2 Introductory questions

3.2.1 Who filled in the questionnaire?

Just under two-thirds of respondents (61%) filled in the survey themselves, as the person living with MSA. Over a third (34%) were responses from a friend or family member, filling it in on behalf of the person with MSA. Just 4% were completed by carers. This is not typical of similar size survey programmes, where most individuals complete the survey themselves but is representative of the condition and its effect on individuals.

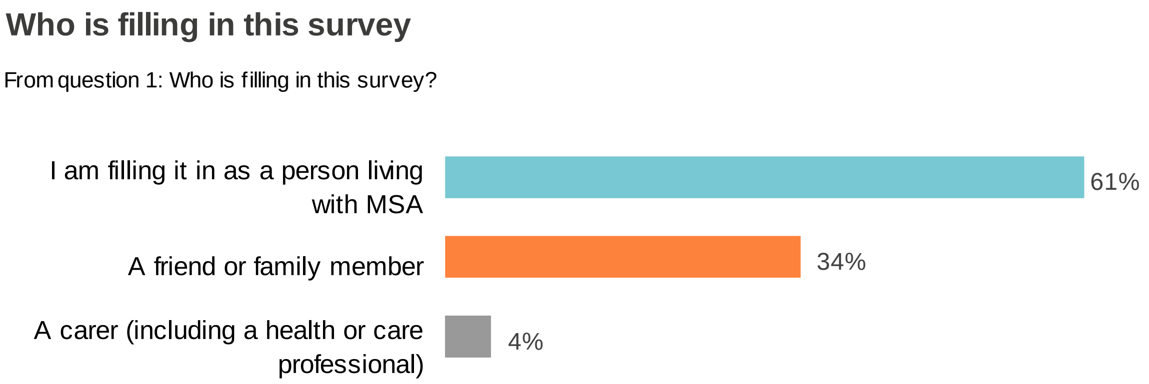


Fig 3. Method of survey completion

3.2.2 Length of time living with MSA

The majority of respondents had been living with MSA for under 10 years. Only a small number of respondents had been living with MSA for over 11 years.

The chart below breaks down the second question of the survey. The blue lines show the proportion of respondents who report experiencing early symptoms of MSA; the orange lines give the time since a formal diagnosis was given. For example, 41% of those surveyed report having experienced early symptoms between 0 and 5 years ago. 74% of those surveyed were diagnosed in the last 5 years.

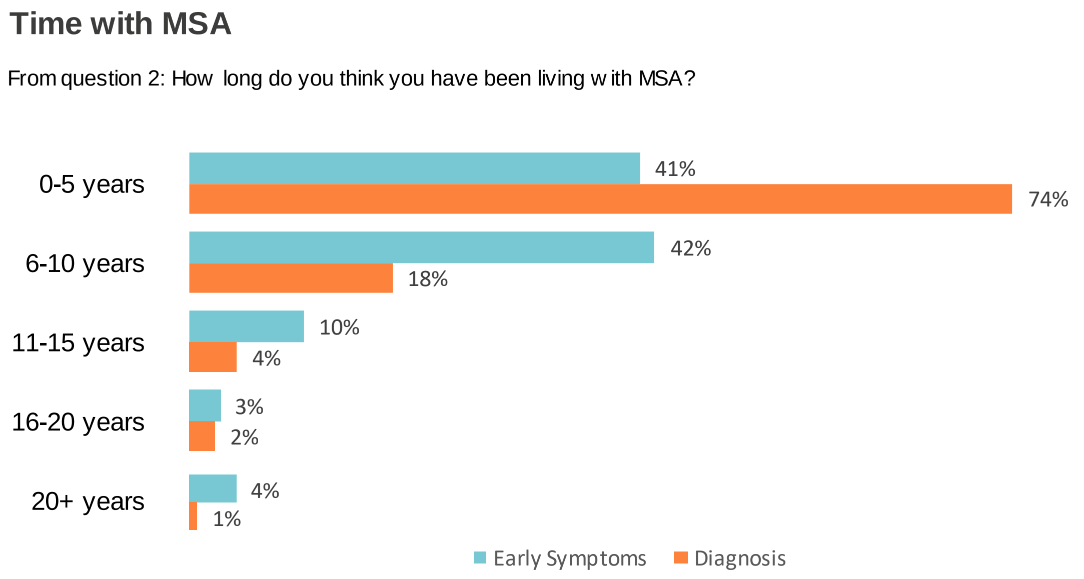


Fig 4. Length of time living with MSA

3.2.3 Living with other conditions

Over two-fifths of respondents (42%, n.115) were living with more than one chronic condition including MSA. 58% (n.160) were not living with another chronic condition in addition to MSA.

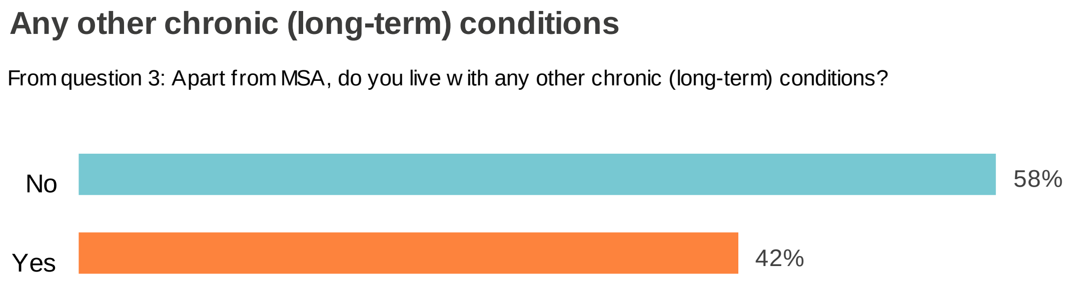


Fig 5. Respondents with additional chronic conditions alongside MSA

3.2.4 Diagnosing MSA

Respondents were asked if their MSA was initially diagnosed as something else. Less than a third of respondents (31%, n.85) were diagnosed with MSA as a first diagnosis. Given the challenging nature of reaching a diagnosis of MSA, this is perhaps unsurprising.

Of the rest:

- 36% (n.98) were diagnosed with Parkinson’s first
- 12% (n.34) were diagnosed with Ataxia first
- 9% (n.24) were diagnosed with Atypical Parkinson’s first
- 1% (n.2) were diagnosed with PSP first
- <1% (n.1) was diagnosed with CBD first

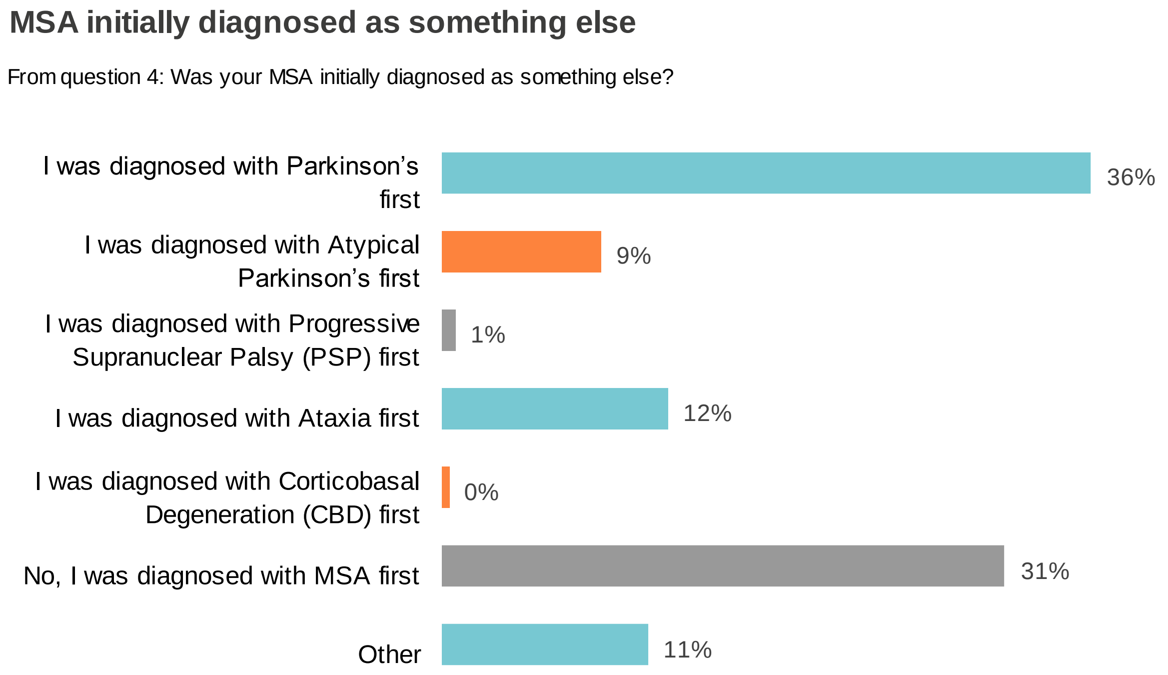
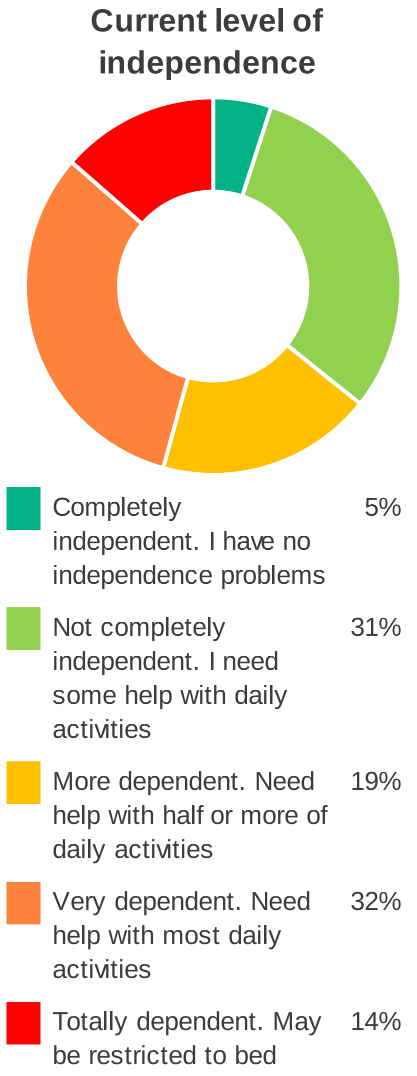


Fig 5. Diagnosing MSA

3.2.5 Levels of independence

The data clearly shows the significant negative impact living with MSA has on the quality of life of respondents and the deleterious effect it has on the way in which individuals are able to carry out activities of daily living.

Almost half of respondents (46%, n.128) reported that they were either very dependent or totally dependent on others for activities of daily living. Almost a fifth (19%, n.52) reported needing help half or more of the time. Around a third (31%, n.86) reported needing some help with daily activities. Just 5% (n.14) of respondents reported having no independence problems.



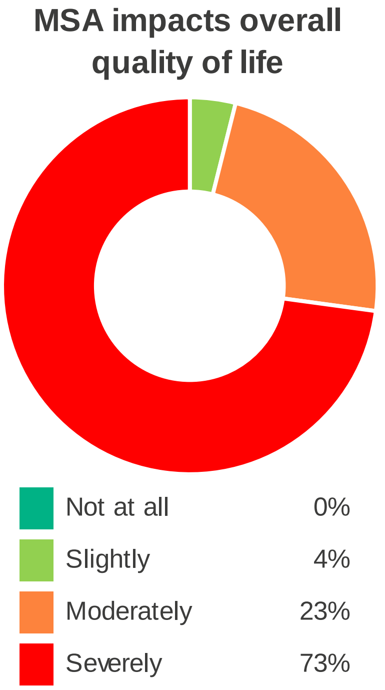
From question 5: How would you describe your current level of independence? (Activities of daily living)

Fig 6. Levels of independence

3.2.6 Quality of life

In the 2018/19 National Neurology Patient Experience Survey[7] MSA was listed as having the second most serious impact on quality of life out of all neurological conditions. This significant level of severity is also demonstrated and confirmed in these results.

The vast majority of respondents (96%, n.269) reported that their quality of life was impacted either moderately or severely. Just 4% (n.11) of respondents reported that MSA affected their quality of life slightly. No respondents reported that MSA did not affect their quality of life at all.



From question 6: To what extent does having MSA impact on your overall quality of life?

Fig 7. Impact of MSA on quality of life

3.2.7 Conclusions

- There continue to be challenges around diagnosis. MSA is most commonly initially diagnosed as Parkinson’s.
- Impact on quality of life is severe – almost the most severe of all neurological conditions.
- MSA impacts severely on ability to carry out day to day activities and levels of independence.

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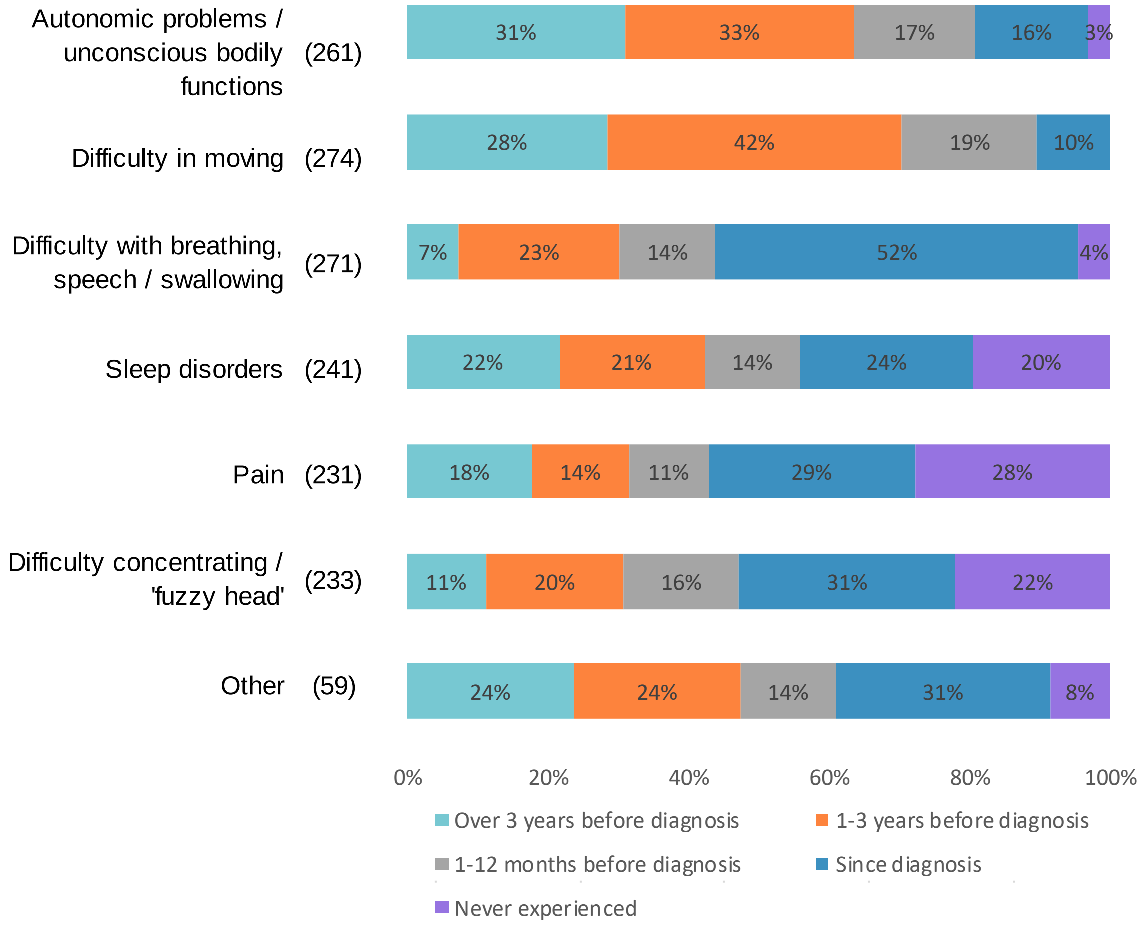
[7] *The National Neurology Patient Experience Survey presents a comprehensive picture of the experiences of people living with a neurological condition in England.* https://www.neural.org.uk/news-neuropatience-updated/

3.3 Physical impact

3.3.1 Symptoms

Due to the nature of MSA, and its effect on autonomic functions of the body, multiple symptoms are likely to be experienced. We looked at what symptoms people experienced and when they first noticed them. Problems with mobility were most widely reported, especially before diagnosis, with them worsening post diagnosis. Over three-quarters of respondents experienced pain associated with their MSA.



When symptoms appeared

From question 7: At which point did any of the following symptoms first appear?

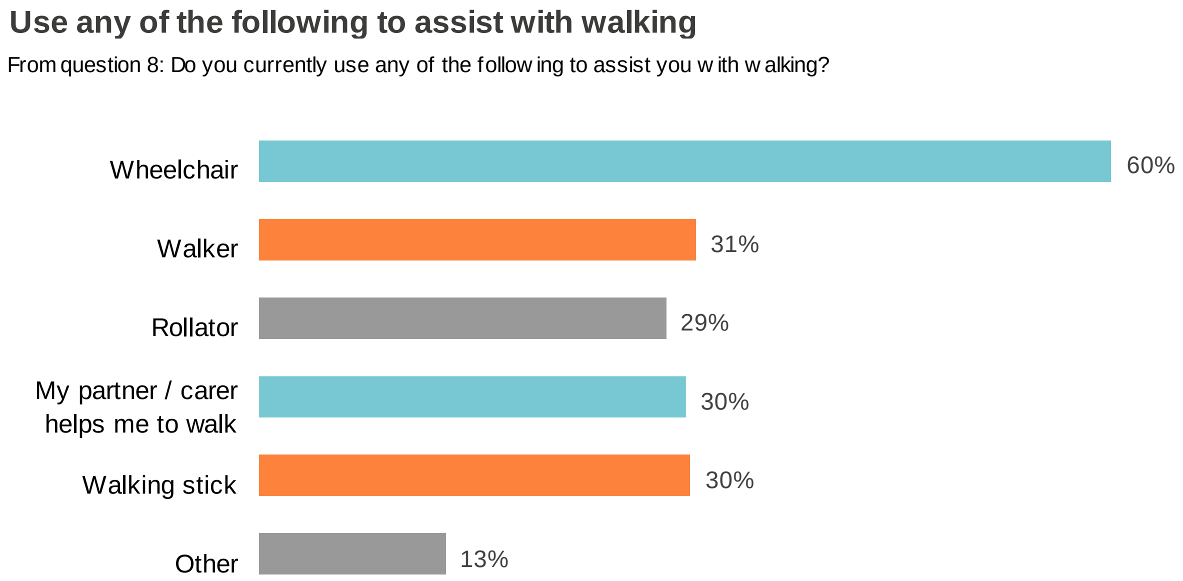
Fig 8. Symptoms

3.3.2 Assistance with walking

What equipment people used is to a certain extent indicative of where they are in their MSA journey. It is also important to note they could be using one or more at any one time.

Almost all respondents used some kind of assistive device to help with walking[8].

- 60% (n.170) reported using a wheelchair
- 31% (n.87) reported using a walker
- 30% (n.86) reported using a walking stick
- 30% (n.85) reported relying on their partner/carer to help them with walking
- 29% (n.81) reported using a rollator


Use any of the following to assist with walking

From question 8: Do you currently use any of the following to assist you with walking?

Fig 9. Assistance with walking

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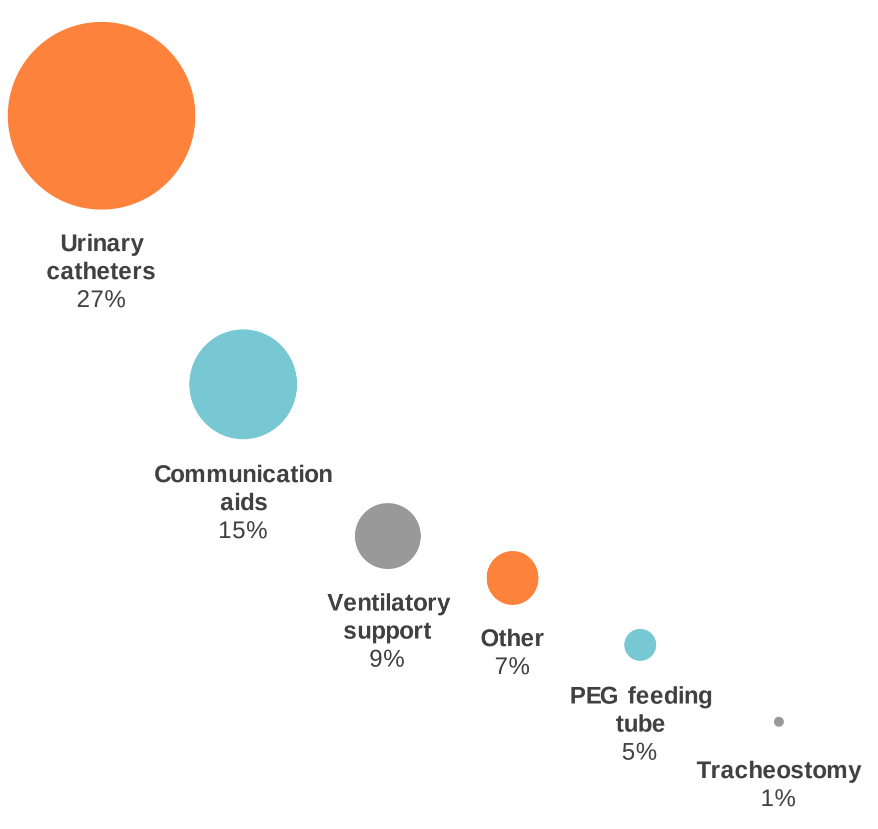
[8] Percentages in this question do not add up to 100 as this was a 'tick all that apply' question

3.3.3 Treatments to help with symptoms of MSA

Of the main treatments to help with symptoms associated with MSA, urinary catheters were most commonly reported with 27% (n.76) of respondents. 15% (n.44) used some kind of communication aid. 9% (n.26) were utilising some kind of ventilatory support. 5% (n.13) had a feeding tube and just 1% (n.4) had a tracheostomy.



Receiving any of the following treatments for MSA

Percentage of respondents answering "tick all that apply" question

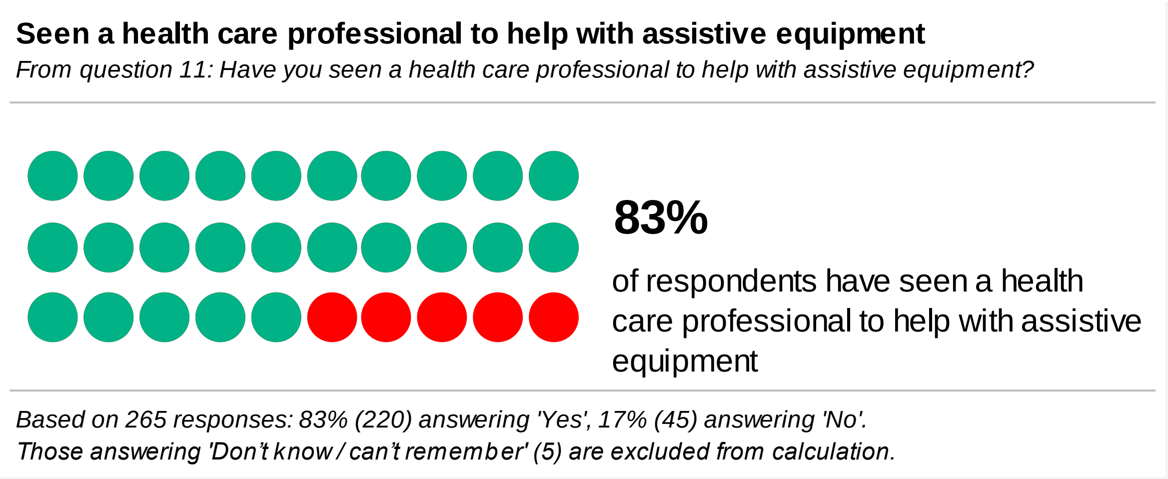
From question 9:

Are you currently receiving any of the following treatments for your MSA?

Fig 10. Treatments for symptoms association with MSA

3.3.4 Assistive equipment

The majority of respondents (83%, n.220) had seen a health care professional to help with assistive equipment.



Seen a health care professional to help with assistive equipment

From question 11: Have you seen a health care professional to help with assistive equipment?

83%

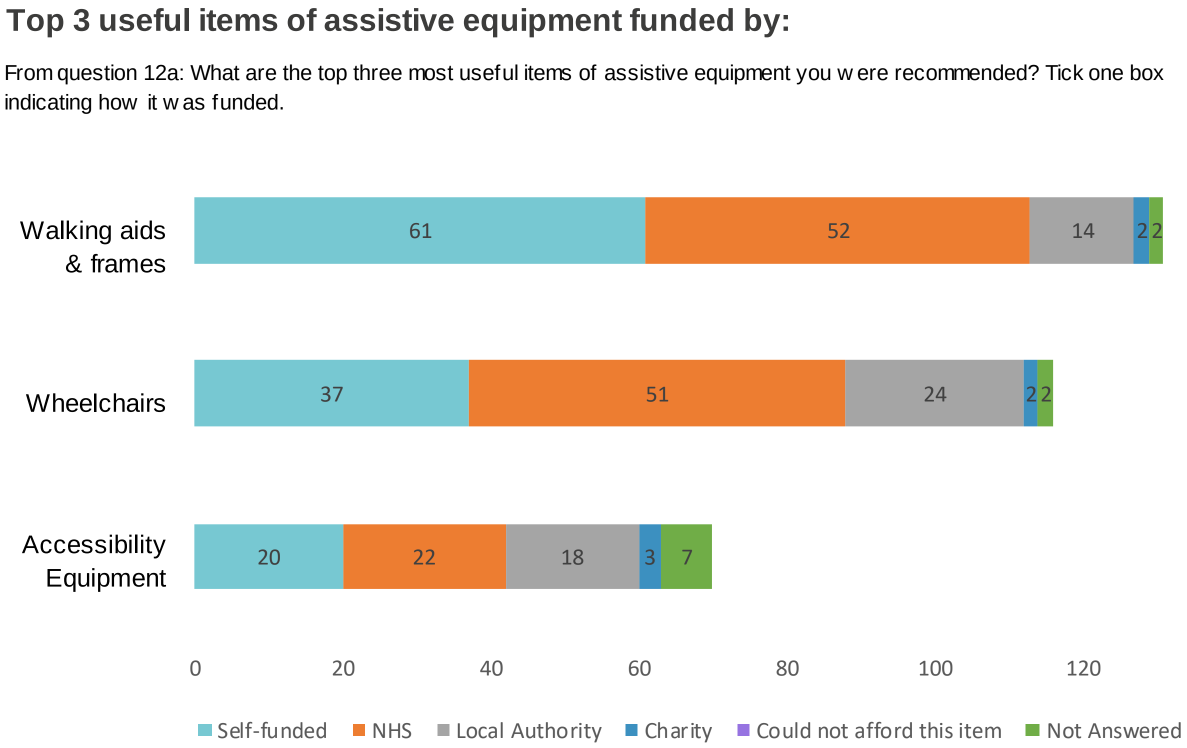
of respondents have seen a health care professional to help with assistive equipment

Based on 265 responses: 83% (220) answering 'Yes', 17% (45) answering 'No'. Those answering 'Don't know / can't remember' (5) are excluded from calculation.

Fig 11. Access to a health care professional for help with assistive equipment

3.3.5 Most popular items of assistive equipment

The chart below shows the most useful items of assistive equipment and how these have been funded. For example, from the chart below you can see that walking aids and frames were the most useful item of assistive equipment – and these were also the most likely to be self-funded.



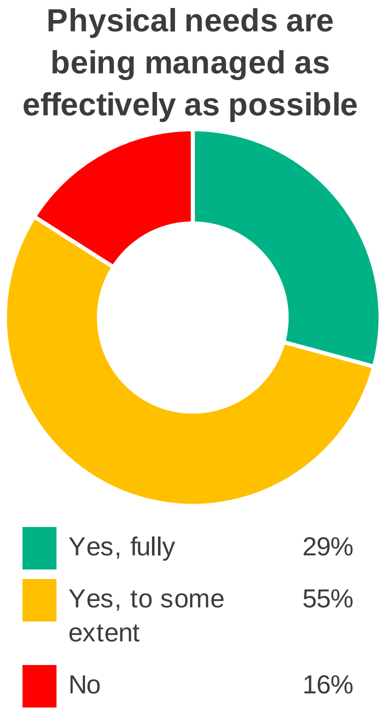
Top 3 useful items of assistive equipment funded by:

From question 12a: What are the top three most useful items of assistive equipment you were recommended? Tick one box indicating how it was funded.

Fig 12. Top three items of assistive equipment and how these were funded

3.3.6 Management of physical needs

Only just under a third of respondents (29%, n.73) felt their physical needs were being fully managed as effectively as possible. Over half (55%, n.137) reported their physical needs being managed to some extent. 16% (n. 40) reported that their physical needs were not being managed at all.



From question 13: Physical needs are being managed as effectively as possible

Fig 13. Management of physical needs

3.3.7 Conclusions

- Due to the nature of MSA, and its effect on autonomic functions of the body, multiple symptoms are likely to be experienced, with a consequent need for support from a range of HCP's.
- Most respondents had seen one or more HCP to help with assistive equipment.
- When combining different devices walking aids are most commonly used[9]
- As a single reported device, wheelchairs were most commonly used by respondents – but it is important to point out that the item of assistive equipment used will be indicative of where they are in their MSA journey.
- Many respondents report having to fund items of assistive equipment themselves: the majority reported having to pay for wheelchairs.
- It would appear that more could be done to help support people living with MSA to manage their physical symptoms.

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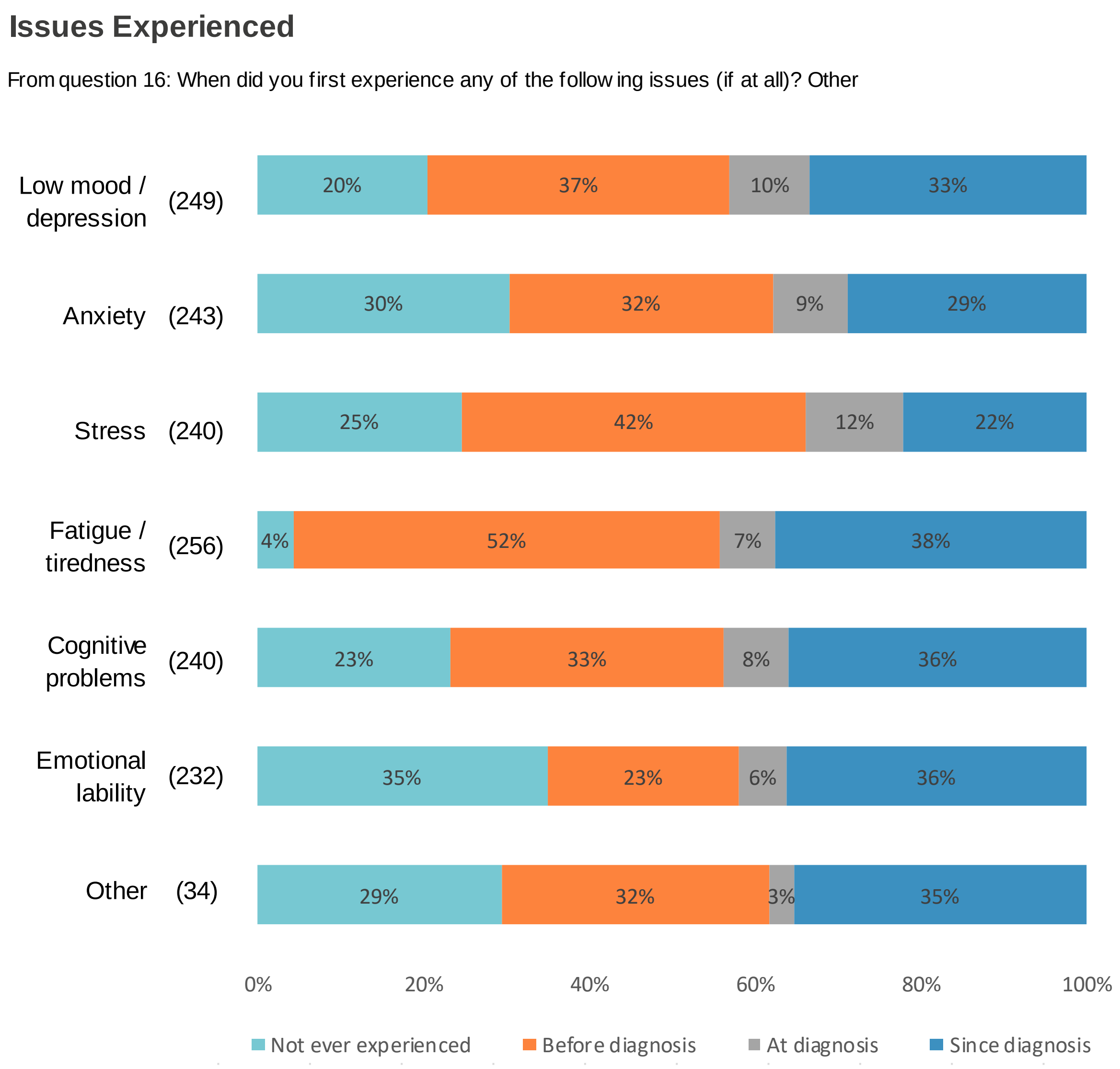
[9] This is a combined figure of walker, rollator and walking sticks

3.4 Emotional impact

3.4.1 Psychological issues experienced by those living with MSA

It is very hard to say whether or not psychological issues are experienced due to the condition itself or as a direct result of being given a terminal diagnosis. However, it is apparent that there is significant need around psychological support manifested by people living with MSA.



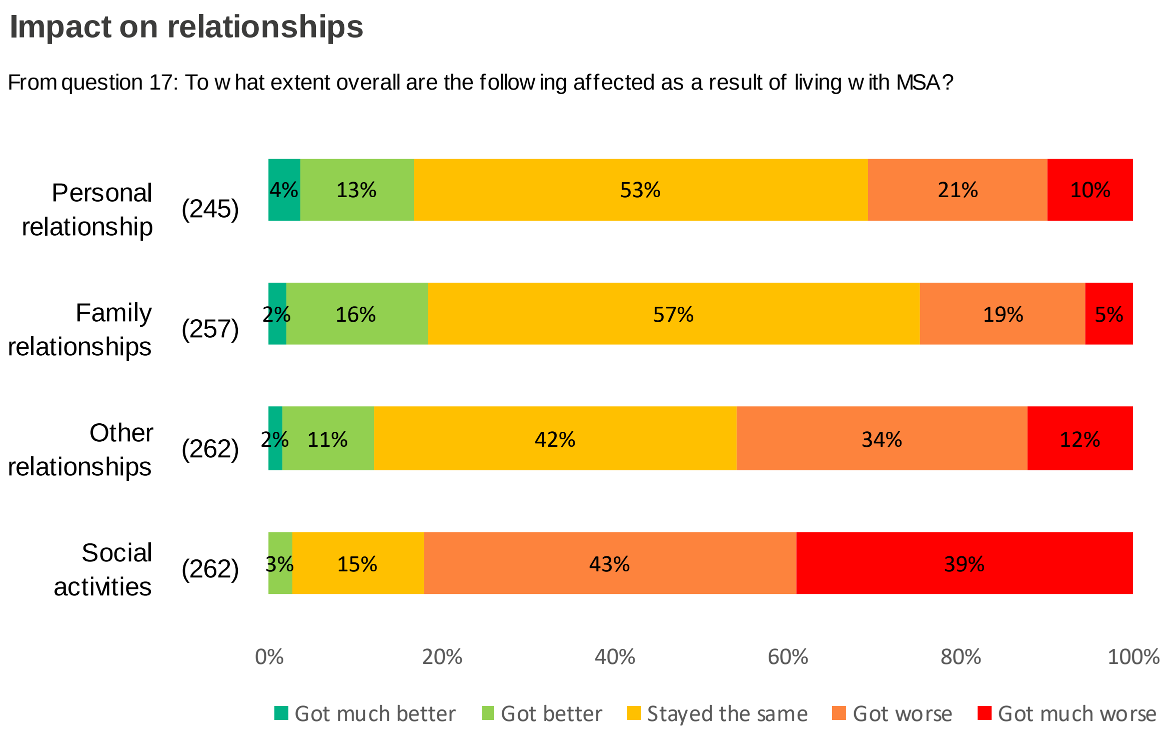
Issues Experienced

From question 16: When did you first experience any of the following issues (if at all)? Other

Fig 14. Psychological issues experienced by those living with MSA and when these present themselves

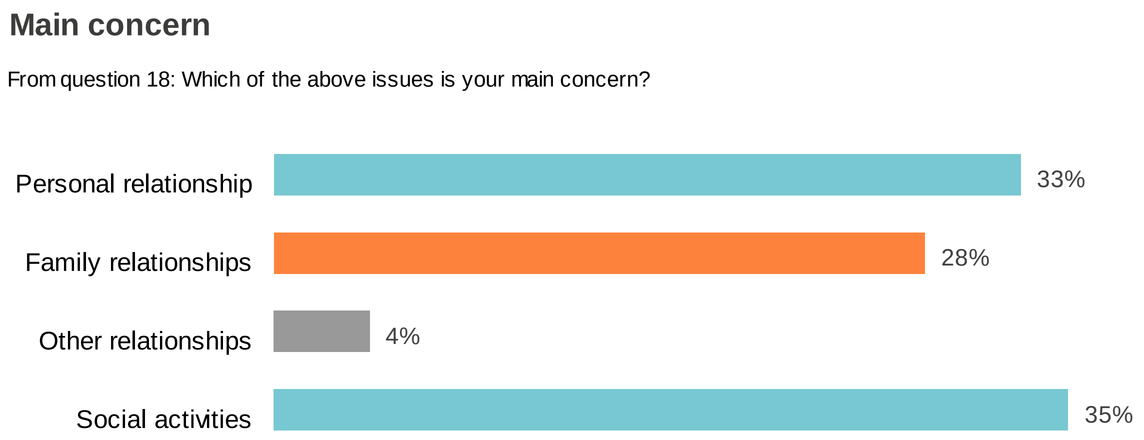
3.4.2 Impact of living with MSA on relationships

Living with a diagnosis of MSA can have a serious and damaging impact on relationships. Respondents were asked how their relationships were affected as a result of having MSA. Relationships with friends were most seriously affected (this is also connected to the score around social isolation which shows serious impact). Almost half of respondents (46% n.120) reported that their relationships with their friends were negatively affected. With all relationships, at least some respondents reported these getting better.


Impact on relationships

From question 17: To what extent overall are the following affected as a result of living with MSA?

Over a third of respondents (35%, n.83) reported that the impact MSA has on their social activities is their main concern. This represents the largest group of respondents for this question and suggests that this is a serious issue for those living with MSA.


Main concern

From question 18: Which of the above issues is your main concern?

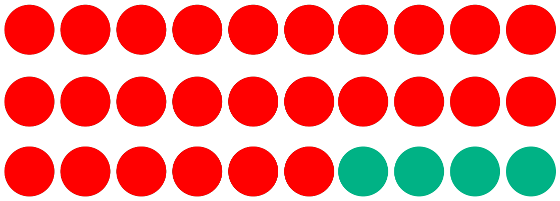
Fig 15. Impact of living with MSA on relationships

3.4.3 Sexual relationships/intimacy issues

The majority of respondents (86%, n.162) reported that their sex life had been directly affected as a result of MSA. Of these, just 7% (n.11) were receiving treatment to help. The most common treatment offered was medication. Of those receiving treatment, the majority found it unhelpful (60%, n.6), though 40% (n.4) found it helpful at least to some extent. Section 4.5 on p52 of this report breaks this down by gender. Female respondents are less likely than male respondents to report problems with their sex lives, and no female respondents were receiving any kind of treatment to help.

Sex life / intimacy affected by MSA

From question 19: Has your sex life / intimacy been affected by your MSA?



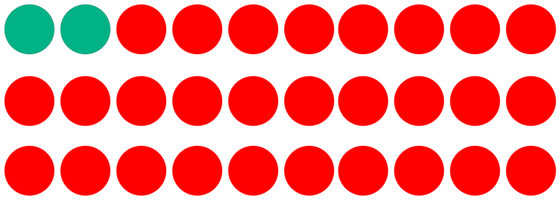
86%

of respondents have sex life / intimacy affected by MSA

Based on 189 responses: 86% (162) answering 'Yes', 14% (27) answering 'No'.
Those answering 'Don't know' (20) or 'Prefer not to say' (47) are excluded from calculation.

Receiving treatment and / or support to improve sex life

From question 21: Are you receiving treatment and / or support to improve your sex life?



7%

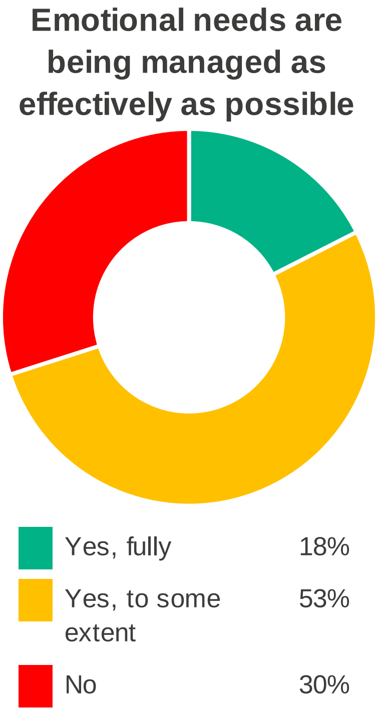
of respondents are receiving treatment and / or support to improve sex life

Based on 158 responses: 7% (11) answering 'Yes', 93% (147) answering 'No'.
Those answering 'Prefer not to say' (3) are excluded from calculation.

Fig 16. Sex life/intimacy issues and treatment support offered

3.4.4 Management of emotional needs

Only just under a fifth of respondents (18%, n.41) felt their emotional needs were being fully managed as effectively as possible. Over half (53%, n.123) reported their emotional needs being managed to some extent. However, a large number of respondents – almost a third (30% n.70) reported that their emotional needs were not being managed at all. This suggests there is an issue around the emotional wellbeing of people living with MSA and that additional support would be helpful.



From question 24: Do you think that your emotional needs are being managed as effectively as possible?

Fig 17. Management of emotional needs

3.4.5 Conclusions

- It is difficult to say whether or not psychological issues are attributed to the condition of MSA or as a result of being given a terminal diagnosis: however, reports of low mood, depression and anxiety are commonplace, and support is needed.
- Fatigue and tiredness are the most commonly experienced issues.
- Living with MSA has a serious and damaging effect on relationships, in particular respondents report that relationships with friends are most seriously affected.
- The majority of respondents reported issues with their sex life as a direct result of their MSA. The majority of respondents are not receiving any treatment to help.
- It would appear that people living with MSA need more support to help manage the psychological symptoms of living with MSA. There is a significant gap in provision here.

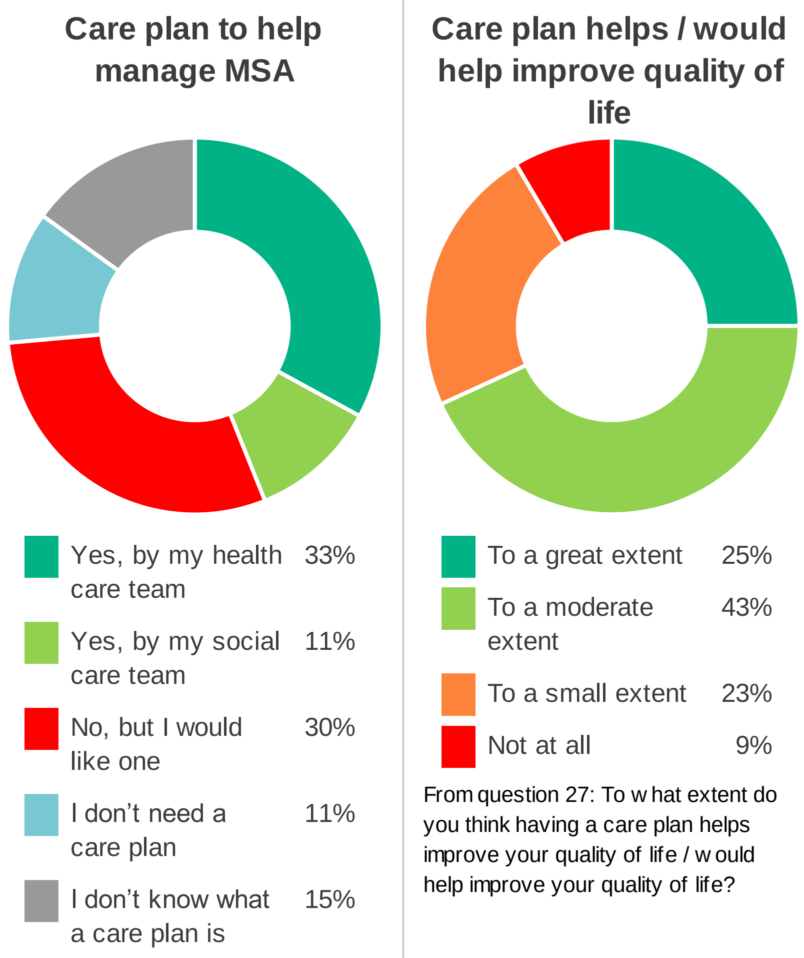
3.5 Support for people living with MSA

3.5.1 Care plans

Care and support plans are for anyone who needs care or cares for someone else. These plans detail the individuals care and/or support needs and how these will be met and financed. Plans should detail the budget that has been allocated by the local authority or the NHS to meet these needs.

Care and support plans are written by health and social care professionals and should be jointly agreed with the person concerned. They are important documents for people living with MSA and their carers and should be regularly reviewed.

From the results of the survey, there appears to be a significant issue surrounding care plans. They are not being offered to people as widely as possible, and they appear to be misunderstood. Well under half of respondents had a care plan (44%, n.108). These are mainly issued by the health team that look after the person living with MSA. Almost a third of respondents (30%, n.73) report not having a care plan but wanting to have one. Just 11% (n.28) report not needing a care plan, and 15% report not knowing what a care plan is. However, over two thirds of respondents (68%, n.120) agreed that a care plan would help improve quality of life at least to a moderate extent.



From question 26: Do you have a care plan to help manage your MSA?

From question 27: To what extent do you think having a care plan helps improve your quality of life / would help improve your quality of life?

Fig 18. Care plans

3.5.2 Support provided by health care professionals

Respondents who were offered information were asked to rate the quality of the support they were offered from various health and care professionals. GPs fare poorly. This is typical of the patient experience with rarer health conditions with over half of respondents (51% n.123) reporting that their GP provides adequate or poor care.

The most positively reported health and care professionals are palliative care / hospice teams (81% of respondents reported that they were either excellent or good), followed by MSA Trust Nurse Specialists (75% of respondents[10] reported that they were either excellent or good). However, almost a third of respondents (32% n.82) reported they have never had contact with an MSA Trust Nurse Specialist.

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[10] This is 75% of respondents who received MSA nurse support. Percentages in this section are calculated from those who received support from that health professional – this is why the percentages about MSA nurses will add to over 100%.

The health and care professional respondents were least likely to access was either a counsellor or psychiatric team, a neurology nurse specialist or a dietitian.

Support from professionals

From question 28: How would you rate the support you have received for your MSA from these professionals?

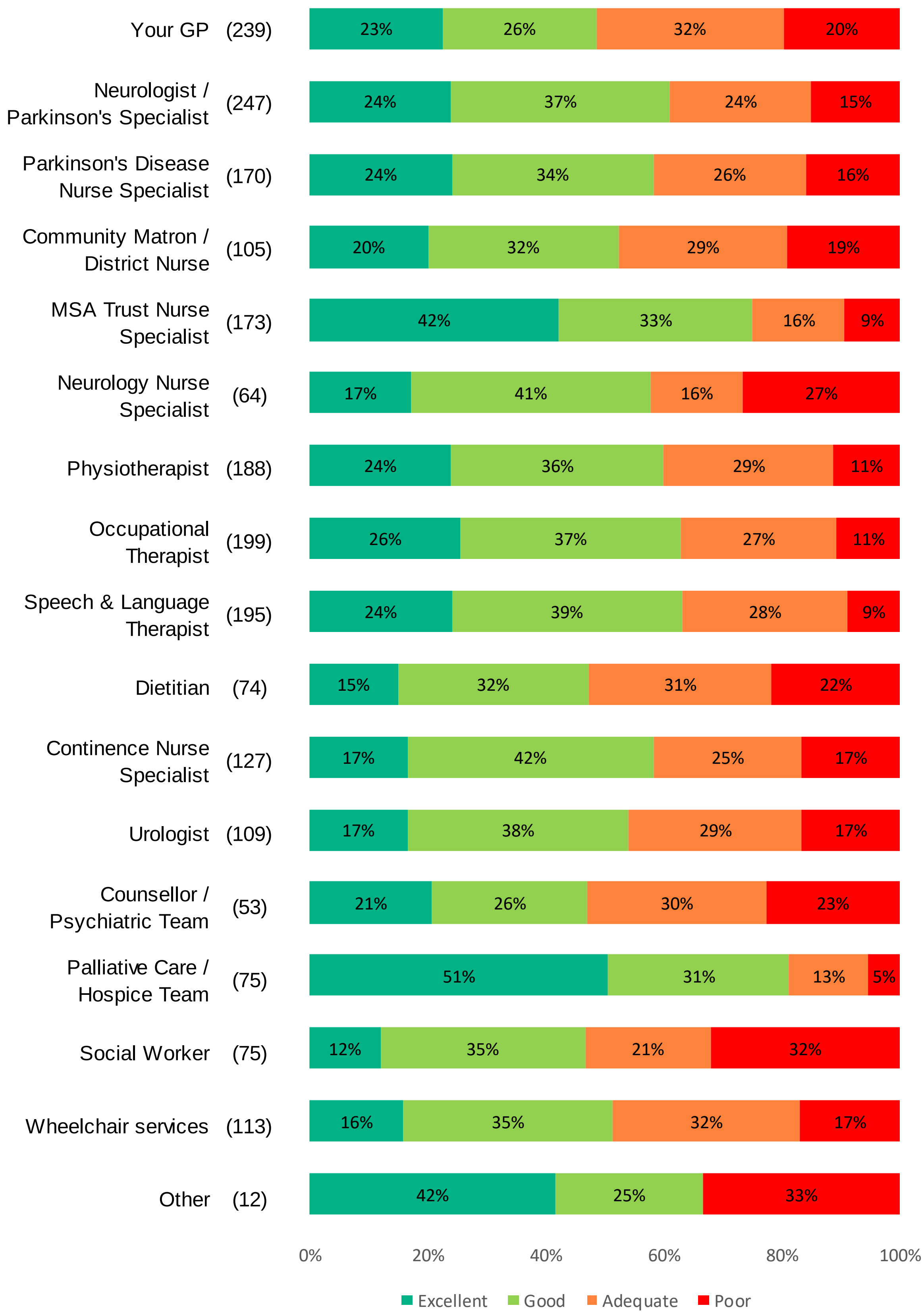


Fig 19. Support provided by health care professionals

3.5.3 Therapies to help with symptoms of MSA

The majority of respondents were not accessing any of the therapies in this section, indicating that many people living with MSA are missing out on this type of support. Of those who are accessing this additional support, the most commonly reported were:

- Physiotherapy (172 respondents); of those only half rated this care as either good or excellent;
- Group or individual counselling (63 respondents), of these only 41% rated this care as either good or excellent.

The most highly rated therapy was music therapy. However, the vast majority of respondents had not accessed or been offered this.

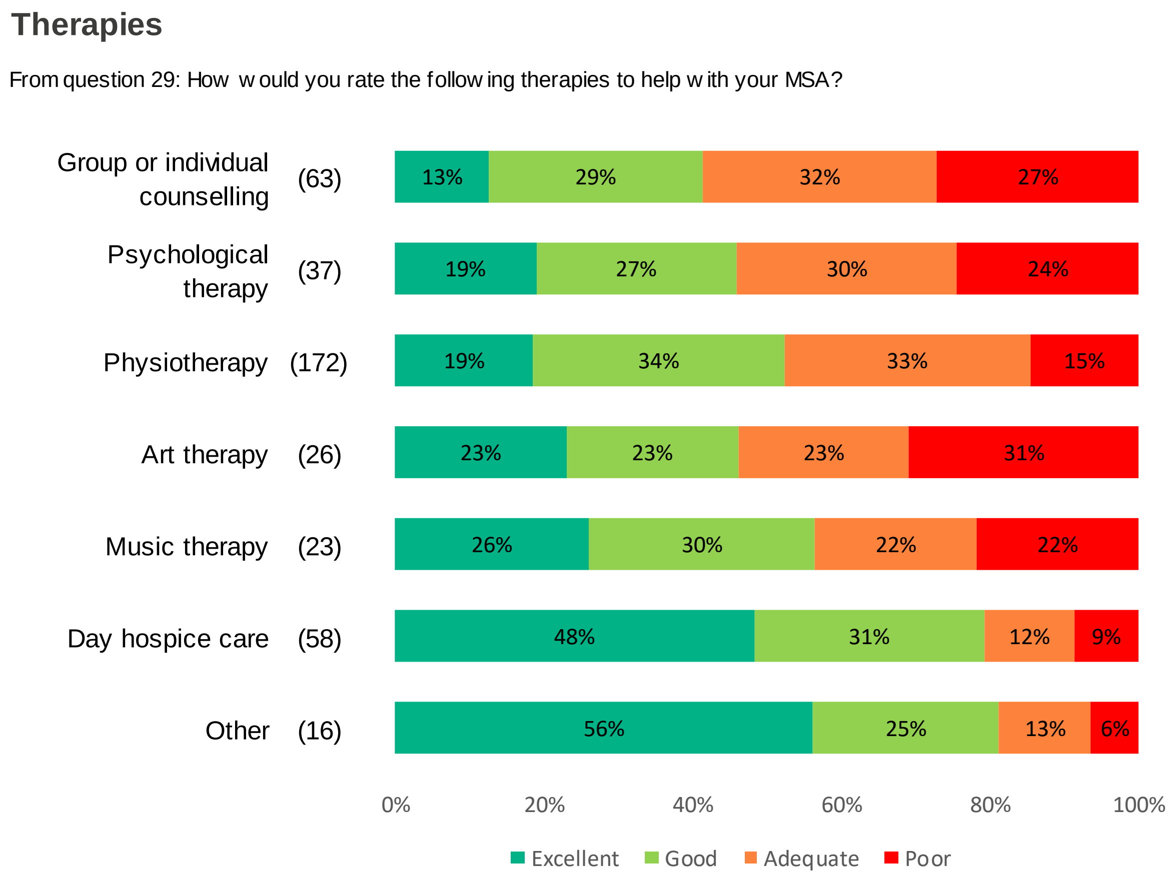


Fig 20. Therapies to help with symptoms of MSA

3.5.4 Complementary therapies to help with symptoms of MSA

Again, the majority of respondents were not accessing any of the therapies in this section, indicating that many people living with MSA are missing out on, or do not want, this type of support. Of those who accessed complementary therapies, the most commonly reported were:

- Exercise (136 respondents), of those 59% rated this as either good or excellent.
- Massage (47 respondents), of these 70% rated this care as either good or excellent.

The most highly rated complementary therapy was hydrotherapy (74% rated this as either good or excellent), however 90% of respondents have not accessed or been offered this.

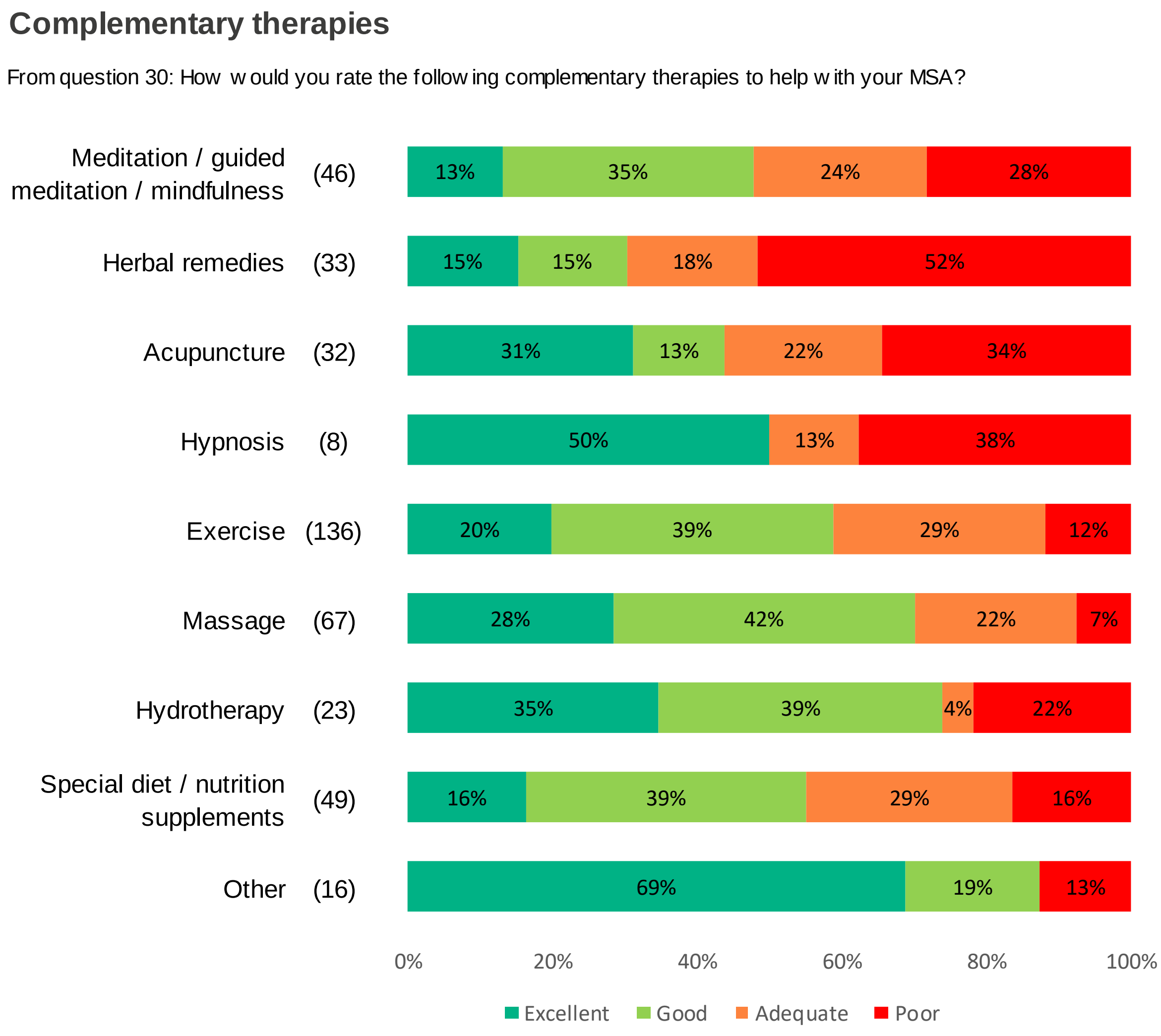


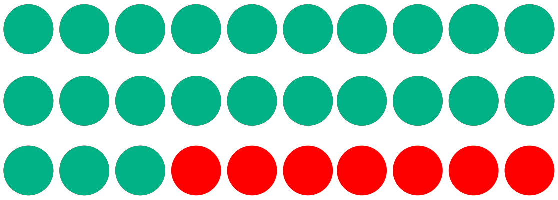
Fig 21. Complementary therapies to help with symptoms of MSA

3.5.5 Information and support

Just over three-quarters of respondents (76%, n.187) had been given information about what to expect from living with a diagnosis of MSA. Just under a quarter of respondents (24%, n.59) had not been given any information at all.

Given information about what to expect from MSA diagnosis

From question 31: Have you been given any form of information about what to expect from living with a diagnosis of MSA?



76%

of respondents given information about what to expect from MSA diagnosis

Based on 246 responses: 76% (187) answering 'Yes', 24% (59) answering 'No'.
Those answering 'Don't know / can't remember' (21) are excluded from calculation.

In terms of the support provided by different organisations/professionals: the most highly rated were from the MSA Trust itself, and then the MSA Trust Nurse Specialists. GPs were rated least favourably.

Information and Support

From question 32: How would you rate the following sources of information and support about MSA?

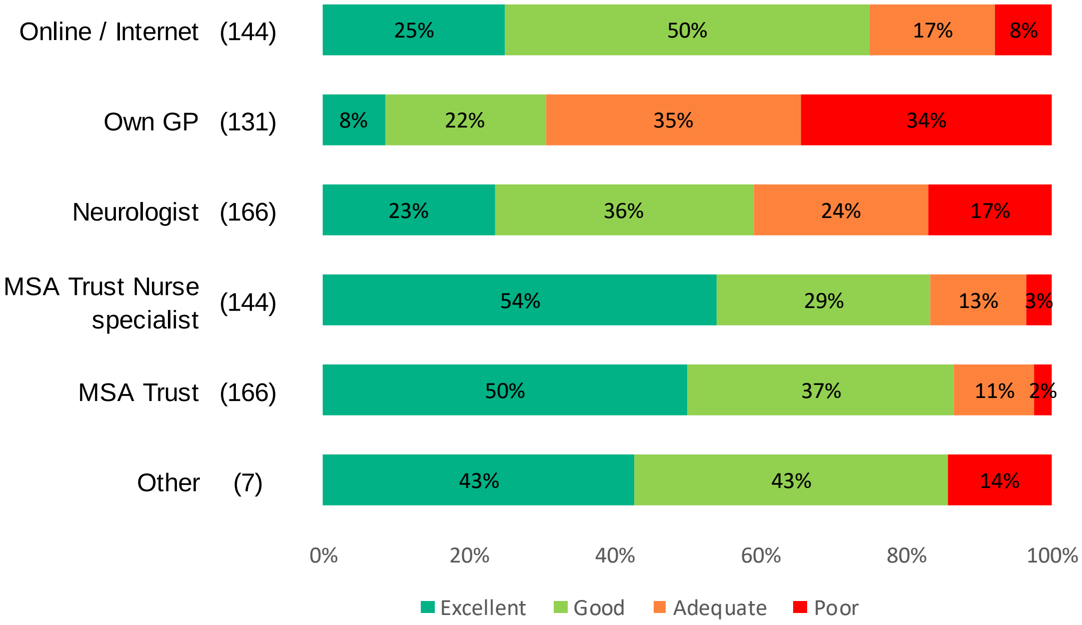


Fig 22. Sources of information and support

3.5.6 Conclusions

- There appears to be a significant issue surrounding care plans. They are not being offered to people as widely as possible, and they appear to be misunderstood. This is a key issue given the severity of impact that MSA entails.
- GPs fare poorly, this is not uncommon with rarer health conditions, but additional support should be considered.
- Hospice care/palliative care teams and MSA Trust Nurse Specialists are rated highly. Focus should be placed on ensuring all of those living with MSA have access.
- Most respondents are not receiving additional therapies to help with their MSA. There is an apparent gap in provision, particularly around psychological therapies such as counselling.
- Most respondents are given information on what to expect from living with MSA: information from MSA Trust itself and MSA Trust Nurse Specialists is rated highly. Focus should be placed on ensuring the maximum number of people with MSA are given this information.

3.6 Financial Impact

3.6.1 Employment

Of those who were still in employment, almost half (48%) chose to take early retirement as a direct result of their MSA; a quarter (25%) chose to leave work due to their MSA; 15% had their contract of employment terminated due to their MSA and 8% were working reduced hours. Just 5% were still working at the time of survey completion.

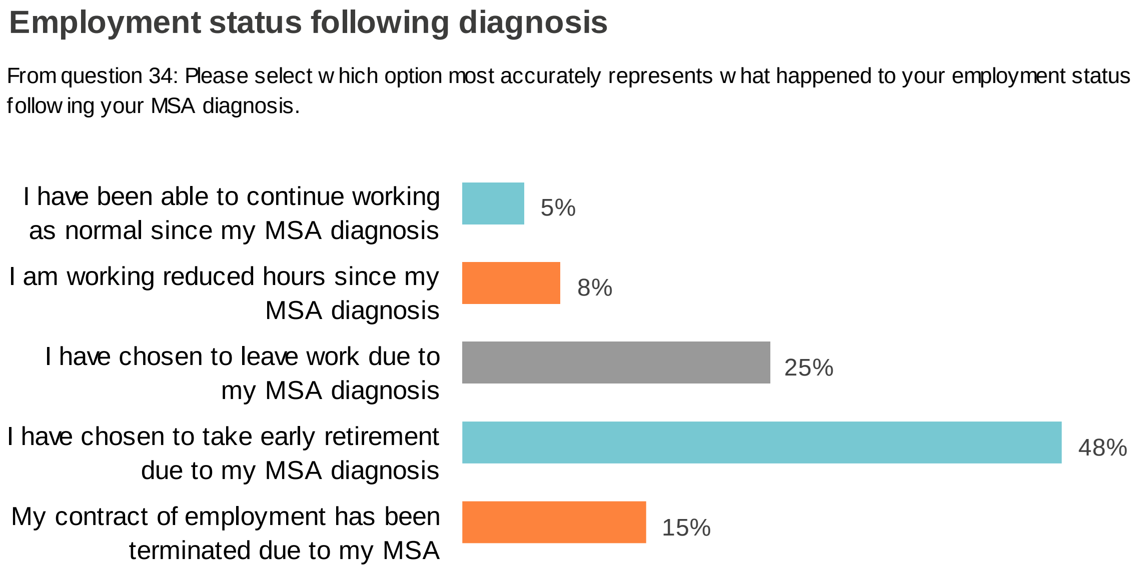


Fig 23. Employment and MSA

3.6.2 Welfare/benefits

Just 12% of respondents (n.33) were not in receipt of any benefits. The most commonly received benefits were a blue badge, PIP and council tax reduction.

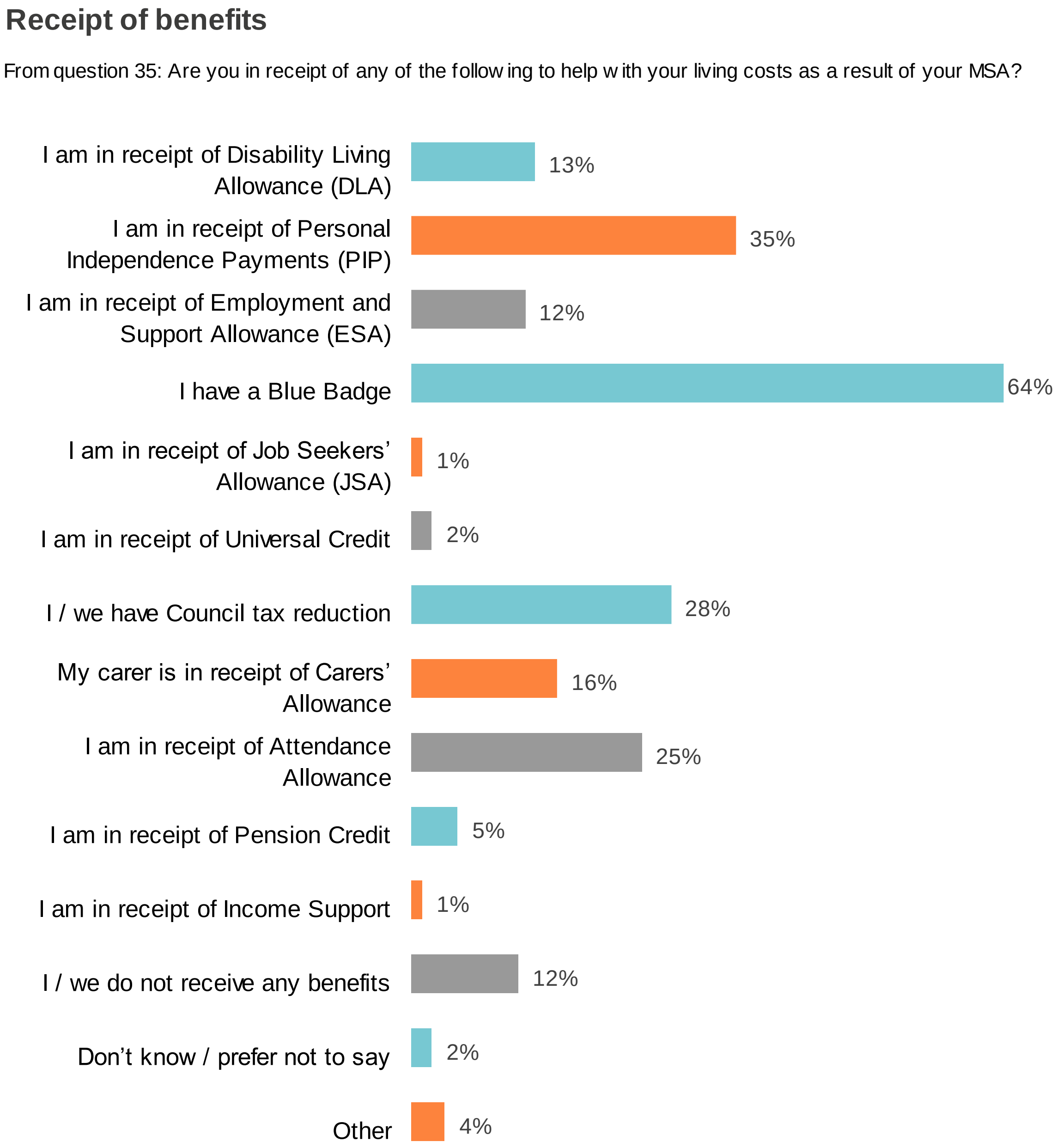
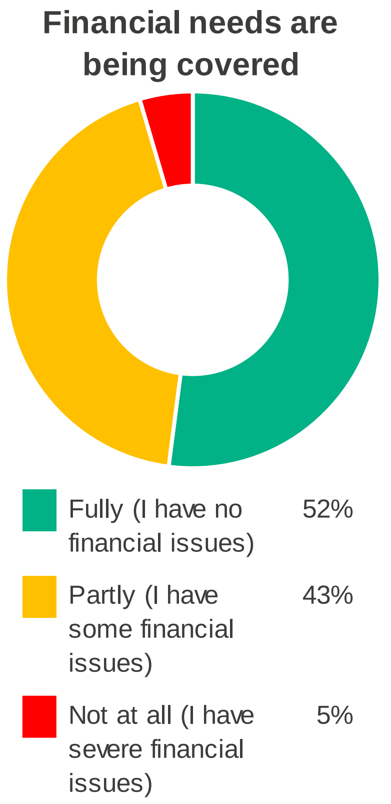


Fig 24. Access to welfare and benefits

3.6.3 Financial needs

There was less of a reported impact on finances than expected. Over half of respondents (52%, n.114) reported having no financial issues whatsoever. Under half (43%, n.95) reported having some financial issues. Just 5% of respondents reported having severe financial issues.



From question 36: To w hat extent do you feel your financial needs are bein covered?

Fig 25. Overall financial needs

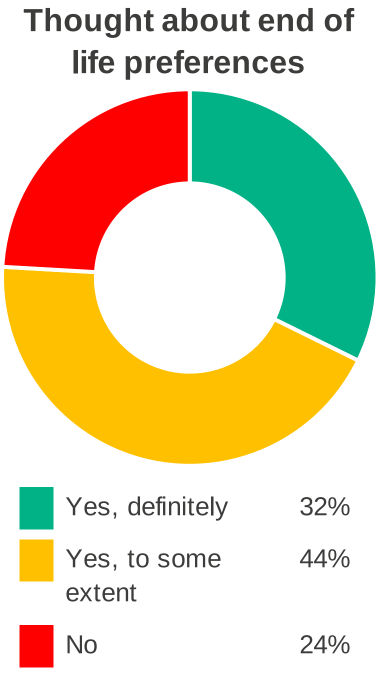
3.6.4 Conclusions

- MSA impacts severely on employment. The vast majority of respondents reported their employment was affected in some way. This has both a financial and psychological impact.
- Most respondents were in receipt of some kind of benefit. The most commonly received benefits were a blue badge, PIP and council tax reduction.
- Access to some benefits will be dependent by age, and this should be considered when looking at the data.
- There was less of a reported impact on finances than expected. Over half of respondents reported having no financial issues whatsoever. Under half reported having some financial issues. Just 5% of respondents reported having severe financial issues. It is important to point out that this finding may be due in part to the age at which MSA manifests itself which is generally near or after the end of working age.

3.7 Palliative care/advance care planning

3.7.1 End of life options

Over three quarters of respondents (76% n.167) had thought about what they wanted to happen towards the end of their lives. Almost a quarter (24% n.53) had not thought about this at all.

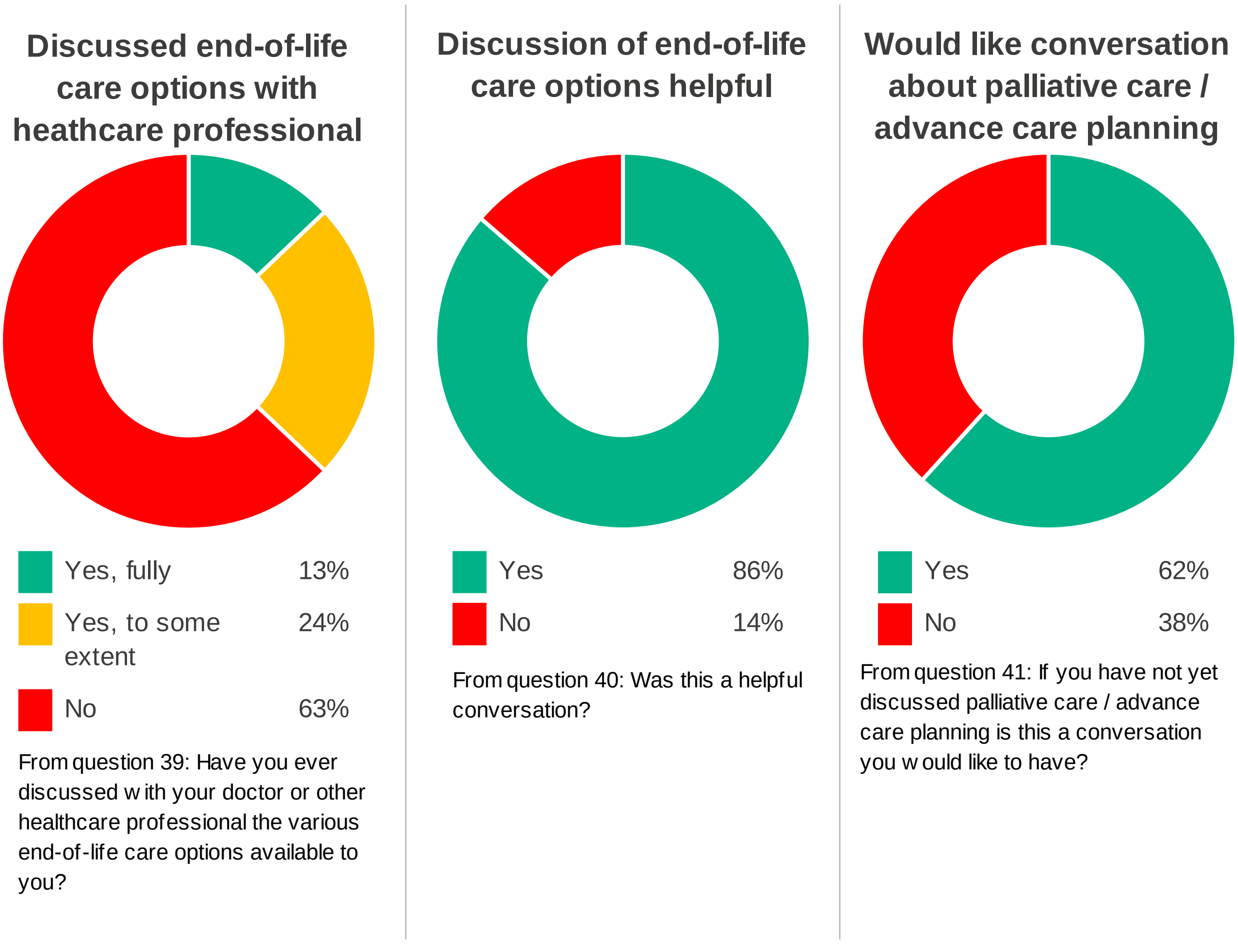


From question 38: Have you thought about w hat you w ould like to happen tow ards the end of your life?

Fig 26. Respondents who had thought about end of life options

3.7.2 Discussion of end of life care with medical professionals

Just over a third of respondents (37% n.86) had discussed with their doctor the various end of life care options which are available. However, almost two thirds (63% n.146) had not had this discussion with a doctor. Of those who had **had** this discussion, the vast majority (86%) found it helpful. Of those who had **not** had this discussion, almost two thirds (62%) would like to have this discussion with their doctor.



From question 39: Have you ever discussed with your doctor or other healthcare professional the various end-of-life care options available to you?

From question 40: Was this a helpful conversation?

From question 41: If you have not yet discussed palliative care / advance care planning is this a conversation you would like to have?

Fig 27. Discussion of end of life care options with health care professionals

3.7.3 Formal advance care planning

In terms of formal advance care planning, the most commonly reported were:

- A will (79% of respondents have one in place and a further 10% are considering this).
- Lasting Power of Attorney (POA) for property and finance (60% of respondents have one in place and a further 19% are considering this).
- Lasting POA for health and welfare (54% of respondents have one in place and a further 21% are considering this).

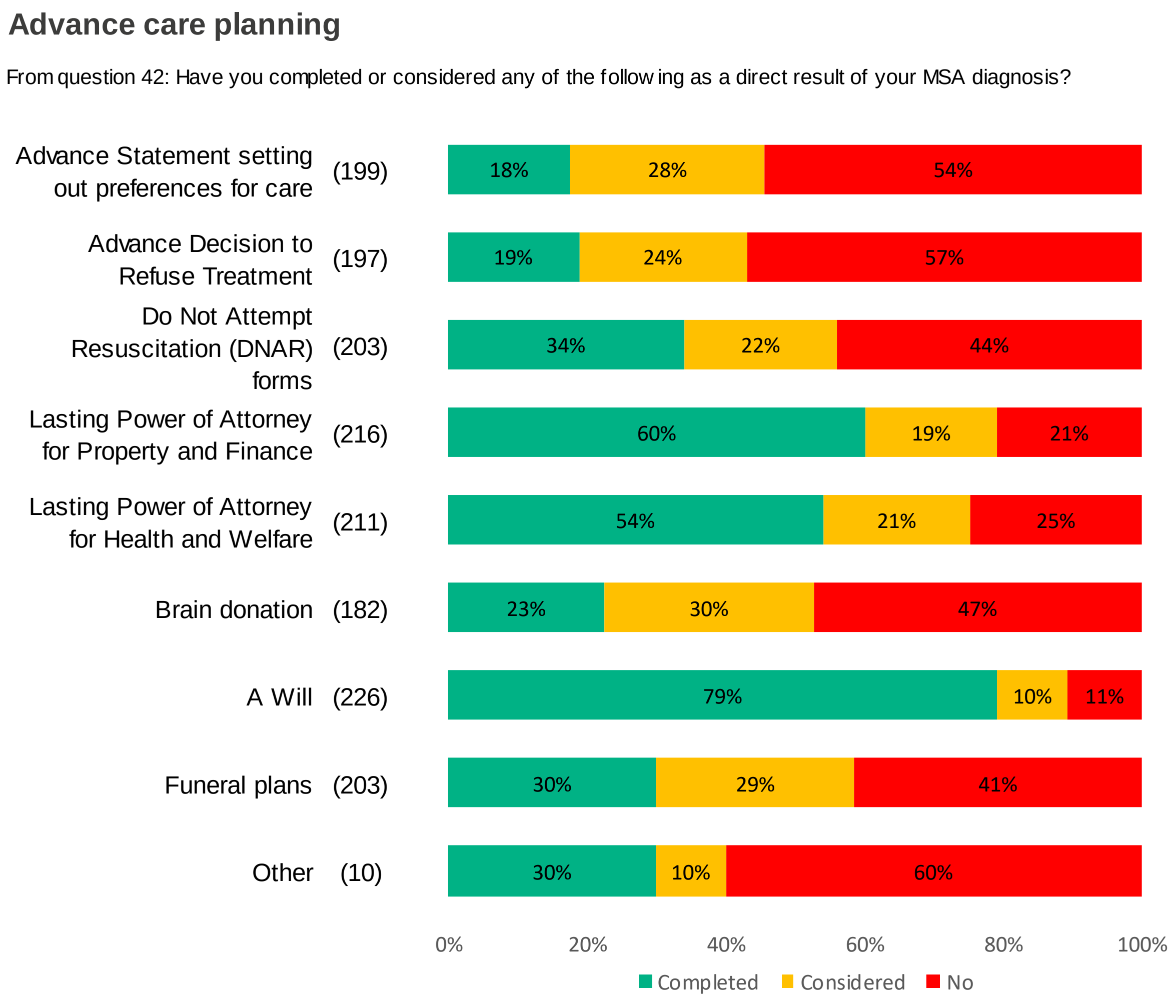


Fig 28. Formal advance care planning

3.7.4 Views on changing the legislation around assisted dying

The vast majority of respondents (85% n.155) feel that the option of assisted dying with legal safeguards should be made legal by parliament.

However, if this choice was available, only 76% of respondents would consider it for themselves.

Feel assisted dying should be made legal

From question 43: Whether or not you would want the choice for yourself, do you feel the option of assisted dying should be made legal by parliament?

Would consider assisted dying if legal

From question 44: If assisted dying, alongside comprehensive end-of-life care, was legal in the UK would you potentially consider it?

Fig 29. Views on changing the legislation around assisted dying

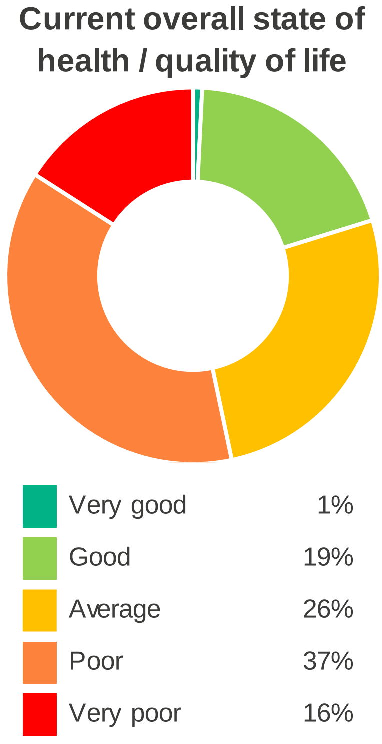
3.7.5 Conclusions

- Almost a quarter of respondents had not thought end of life care options at all. This suggests more could be done to support people living with MSA have these conversations at an early stage.
- The vast majority of respondents have not discussed end of life care options with a health and care professional; those that have reported finding this conversation helpful. This suggests that people living with MSA should be supported to have this conversation earlier.
- For formal advance care planning, the most commonly reported items were a Will and Lasting Power of Attorney for property and finance. More could be done to inform people living with MSA of Advance Statements setting out preferences of care, and the option of brain donation: both of these are reported less frequently.
- The majority of respondents feel assisted dying should be made legal by Parliament, however, slightly less would want this choice for themselves.

3.8 Overall including questions about the MSA Trust

3.8.1 Overall quality of life

Overall quality of life for people living with MSA is poor. It is noticeably more severe when compared to other neurological conditions[11]. Almost two thirds of respondents (64% n.164) rated their quality of life as average or poor. Just under a fifth (19% n. 50) rated their quality of life as good. Just 1% rated it as very good.



From question 46: How would you rate your current overall state of health / quality of life?

Fig 30. Overall quality of life

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[11] Neuro Patience – https://www.neural.org.uk/resource_library/neuro-patience/

3.8.2 MSA Trust services

The most commonly accessed MSA Trust services are MSA News Magazine and MSA Trust Factsheets.

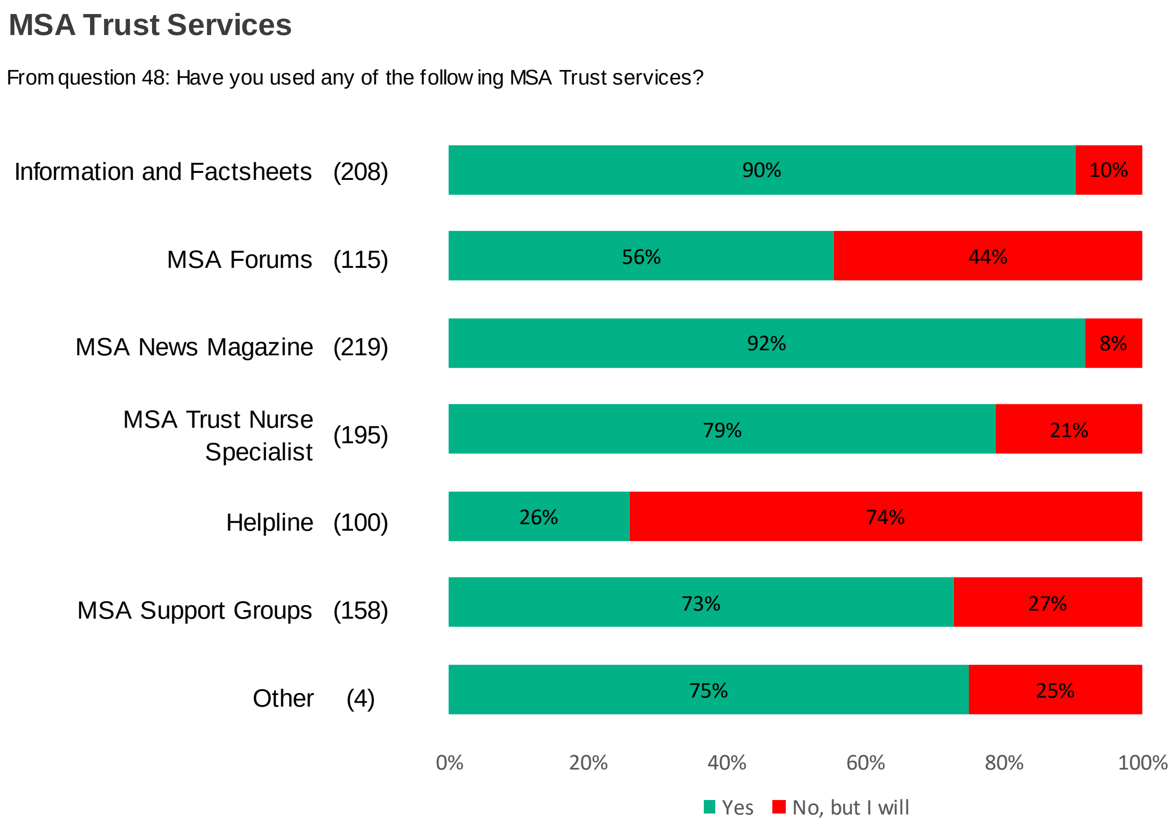

Fig 31. MSA Trust services

3.8.3 Conclusions

- The overall impact of living with MSA is severe and respondents are very dependent on help from others.
- MSA Trust services are universally well received by respondents.
- MSA News Magazine and MSA Information and Factsheets are the services most frequently accessed.
- MSA Forums and the MSA Helpline are the least accessed services which suggests more could be done to promote these services to people living with MSA and their families.

4. Data breakdown analysis

To identify issues within different demographics, further analysis was undertaken using the following key variables:

- Who completed the survey (self-completed vs carer)
- Age
- Time since symptoms first experienced
- Year of diagnosis
- Gender
- Independence
- Financial needs

4.1 Who completed the survey (self-completed vs completed by carer)

The data was broken down by whether or not the survey was completed by the person living with MSA or someone else (usually a friend/family member or a carer). For the purposes of this breakdown analysis, all numbers are taken from the scored data.[12]

The most noticeable differences were as follows:

Survey completed by person living with MSA	**Survey completed by a carer**
More independent (51%)[13]	Much less independent (12%)
Less severe impact on quality of life (though still severe) (94%)	More severe impact on quality of life (99%)
Less likely to have received help with assistive equipment (79%)	More likely to have received help with assistive equipment (89%)
Less likely to experience all side effects	More likely to experience all side effects
More likely to be receiving treatment and support to help with sex life (10%)	Less likely to be receiving treatment and support to help with sex life (3%)
Less likely to have a care plan (46%)	More likely to have a care plan (75%)
More positive about a Neurologist (65%)	Less positive about a Neurologist (57%)
Less positive about District Nurse (46%)	More positive about District Nurse (57%)
More positive about MSA Trust nurse specialist (80%)	Less positive about MSA Trust nurse specialist (70%)
More positive about Physiotherapists (63%)	Less positive about Physiotherapists (57%)
More positive about SLTs (69%)	Less positive about SLTs (56%)
Less positive about dietitians (38%)	More positive about dietitians (53%)
Less positive about counsellors/psychotherapy teams (41%)	More positive about counsellors/psychotherapy teams (55%)

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[12] Appendix A contains the scored methodology

[13] For an explanation of how these percentages are calculated, please refer to Appendix A

4.2 Age

The breakdown analysis by Age was carried out on the results to Q5 which asked about current levels of independence.

45-54	**55-64**	**65-74**	**75+**
Completely independent: **0%**	Completely independent: **8%**	Completely independent: **4%**	Completely independent: **4%**
Dependent – needing help with up to half activities of daily living: **60%**	Dependent – needing help with up to half activities of daily living: **50%**	Dependent – needing help with up to half activities of daily living: **53%**	Dependent – needing help with up to half activities of daily living: **45%**
Very dependent: need help with most activities or may be restricted to bed: **27%**	Very dependent: need help with most activities or may be restricted to bed: **42%**	Very dependent: need help with most activities or may be restricted to bed: **43%**	Very dependent: need help with most activities or may be restricted to bed: **51%**

4.3 Time since symptoms first experienced

The breakdown analysis by ‘time since symptoms first experienced was carried out on the results to Q5 which asked about current levels of independence.

0-5 years	**6-10 years**	**11-15 years**	**16+ years**
Completely independent: **0%**	Completely independent: **3%**	Completely independent: **5%**	Completely independent: **0%**
Dependent – needing help with up to half activities of daily living: **63%**	Dependent – needing help with up to half activities of daily living: **36%**	Dependent – needing help with up to half activities of daily living: **45%**	Dependent – needing help with up to half activities of daily living: **47%**
Very dependent: need help with most activities or may be restricted to bed: **27%**	Very dependent: need help with most activities or may be restricted to bed: **60%**	Very dependent: need help with most activities or may be restricted to bed: **50%**	Very dependent: need help with most activities or may be restricted to bed: **53%**

4.4 Year of diagnosis

The year of diagnosis breakdown looked at the year of diagnosis alongside Q9: are you receiving any of the following treatments for your MSA?

	Tracheostomy	PEG feeding tube	Ventilatory support	Communication aid	Catheters
Diagnosed before 2012	0%	3%	19%	25%	28%
Diagnosed 2012	8%	8%	8%	15%	46%
Diagnosed 2013	6%	13%	6%	31%	25%
Diagnosed 2014	0%	8%	0%	15%	38%
Diagnosed 2015	5%	5%	5%	5%	21%
Diagnosed 2016	0%	8%	16%	19%	32%
Diagnosed 2017	0%	8%	3%	20%	23%
Diagnosed 2018	2%	2%	9%	13%	25%
Diagnosed 2019	0%	0%	14%	10%	19%

4.5 Gender

The Gender breakdown was carried out on questions around sex life and intimacy.

Male	Female
More likely to report sex life has been affected (95%)	Less likely to report sex life has been affected (73%)
More likely to be having treatment to help with sex life (10%)	Not likely at all to be having treatment for sex life (0%)
Treatment to most likely be some kind of medication (5%)	Not likely at all to receive any treatment (0%)
44% report being helped by their treatment for their sex life, 56% report being not helped at all	N/A (not in receipt of treatment)

4.6 Independence

The breakdown for independence was carried out looking at Q26. Do you have a care plan to help manage your MSA?

Completely independent	**Not completely independent**	**More dependent**	**Very dependent**	**Totally dependent**
Has a care plan: **14%**	Has a care plan: **41%**	Has a care plan: **51%**	Has a care plan: **68%**	Has a care plan: **82%**
Does not have a care plan but would like one: **86%**	Does not have a care plan but would like one: **59%**	Does not have a care plan but would like one: **49%**	Does not have a care plan but would like one: **32%**	Does not have a care plan but would like one: **18%**

4.7 Financial Needs

This breakdown looked at receipt of benefits vs reported financial issues. It is important to point out here that it is not always appropriate to look at this data in such a simplistic way as some benefits e.g. PIP, DLA and Pension Credit are determined by age[14] so not applicable to all respondents. There are a limited number of responses to this question which makes it difficult to analyse the data and make any further meaningful conclusions.

No Financial Issues	Some financial issues	Severe financial issues
Most likely to be in receipt of Disability Living Allowance (DLA): 17%	Less likely to be in receipt of DLA: 12%	Least likely to be in receipt of DLA: 10%
Less likely to be in receipt of Personal Independence Payments (PIP): 38%	Most likely to be in receipt of PIP: 46%	Least likely to be in receipt of PIP: 30%
Least likely to be in receipt of Employment and Support Allowance (ESA): 8%	Most likely to be in receipt of ESA: 21%	Less likely to be in receipt of ESA: 10%
Most likely to have a Blue Badge: 74%	Less likely to have a Blue Badge: 69%	Least likely have a Blue Badge: 50%
Least likely to be in receipt of Universal Credit: 0%	Less likely to be in receipt of Universal Credit: 5%	Most likely to be in receipt of Universal Credit: 10%
Least likely to have council tax reduction: 29%	Most likely to have council tax reduction: 32%	Less likely to have council tax reduction: 30%
Less likely to be in receipt of Attendance Allowance: 27%	Most likely to be in receipt of Attendance Allowance: 31%	Least likely to be in receipt of Attendance Allowance: 20%
Most likely to be in receipt of Pension Credit: 8%	Less likely to be in receipt of Pension Credit: 4%	Least likely to be in receipt of Pension Credit: 0%
Less likely to report not being in receipt of any benefits: 13%	Least likely to report not being in receipt of any benefits: 4%	Most likely to report not being in receipt of any benefits: 40%

However, even with the caveat above, there are some anomalies contained in this breakdown which are highlighted in red.

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[14] A list of benefits available can be found at https://www.gov.uk/browse/disabilities

5. Conclusions and recommendations

5.1 Introductory questions conclusions and recommendations

- There continue to be challenges around diagnosis. MSA is most commonly initially diagnosed as Parkinson's.
- Impact on quality of life is severe – almost the most severe of all neurological conditions.
- MSA impacts severely on ability to carry out day to day activities and levels of independence.

Recommendations:

- Challenges around diagnosis are likely to continue to be experienced by those who are ultimately diagnosed with MSA. Further research into the condition is likely to improve this over time, but no immediate short-term solution is identified.
- Additional support should be provided for people living with MSA around quality of life issues.
- MSA Trust to consider extending the offer of Support Groups or Befriending Services and access to MSA Trust Nurse Specialists.
- MSA Trust to try to ensure that every person given a diagnosis is given the Trust's information at point of diagnosis.

5.2 Physical impact conclusions and recommendations

- Due to the nature of MSA, and its effect on autonomic functions of the body, multiple symptoms are likely to be experienced.
- Most respondents had seen a health and care professional(s) to help with assistive equipment.
- Wheelchairs were most commonly used by respondents – but it is important to point out that the item of assistive equipment used will be indicative of where they are in their MSA journey.
- Many respondents report having to fund items of assistive equipment themselves: the majority reported having to pay for wheelchairs.
- It would appear that more could be done to help support people living with MSA to manage their physical symptoms.

Recommendations:

- People living with MSA should be afforded the opportunity to live dignified, fulfilled lives, maximising their wellbeing through:
    - Additional support for managing physical symptoms of MSA;
    - Expansion of advice and guidance offered by MSA Trust Nurse Specialists;
    - Empowering those living with MSA to seek the support of a professional to help with assistive equipment – at an early stage following diagnosis;

- The social care system must change to better serve its purpose in enabling people to get on with their lives in spite of their MSA. Barriers to free assistive equipment remains a significant issue especially for those most at risk.
- MSA Trust to consider campaigning for improved access to wheelchair services.

5.3 Psychological impact conclusions and recommendations

- It is difficult to say whether or not psychological issues are attributed to the condition of MSA or as a result of being given a terminal diagnosis: however, reports of low mood, depression and anxiety are commonplace, and support is needed.
- Fatigue and tiredness are the most commonly experienced.
- Living with MSA has a serious and damaging effect on relationships, in particular respondents report that relationships with friends are most seriously affected.
- The majority of respondents reported issues with their sex life as a direct result of their MSA. The majority of respondents are not receiving any treatment to help.
- It would appear that people living with MSA need more support to help manage the psychological symptoms of living with MSA. There is a significant gap in provision.

Recommendations:

- Every person living with MSA should have their mental, emotional and cognitive wellbeing effectively and systematically screened wherever they live, to pick up on their changing needs, from predictive testing, first symptoms and diagnosis, through to the end of their life. This is not currently happening and there are significant gaps.
- Access to counselling and psychotherapy for those living with MSA needs to be improved.
- Support focused on MSA and the negative effect on relationships should be considered.
- Every person living with MSA who wants treatment to help with the negative impact on their sex life should have access to the most effective and up to date treatments available.
- Impact of social isolation is severe. MSA Trust to consider a service to support this, e.g. befriender service.

5.4 Support for people with MSA conclusions and recommendations

- There appears to be a significant issue surrounding care plans. They are not being offered to people as widely as possible, and they appear to be misunderstood.
- GPs fare poorly, this is not uncommon with rarer health conditions, but additional support should be considered.
- Hospice care/palliative care teams and MSA Trust Nurse Specialists are rated highly. Focus should be placed on ensuring all of those living with MSA have access.
- Most respondents are not receiving additional therapies to help with their MSA. There is an apparent gap in provision, particularly around psychological therapies such as counselling.
- Most respondents are given information on what to expect from living with MSA: information from MSA Trust itself and MSA Trust Nurse Specialists nurses is rated highly. Focus should be placed on ensuring most people with MSA are given this information and support.

Recommendations:

- Personalised and integrated care is a core element of the NHS Long Term Plan; it is essential that this policy intent is translated into practice for people with MSA with a particular focus on access to care plans.
- Care planning for people with MSA accessing primary, community and specialised care services needs improvement. MSA Trust to work with the Neurological Alliance and the National Neuro Advisory Group (NNAG) to support its care planning priority.
- In addition, MSA Trust to provide more information to its members about care plans and how to ensure they have one.
- Explore the barriers to information provision at the time of diagnosis in order to better support healthcare professionals to provide information at this critical point in an individual’s care journey addressing the identified gaps in support from GPs in particular. Consider working with professional bodies including the Association of British Neurologists and the Royal College of General Practitioners to explore further the barriers.
- Expand MSA Trust information service to fully meet the needs of all those diagnosed with MSA, including issues around dealing with advanced MSA.

5.5 Financial impact conclusions and recommendations

- MSA impacts severely on employment. The vast majority of respondents reported their employment was affected in some way. This has both a financial and psychological impact.
- Most respondents were in receipt of some kind of benefit. The most commonly received benefits were a blue badge, PIP and council tax reduction.
- Access to some benefits will be dependent by age, and this should be considered when looking at the data.
- There was less of a reported impact on finances than expected. Over half of respondents reported having no financial issues whatsoever. Under half reported having some financial issues. Just 5% of respondents reported having severe financial issues.

Recommendations:

- The benefits system needs to be more flexible to better serve its purpose in enabling people to get on with their lives in spite of their condition. This would include easier access to benefits when MSA has advanced and other issues relating to self-funding of assistive equipment, social care and personal care. MSA Trust to address issues around accessing benefits through an MSA Trust Social Welfare Specialist.

5.6 Palliative care conclusions and recommendations

- Almost a quarter of respondents had not thought end of life care options at all. This suggests more could be done to support people living with MSA have these conversations at an early stage.
- The vast majority of respondents have not discussed end of life care options with a healthcare professional; those that have reported finding this conversation helpful. This suggests that people living with MSA should be supported to have this conversation earlier.
- For formal advance care planning, the most commonly reported items were a will and Lasting Power of Attorney for property and finance. More could be done to inform people living with MSA of Advance Statements setting out preferences of care, and the option of brain donation: both of these are reported less frequently.
- The majority of respondents feel assisted dying should be made legal by parliament, however, slightly less would want this choice for themselves.

Recommendations:

- People living with MSA to be better supported at accessing palliative care support. This provides a touch point for offering a discussion with the person living with MSA to explore end of life options.
- MSA Trust to support more health and care professionals through education, training and awareness raising with a focus on ensuring they feel able to start conversations with people about end of life support.

5.7 Overall conclusions and recommendations

- The overall impact of living with MSA is severe and respondents are very dependent on help from others.
- MSA Trust services are universally well received by respondents.
- MSA News Magazine and MSA Information and Factsheets are the services most frequently accessed.
- MSA Forums and the MSA Helpline are the least accessed services which suggests more could be done to promote these services to people living with MSA and their families.

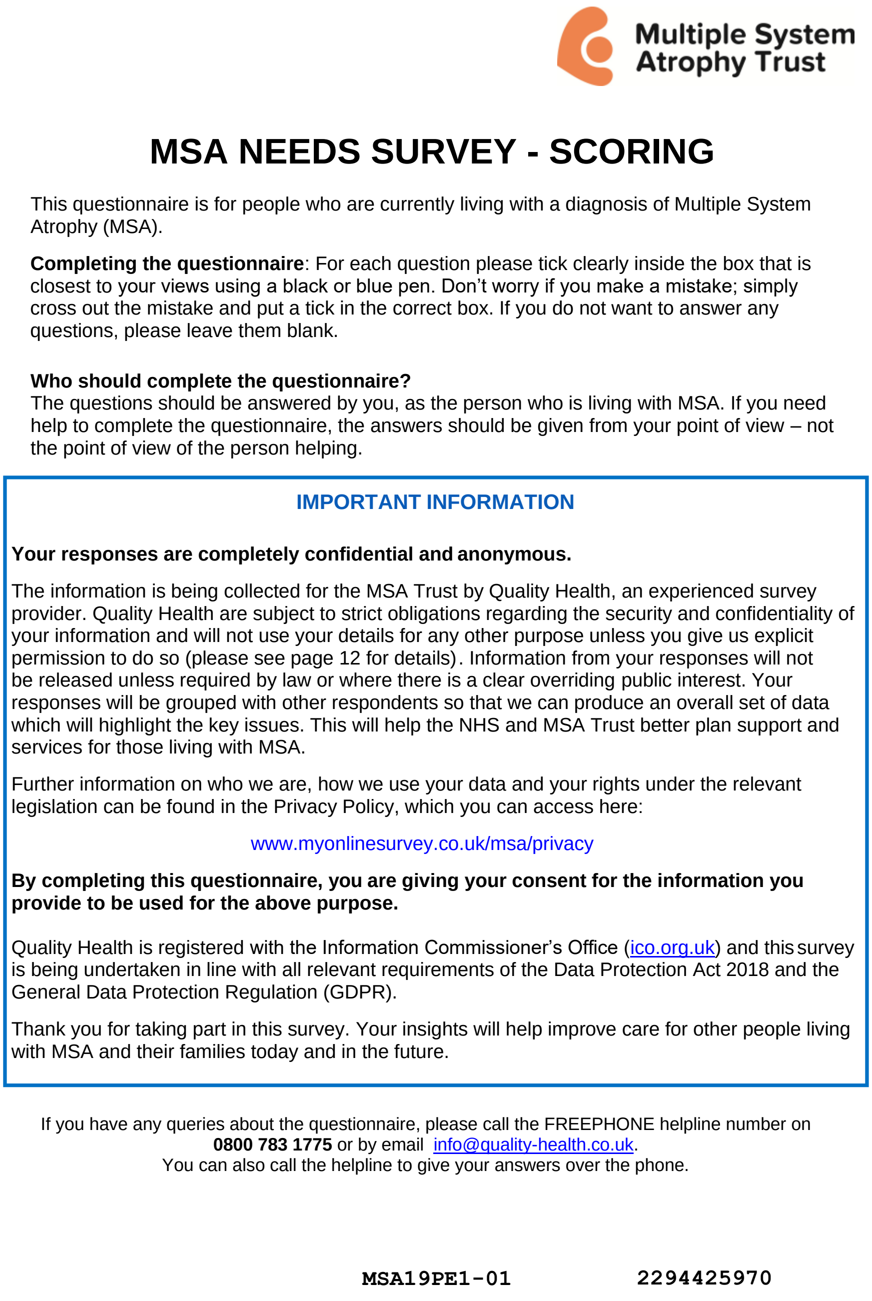
Recommendations:

- It is particularly important that people with MSA are provided with written as well as verbal information at the point of diagnosis.
- Continue to provide all those with a new diagnosis of MSA the high-quality information produced from MSA Trust.
- Consider further promotion of MSA Trust forums and helpline service.

APPENDIX A

APPENDIX A
SCORING METHODOLOGY

The table below details the scoring methodology for all scored questions within the 2019 MSA Needs Survey.



Multiple System Atrophy Trust

MSA NEEDS SURVEY - SCORING

This questionnaire is for people who are currently living with a diagnosis of Multiple System Atrophy (MSA).

Completing the questionnaire: For each question please tick clearly inside the box that is closest to your views using a black or blue pen. Don't worry if you make a mistake; simply cross out the mistake and put a tick in the correct box. If you do not want to answer any questions, please leave them blank.

Who should complete the questionnaire?
The questions should be answered by you, as the person who is living with MSA. If you need help to complete the questionnaire, the answers should be given from your point of view – not the point of view of the person helping.

IMPORTANT INFORMATION

Your responses are completely confidential and anonymous.

The information is being collected for the MSA Trust by Quality Health, an experienced survey provider. Quality Health are subject to strict obligations regarding the security and confidentiality of your information and will not use your details for any other purpose unless you give us explicit permission to do so (please see page 12 for details). Information from your responses will not be released unless required by law or where there is a clear overriding public interest. Your responses will be grouped with other respondents so that we can produce an overall set of data which will highlight the key issues. This will help the NHS and MSA Trust better plan support and services for those living with MSA.

Further information on who we are, how we use your data and your rights under the relevant legislation can be found in the Privacy Policy, which you can access here:

www.myonlinesurvey.co.uk/msa/privacy

By completing this questionnaire, you are giving your consent for the information you provide to be used for the above purpose.

Quality Health is registered with the Information Commissioner's Office (ico.org.uk) and this survey is being undertaken in line with all relevant requirements of the Data Protection Act 2018 and the General Data Protection Regulation (GDPR).

Thank you for taking part in this survey. Your insights will help improve care for other people living with MSA and their families today and in the future.

If you have any queries about the questionnaire, please call the FREEPHONE helpline number on **0800 783 1775** or by email info@quality-health.co.uk.
You can also call the helpline to give your answers over the phone.

MSA19PE1-01 2294425970

INTRODUCTORY QUESTIONS

1. Who is filling in this survey? ***If you are filling in this survey on someone else's behalf, the answers must be given from <u>their point of view, not your own,</u>*** **NOT SCORED**

1 ☐ I am filling it in as a person living with MSA

2 ☐ A friend or family member

3 ☐ A carer (including a health or care professional)

Y	Y	Y	Y

Y	Y	Y	Y

3. Apart from MSA, do you live with any other chronic (long-term) conditions?

1 ☐ No **0**

2 ☐ Yes (please specify below) **1**

4. Was your MSA initially diagnosed as something else? **NOT SCORED**

1 ☐ I was diagnosed with Parkinson's first

2 ☐ I was diagnosed with Atypical Parkinson's first

3 ☐ I was diagnosed with Progressive Supranuclear Palsy (PSP) first

4 ☐ I was diagnosed with Ataxia first

5 ☐ I was diagnosed with Corticobasal Degeneration (CBD) first

6 ☐ No, I was diagnosed with MSA first

7 ☐ Other (please specify)

5. How would you describe your current level of independence? (Activities of daily living)

1 ☐ Completely independent. I have no independence problems **1**

2 ☐ Not completely independent. I need some help with daily activities **1**

3 ☐ More dependent. Need help with half or more of daily activities **0**

4 ☐ Very dependent. Need help with most daily activities **0**

5 ☐ Totally dependent. May be restricted to bed **0**

6 ☐ Don't know **NS**

6. To what extent does having MSA impact on your overall quality of life?

1 ☐ Not at all **0**

2 ☐ Slightly **0**

3 ☐ Moderately **1**

4 ☐ Severely **1**

5 ☐ Don't know **NS**

PHYSICAL IMPACT

7. At which point did any of the following symptoms first appear? **NOT SCORED**

Please tick once only on each line (emotional impact features later in this questionnaire)		Over 3 years before diagnosis	1-3 years before diagnosis	1-12 months before diagnosis	Since diagnosis	Never experienced	Don't know
a.	Autonomic problems / unconscious bodily functions (e.g. bladder / bowel problems, temperature control, sexual dysfunction, blood pressure / pulse rate)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
b.	Difficulty in moving (e.g. balance, coordination, tremor, slowness / stiffness)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
c.	Difficulty with breathing, speech / swallowing (e.g. speech impairment, difficulty managing saliva)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
d.	Sleep disorders (e.g. difficulty sleeping or staying asleep, sleep apnoea)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
e.	Pain	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
f.	Difficulty concentrating / 'fuzzy head'	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
g.	Other (please specify below)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

8. Do you currently use any of the following to assist you with walking? ***This might be for some or all of the time.*** **Please tick all that apply.** **NOT SCORED**

1 ☐ Wheelchair	2 ☐ Walker	3 ☐ Rollator	4 ☐ My partner / carer helps me to walk
5 ☐ Walking stick	6 ☐ Other (please specify)		

9. Are you currently receiving any of the following treatments for your MSA? **NOT SCORED**

1 ☐ Tracheostomy (breathing support with an opening into the windpipe)	2 ☐ PEG feeding tube (tube inserted into the stomach to provide food)	3 ☐ Ventilatory support - NIV or C-PAP - (mechanical support to help you breathe)
4 ☐ Communication aids	5 ☐ Urinary catheters to help with passing urine (indwelling or intermittent)	6 ☐ Other (please specify)

10. Which of the medications that you have taken for MSA have you found the most effective?
(Please specify the top three below)

1.	**NOT SCORED**
2.	**NOT SCORED**
3.	**NOT SCORED**

11. Have you seen a health care professional to help with assistive equipment?
(this is any kind of tool or device designed to make certain tasks easier, e.g. a wheelchair).

1 ☐ Yes ➔ **GO TO Q12** **1**
2 ☐ No ➔ **GO TO Q13** **0**
3 ☐ Don't know / can't remember ➔ **GO TO Q13** **NS**

12. What are the **top three most useful** items of assistive equipment you were recommended?
Please write one in each of the 3 boxes below and then tick one box indicating how it was funded.

	How was this item funded? ➔	Self-funded	NHS	Local Authority	Charity	Could not afford this item
1.	**NOT SCORED**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
2.	**NOT SCORED**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
3.	**NOT SCORED**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

13. Do you think that your physical needs are being managed as effectively as possible?

1 ☐ Yes, fully **1**
2 ☐ Yes, to some extent **1**
3 ☐ No **0**
4 ☐ Don't know **NS**

14. Please rate the top three physical symptoms / problem(s) which affect your quality of life the most?
Please use the boxes below. List the symptom that affects you the most as number 1.

1.	**NOT SCORED**
2.	**NOT SCORED**
3.	**NOT SCORED**

15. If you would like to say anything else about the physical impact of living with MSA, please use this box.

NOT SCORED

Please tick once only on each line.	Not ever experienced **0**	Before diagnosis **1**	At diagnosis **1**	Since diagnosis **1**	Don't know **NS**
a. Low mood / depression, including					

17. To what extent **overall** are the following **affected** as a result of living with MSA?
Whilst it is expected that this will vary on a day to day basis, please give an overall indication.

Please tick once only on each line.	Got much better **0**	Got better **0**	Stayed the same **0**	Got worse **1**	Got much worse **1**
a. Personal relationship e.g. partner / spouse	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
b. Family relationships e.g. grandchildren / children / siblings	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
c. Other relationships e.g. friends	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
d. Social activities e.g. feeling isolated	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

18. Which of the above issues is your **main concern?** **NOT SCORED**

1 ☐ Personal relationship
2 ☐ Family relationships
3 ☐ Other relationships
4 ☐ Social activities

19. Has your sex life / intimacy been affected by your MSA?

1 ☐ Yes **1** **→ GO TO Q20**
2 ☐ No **0** **→ GO TO Q24**
3 ☐ Don't know **NS** **→ GO TO Q24**
4 ☐ Prefer not to say **NS** **→ GO TO Q24**

20. Can you explain in more detail how your sex life has been affected and what you would find helpful?

NOT SCORED

21. Are you receiving treatment and / or support to improve your sex life?

1 ☐ Yes **1** **→ GO TO Q22**
2 ☐ No **0** **→ GO TO Q24**
3 ☐ Prefer not to say **NS** **→ GO TO Q24**

22. What treatment / support have you received? **Please tick all that apply. NOT SCORED**

1 ☐ Referral to specialist services
2 ☐ Counselling
3 ☐ Medication
4 ☐ Other (please specify)

23. Has this treatment helped improve your sex life?

1 ☐ Yes, definitely **1**
2 ☐ Yes, to some extent **1**
3 ☐ No **0**
4 ☐ Prefer not to say **NS**

24. Do you think that your **emotional needs** are being managed as effectively as possible?

1 ☐ Yes, fully **1**
2 ☐ Yes, to some extent **1**
3 ☐ No **0**
4 ☐ Don't know / can't remember **NS**

26. Do you have a care plan to help manage your MSA?

A care plan shows what care and support will meet your needs and includes which needs your local council will meet. It also contains a named person for you to contact.

1 ☐ Yes, by my health care team **1**	2 ☐ Yes, by my social care team **1**	3 ☐ No, but I would like one 0
4 ☐ I don't need a care plan **NS**	5 ☐ I don't know what a care plan is **NS**	6 ☐ Don't know / can't remember **NS**

27. To what extent do you think having a care plan helps improve your quality of life / would help improve your quality of life?

1 ☐ To a great extent **1**	2 ☐ To a moderate extent **1**	3 ☐ To a small extent **0**
4 ☐ Not at all **0**	5 ☐ Don't know / N/A **NS**	

28. How would you rate the support you have received for your MSA from these professionals?

Please tick once only on each line.	Excellent **1**	Good **1**	Adequate **0**	Poor **0**	Did not receive **NS**
a. Your GP (*the GP you see most frequently, not an out of hours service)*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
b. Neurologist / Parkinson's Specialist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
c. Parkinson's Disease Nurse Specialist (PDNS)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
d. Community Matron / District Nurse	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
e. MSA Trust Nurse Specialist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
f. Neurology Nurse Specialist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
g. Physiotherapist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
h. Occupational Therapist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
i. Speech & Language Therapist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
j. Dietitian	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
k. Continence Nurse Specialist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
l. Urologist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
m. Counsellor / Psychiatric Team	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
n. Palliative Care / Hospice Team	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
o. Social Worker	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
p. Wheelchair services	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

29. How would you rate the following therapies to help with your MSA?

Please tick once only on each line.	Excellent 1	Good 1	Adequate 0	Poor 0	Have never received NS
a. Group or individual counselling	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
b. Psychological therapy	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
c. Physiotherapy	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
d. Art therapy	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
e. Music therapy	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
f. Day hospice care	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
g. Other (please specify) ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

30.. How would you rate the following complementary therapies to help with your MSA?

Please tick once only on each line.	Excellent 1	Good 1	Adequate 0	Poor 0	Have never received NS
a. Meditation / guided meditation / mindfulness	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
b. Herbal remedies	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
c. Acupuncture	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
d. Hypnosis	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
e. Exercise	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
f. Massage	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
g. Hydrotherapy	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
h. Special diet / nutrition supplements	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
i. Other (please specify) ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

31. Have you been given any form of information about what to expect from living with a diagnosis of MSA?

1 ☐ Yes ➔ **GO TO Q32 1**

2 ☐ No ➔ **GO TO Q33 0**

3 ☐ Don’t know / can’t remember ➔ **GO TO Q33 NS**

32. How would you rate the following sources of information and support about MSA?

Please tick once only on each line.	Excellent 1	Good 1	Adequate 0	Poor 0	Have never received NS
a. Online / Internet	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
b. Own GP	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
c. Neurologist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
d. MSA Trust Nurse specialist	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
e. MSA Trust	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
					5 ☐

33. If you would like to say anything else about the additional support for people living with MSA, please use this box. Please include anything you feel is missing from the information and support you have received or would like to receive. NOT SCORED

34. Please select which option most accurately represents what happened to your employment status following your MSA diagnosis. ***Please tick only one.*** NOT SCORED

1	☐	I have been able to continue working as normal since my MSA diagnosis	2	☐	I am working reduced hours since my MSA diagnosis
3	☐	I have chosen to leave work due to my MSA diagnosis	4	☐	I have chosen to take early retirement due to my MSA diagnosis
5	☐	My contract of employment has been terminated due to my MSA	6	☐	I was already retired at the time of my diagnosis
7	☐	I was already unemployed at the time of my diagnosis			

35. Are you in receipt of any of the following to help with your living costs as a result of your MSA? ***Please tick all that apply.*** NOT SCORED

1	☐	I am in receipt of Disability Living Allowance (DLA)	2	☐	I am in receipt of Personal Independence Payments (PIP)	3	☐	I am in receipt of Employment and Support Allowance (ESA)
4	☐	I have a Blue Badge	5	☐	I am in receipt of Job Seekers' Allowance (JSA)	6	☐	I am in receipt of Universal Credit
7	☐	I / we have Council tax reduction	8	☐	My carer is in receipt of Carers' Allowance	9	☐	I am in receipt of Attendance Allowance
10	☐	I am in receipt of Pension Credit	11	☐	I am in receipt of Income Support	12	☐	I / we do not receive any benefits
13	☐	Don't know / prefer not to say	14	☐	Other (please specify)			

36. To what extent do you feel your financial needs are being covered?

1	☐	Fully (I have no financial issues) 1	2	☐	Partly (I have some financial issues) 1	3	☐	Not at all (I have severe financial issues) 0	4	☐	Prefer not to say NS

37. If you would like to say anything else about the financial impact living with MSA, please use this box. In particular we are interested in the additional costs you have incurred, or extra things you have had to pay for as a result of your MSA diagnosis.

NOT SCORED

38. Have you thought about what you would like to happen towards the end of your life?

1	☐	Yes, definitely 1	2	☐	Yes, to some extent 1	3	☐	No 0	4	☐	Prefer not to say NS

39. Have you ever discussed with your doctor or other healthcare professional the various end-of-life care options available to you (*e.g. hospice care, staying at home, sedation, refusal of life prolonging treatment, deciding against resuscitation*)?

1 ☐ Yes, fully **1** ➔ **GO TO Q40**	2 ☐ Yes, to some extent **1** ➔ **GO TO Q40**	3 ☐ No **0** ➔ **GO TO Q41**	4 ☐ Prefer not to say **NS** ➔ **GO TO Q41**

40. Was this a helpful conversation?

1 ☐ Yes **1**	2 ☐ No **0**	3 ☐ Don't know **NS**	4 ☐ Prefer not to say **NS**

41. If you have not yet discussed palliative care / advance care planning is this a conversation you would like to have?

1 ☐ Yes **1**	2 ☐ No **0**	3 ☐ Don't know **NS**	4 ☐ Prefer not to say **NS**

42. Have you completed or considered any of the following as a direct result of your MSA diagnosis?

Please tick once only on each line.	Completed **1**	Considered **0**	No **0**	Don't know **NS**	N/A **NS**
a. Advance Statement setting out preferences for care (*a written statement that sets down your preferences, wishes, beliefs and values regarding your future care)*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
b. Advance Decision to Refuse Treatment *(a specific legal document explaining what treatments you do not wish to receive)*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
c. Do Not Attempt Resuscitation (DNAR) forms *(legal order to withhold resuscitation)*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
d. Lasting Power of Attorney for Property and Finance *(giving someone else the legal power to make decisions on your behalf)*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
e. Lasting Power of Attorney for Health and Welfare *(giving someone else the legal power to make decisions on your behalf)*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
f. Brain donation *(this is where you agree to donate your brain after death for the purposes of medical research)*	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
g. A Will	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
h. Funeral plans	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
i. Other (please specify)	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

43. ***There has been ongoing attention in the media and more widely about assisted dying for people who have a progressive condition and who are in the last six months of life. The MSA Trust, which has always held a neutral stance on this issue, is interested in any views you may have on this.***

Whether or not you would want the choice for yourself, do you feel the option of assisted dying should be made legal by parliament?

1 ☐ Yes **1**	2 ☐ No **0**	3 ☐ Don't know **NS**	4 ☐ Prefer not to say **NS**

44. If assisted dying, alongside comprehensive end-of-life care, was legal in the UK would you potentially consider it?

1 ☐ Yes **1**	2 ☐ No **0**	3 ☐ Don't know **NS**	4 ☐ Prefer not to say **NS**

45. If you have any further thoughts about palliative care / end-of-life care (including assisted dying) which you would like to share, please do so here.

NOT SCORED

46. How would you rate your current overall state of health / quality of life?

1 ☐ Very good**1**	2 ☐ Good**1**	3 ☐ Average **0**
4 ☐ Poor **0**	5 ☐ Very poor**0**	6 ☐ Don't know / prefer not to say **NS**

47. What one thing would most improve your quality of life?

NOT SCORED

48. Have you used any of the following MSA Trust services?

Please tick once only on each line.	Yes **1**	No, but I will **0**	No, this is not necessary **NS**	Don't know / can't remember **NS**
a. Information and Factsheets	1 ☐	2 ☐	3 ☐	4 ☐
b. MSA Forums	1 ☐	2 ☐	3 ☐	4 ☐
c. MSA News Magazine	1 ☐	2 ☐	3 ☐	4 ☐
d. MSA Trust Nurse Specialist	1 ☐	2 ☐	3 ☐	4 ☐
e. Helpline	1 ☐	2 ☐	3 ☐	4 ☐
f. MSA Support Groups	1 ☐	2 ☐	3 ☐	4 ☐
g. Other (please specify)			3 ☐	4 ☐

Quality Health is a specialist health and social care survey organisation, working for public, private and not-for-profit sectors, in the UK and overseas.

For more information

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