Multiple System Atrophy Trust

Survey of Former Carers of People Living with MSA 2019: Technical report

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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, though 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).

As a result of the devastating impact of the condition, many of those living with MSA will turn to family members to care for them. With no dedicated study in the UK examining the experiences of caring for people living with MSA, MSA Trust commissioned Quality Health to work with them on the largest study of its kind in the UK.

The 2019 National MSA Survey of Former Carers 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 supporting symptom management, 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 caring for someone living with MSA. This report provides intelligence about how well supported carers are and where there are gaps in the system for carers who are looking after someone 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

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[1] Insert link to MSA Trust summary document

in relation to the policy context, draws conclusions, and makes recommendations for system change accordingly.

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

1. Most former carers report caring for their spouse or partner at home. The caring commitment can be long and demanding.
2. A large proportion of people living with MSA are dying unexpectedly – that is at a time which is not considered to be at the end of their lives by a medical professional. This can have a damaging impact on the mental and emotional wellbeing of the carer.
3. All carers need to be empowered to seek a carers' assessment.
4. Carers rate highly the support provided by MSA Trust Nurse Specialists and Hospice Care teams.
5. Caring is physically demanding. Most carers struggle managing issues surrounding many aspects of MSA such as mobility, autonomic failure and communication.
6. There is a significant impact on the mental and emotional wellbeing of carers when looking after someone living with MSA. Fatigue is most commonly experienced. Anxiety, depression and general low mood are also widely experienced.
7. Additional support groups for carers would be welcome, but logistical issues around location may prevent access.
8. Caring for someone living with MSA has a serious and damaging effect on relationships, in particular carers report that relationships with friends are most seriously affected.
9. The benefits system must change to better serve its purpose in enabling carers to get on with their lives.
10. End of life planning and discussion needs significant improvement with a focus on carers. More needs to be done to support carers to have these discussions at an earlier stage.
11. Caring for someone at the end of their lives is emotionally and physically demanding this is compounded when the person is not able to die at a place of their choosing.
12. MSA Trust services are universally well received by carers and additional effort should be placed in ensuring all new carers have access to this information.
13. The vast majority of former carers reported that they did not want ongoing support, however this should be considered for those who have experienced a very recent death.

2. Background and methodology

2.1 Background

- This is the first ever MSA Trust survey of former carers.
- The MSA Trust engaged survey company Quality Health to undertake the survey. The 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.
- Data was collected between June and August 2019. The survey received 371 responses.

2.2 Objectives

The survey had five main objectives, to gather data about the experience of former carers who had previously cared for someone living with MSA in order to:

1. To better understand existing data about living with MSA (including that collected in the MSA Needs Survey[2]) by exploring the issues faced through the eyes of someone who had cared for someone living with the condition.
2. Enhance nationally collected data and intelligence about life as a carer, by providing evidence about the experience of people who have previously cared for someone.
3. Provide the health sector with evidence about the experience of carers in order to influence national policy.
4. Provide intelligence about the experiences of former carers of people with MSA to inform MSA Trust's strategic priorities and longer-term work. With a specific focus on identifying where there are gaps in provision for those who are caring for a loved one who is living with the condition and also better understand the needs of people living with MSA.
5. Produce a report about former carers of people living with MSA.

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

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 former carers who had previously cared for someone living with MSA and whose details were held on MSA Trust's database. This method was chosen as many individuals did not have email addresses. 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. 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 Specialist Nurses and Neurologists with direct experience of MSA.
- Cognitive testing was carried out with 9 people who were all former carers of a person who had been living with MSA but had since died. This was 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.

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 specialist nurses and Neurologists with direct experience of MSA.

As a part of the process, cognitive testing was carried out with 9 volunteers all of whom were former carers of someone who had been 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. Scored results are not being used in this report and therefore the scoring methodology is not included but is available on request.

2.3.3 Sampling and data

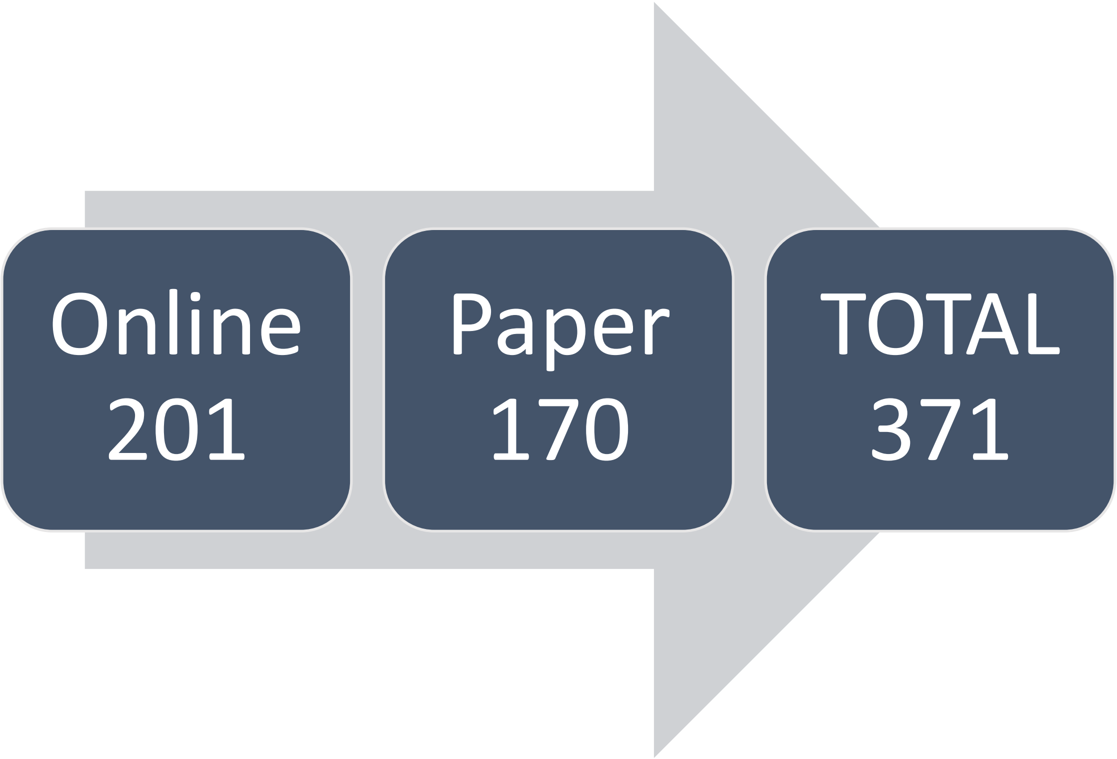
The online survey was promoted using MSA Trust’s database of former carers who had consented to be contacted further. There was also an anonymous link which was available to all respondents. Paper copies were sent to named individuals. Due to MSA Trust’s stringent data protection rules, data was not sent between Quality Health and MSA Trust. Quality Health therefore sent paper packs to MSA Trust, who addressed and sent them 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 873[3], this represents a response rate of 39%.

This should be considered a highly successful survey. Such a positive response means we can consider the results robust, which allow us to make meaningful conclusions.

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[3] The sample was drawn from the MSA Trust database and included those known to the Trust who were former carers of someone who had been living with MSA and had consented to further contact. This number includes 27 anonymous carer responses which all came online.

3. Results of the questionnaires

3.1 Respondent characteristics

3.1.1 Age

All respondents were aged over 25. Three-quarters of respondents (75%) were aged over 65.

The chart below breaks this down in more detail.

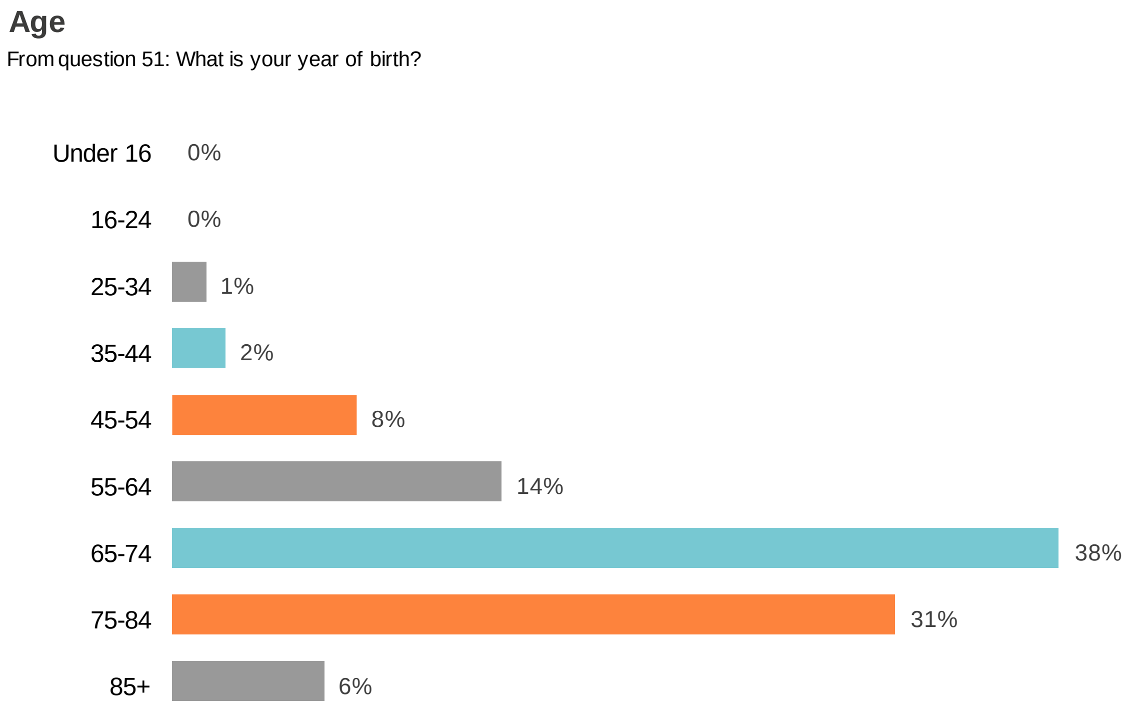


Fig 1. Age range of respondents

3.1.2 Relation to the person living with MSA

The vast majority (89% n.328) were a spouse or partner of the person who lived with MSA. Just 6% were a parent or guardian of the person who lived with MSA. Just 4% were a son or daughter of the person who lived with MSA.

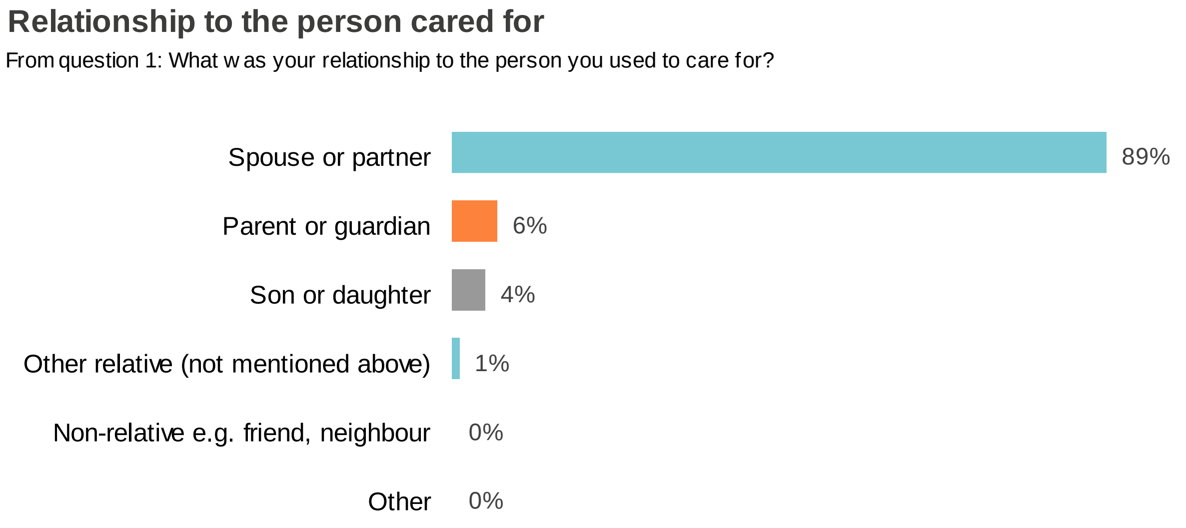


Fig 2. Relationship the person cared for

3.1.3 Gender

There was an over-representation of female respondents. Almost three-quarters of respondents identified themselves as Female (71%). Only just over a quarter of respondents identified themselves as Male (28%).

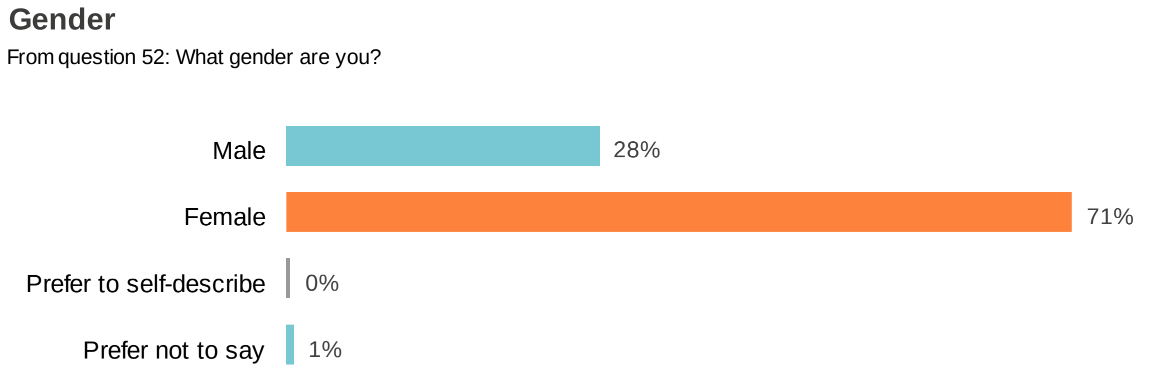


Fig 3. Relationship the person cared for

3.2 Introductory questions

3.2.1 How long ago did the person living with MSA die?

The largest set of respondents had previously cared for someone living with MSA who had died over six years ago. There was a broad split between the other categories.

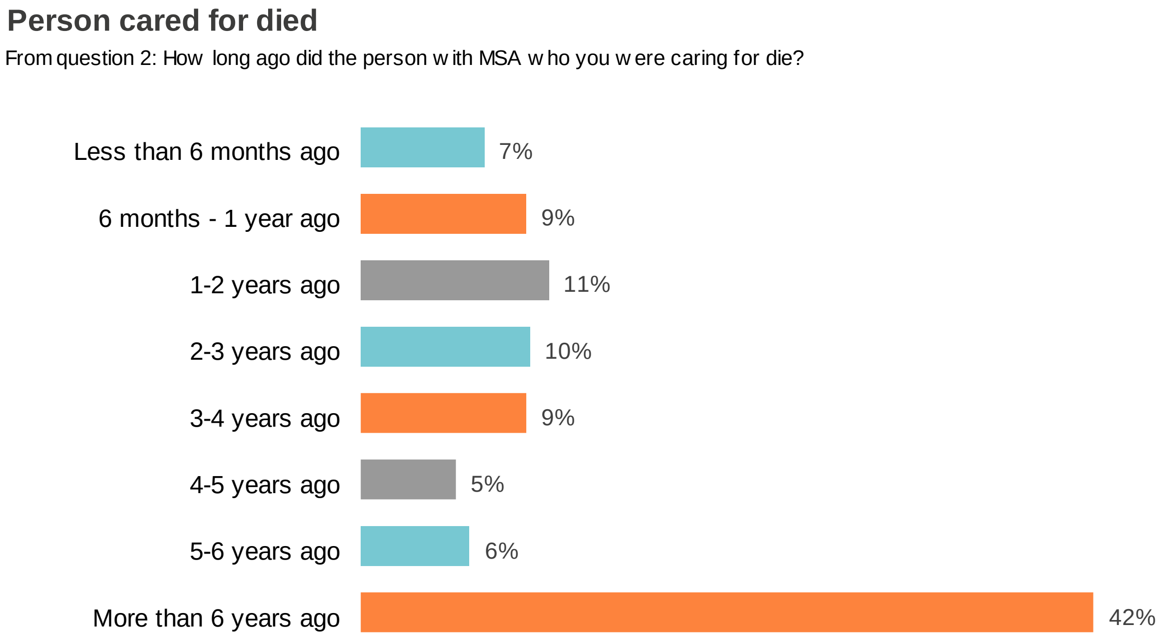


Fig 4. Time since person living with MSA died

3.2.2 Lived with the person cared for

Over three-quarters of former carers (78%, n.288) had lived with the person they were caring for until their death. 15% (n.55) cared for the person living with MSA up until the point they moved into a care or nursing home. Just 7% (n.24) did not live with the person they were caring for.

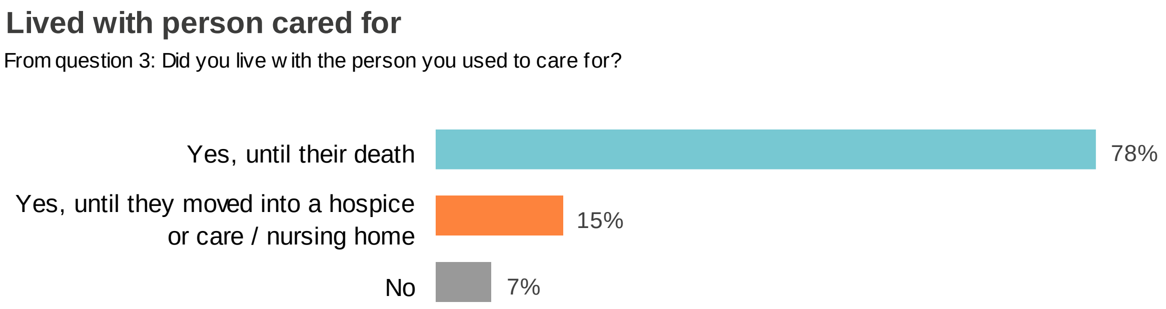


Fig 5. Lived with the person cared for

3.2.3 How long did the person you were caring for live with MSA

Just under a third of respondents (32%, n.104) reported that the person they were caring for lived with MSA for 5 years or less before they died. The largest proportion of respondents (51%, n.163) reported that the person they were caring for lived with MSA for between 6 and 10 years. Just 1% (n.2) reported the person with MSA lived with the condition for over 20 years.

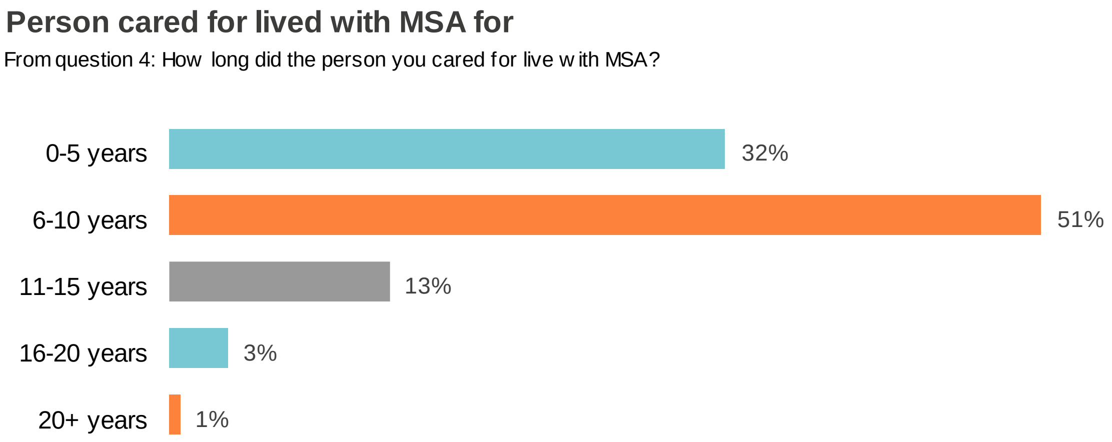


Fig 6. How long did the person you were caring for live with MSA?

3.2.4 Cause of death

Respondents were asked what was officially recorded on the death certificate as cause of death:

- 62% (n.231) had **MSA as the cause of death** on the death certificate of the person they were caring for
- 41% (n.153) had **chest infection/pneumonia as the cause of death** on the death certificate of the person they were caring for
- 12% (n.45) had **heart failure as the cause of death** on the death certificate of the person they were caring for
- 8% (n.28) had **urine infection/sepsis as the cause of death** on the death certificate of the person they were caring for

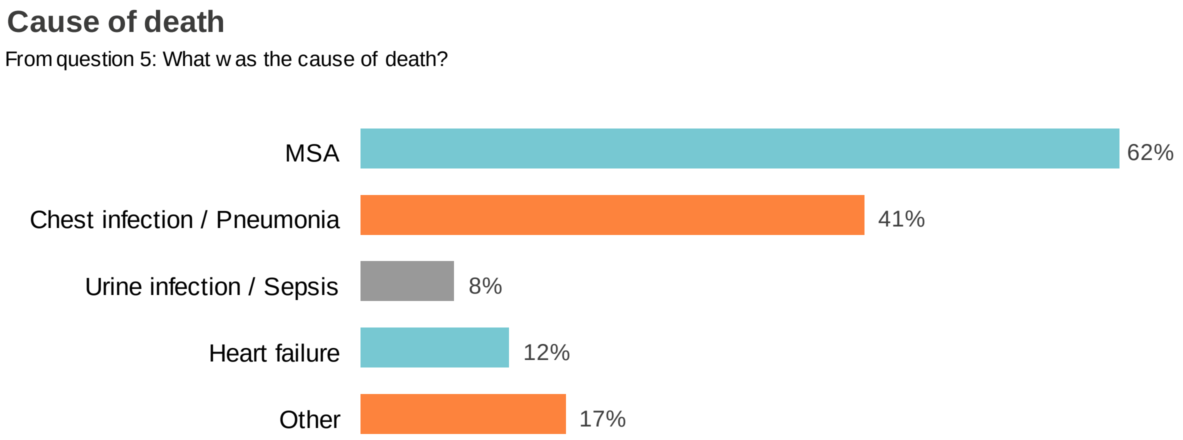
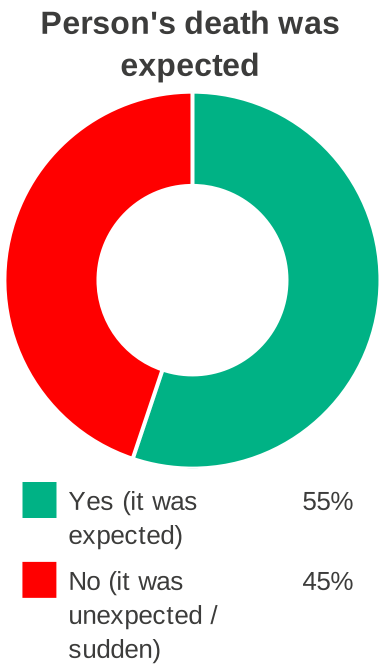


Fig 7. Cause of death

3.2.5 Was the death expected or unexpected

Over half of respondents (55% n.198) indicated that the person living with MSA died at a time when it was expected to happen. This means that a doctor or other healthcare professional had told them that the person they were caring for was at the end of their life. However, 45% (n.161) of respondents indicated that death was sudden and unexpected.



Person's death was expected

From question 6: Did the person living with MSA die when it was expected to happen?

Fig 8. Was the person’s death expected?

3.2.6 Duration of main carer

Well over half of respondents (57% n.211) were a main carer for the person living with MSA for over 5 years. The data shows that caring for someone with MSA can last for a number of years.

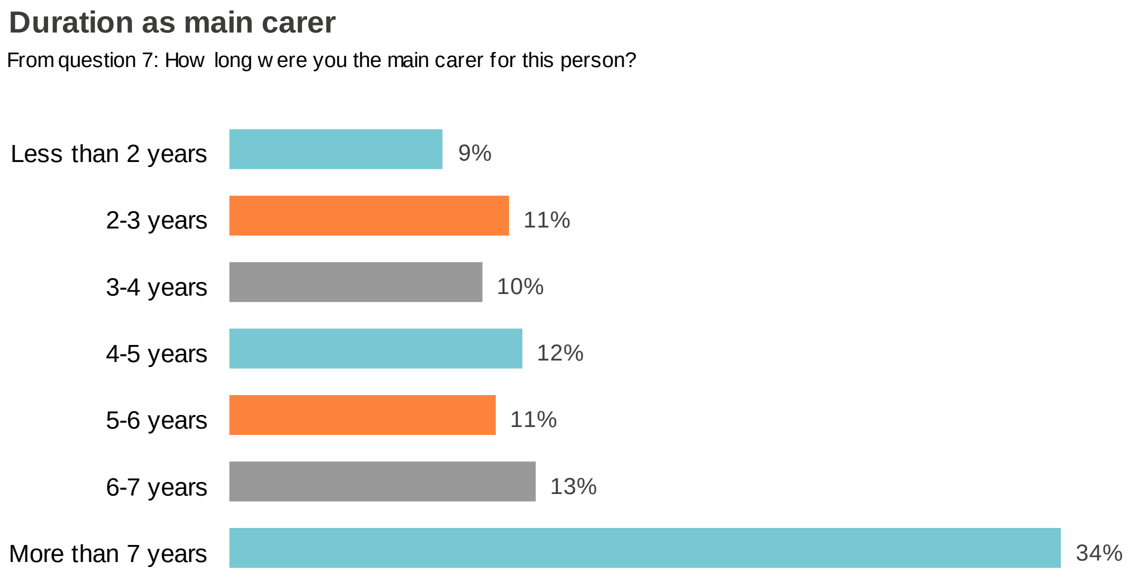
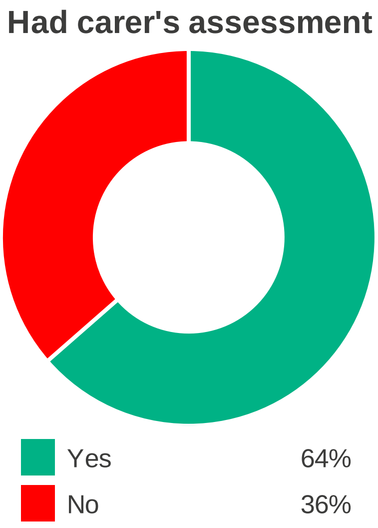


Fig 9. Length of time as carer

3.2.7 Carers’ assessments

It was encouraging that during their time as a carer for someone living with MSA, almost two thirds of respondents (64% n.220) had a carers’ assessment. However, this still leaves over a third of respondents (36%, n.126) who did not have one.



From question 8: Whilst you were caring for the person with MSA, did you have a carer’s assessment?

Fig 10. Carers’ assessments

3.2.8 Conclusions

- Most former carers report caring for their spouse or partner at home. The caring commitment can be long and demanding.
- A large proportion of people living with MSA are dying unexpectedly – that is at a time which is not considered to be at the end of their lives by a medical professional.
- Although a large number of former carers report having a carers’ assessment, there remains a large proportion who report not having one.

3.2 Healthcare team

3.3.1 Health and care professionals

Former carers are generally more positive about health and care professionals than those currently living with MSA: there is a noticeable difference in results. Again, GPs do not fare particularly well but do perform better than the views of people living with MSA. However, over a third (36% n.124) did still report that their GP provided adequate or poor care.

The most positively reported health and care professionals were MSA Trust Nurse Specialists (84% of respondents reported that they were either excellent or good) and then palliative care / hospice teams (80% of respondents reported that they were either excellent or good). This broadly mirrors the views of people living with MSA. However, well over a third (37%) did not access any support from an MSA Trust Nurse Specialist.[4]

The chart over the page shows this in more detail.

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[4] it is acknowledged that for some of the respondents the MSA Nurse Specialist service would have been much less comprehensive than it is now.

Support from professionals

From question 10: How would you rate the support you received to help with caring for someone living with MSA?

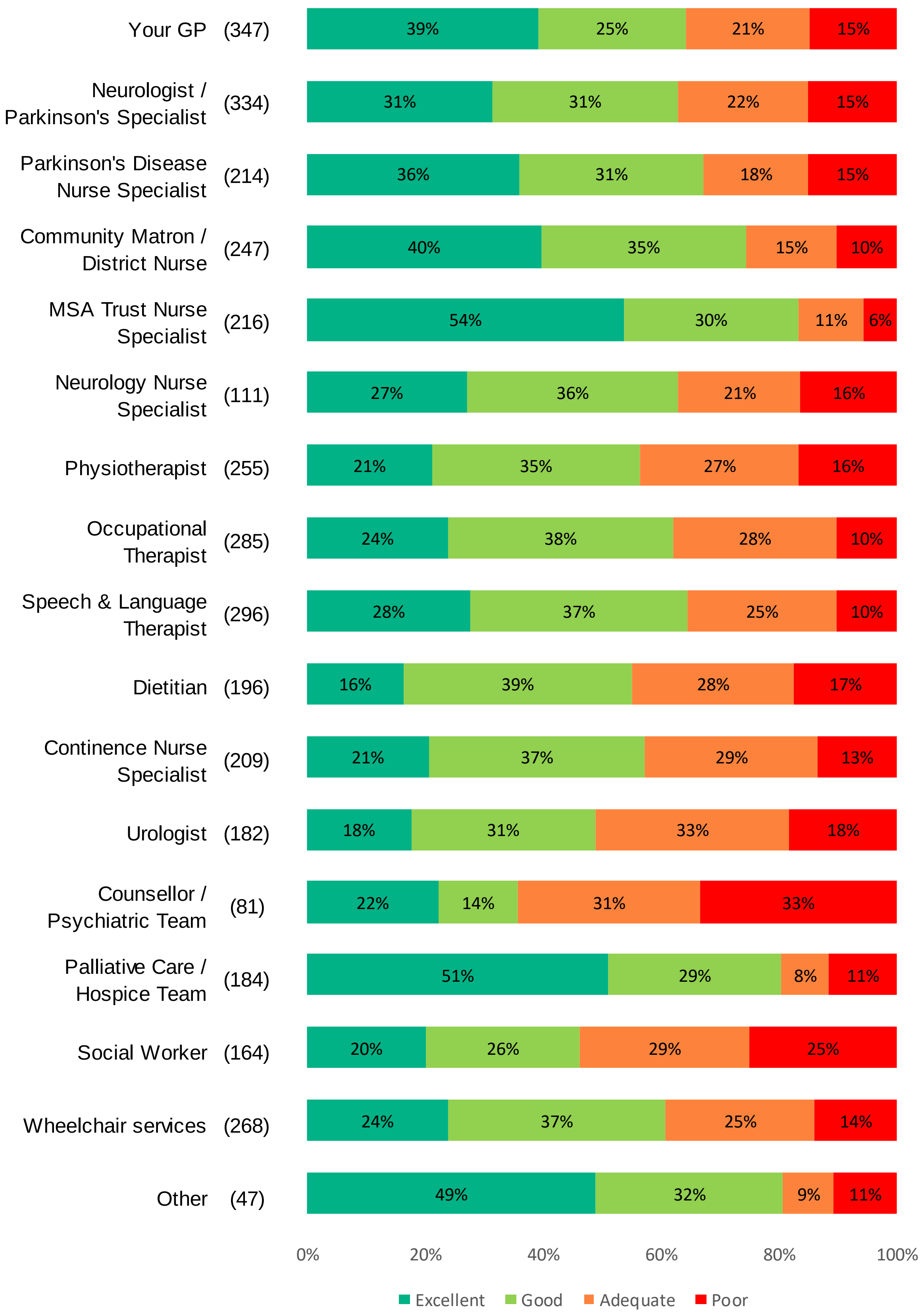


Fig 11. Healthcare team

3.3.2 Conclusions

- GPs fare poorly, this is not uncommon with rarer health conditions, but additional support should be considered. Former carers are however more positive than those living with MSA.
- 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.

3.4 Physical symptom management

3.4.1 How easy or difficult was it to manage certain symptoms?

Of the most commonly reported physical impacts:

- **Difficulty in moving**
    - The vast majority (91% n.330) found this difficult or very difficult to manage and care for the person living with MSA in this area.
    - Just 2% (n.8) of respondents found this easy to manage.
- **Autonomic problems**
    - The vast majority (85% n.302) found this difficult or very difficult to manage and care for the person living with MSA in this area.
    - Just 4% (n.17) of respondents found this easy to manage.
- **Speech / swallowing difficulties**
    - The vast majority (82% n.293) found this difficult or very difficult to manage and care for the person living with MSA in this area.
    - Just 7% (n.23) of respondents found this easy to manage.

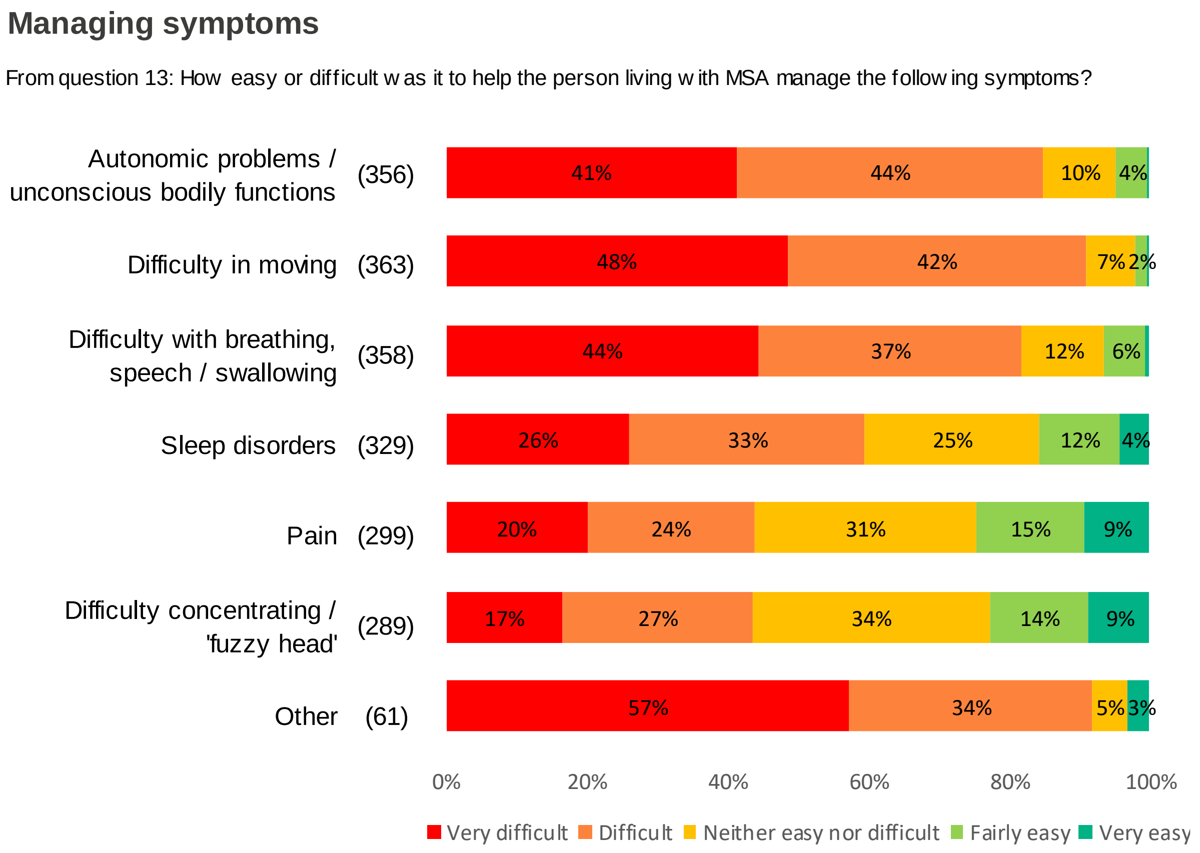


Fig 12. Carers helping with physical symptoms of MSA

3.4.2 Extra support offered to carers to help manage the symptoms of MSA

In terms of the carer accessing support in these areas:

- **Difficulty in moving**
    - Almost two thirds (63% n.221) accessed support in this area.
    - Almost a third (30% n.105) didn't access any support but would have liked to receive support.
    - Just 8% (n.27) felt they did not need support in this area.
- **Autonomic problems**
    - Over two thirds (68% n.239) accessed support in this area.
    - Over a fifth (22% n.78) didn't access any support but would have liked to receive support.
    - Just 10% (n.35) felt they did not need support in this area.
- **Speech / swallowing difficulties**
    - Over two thirds (69% n.242) accessed support in this area.
    - Over a fifth (21% n.72) didn't access any support but would have liked to receive support.
    - Just 10% (n.35) felt they did not need support in this area.

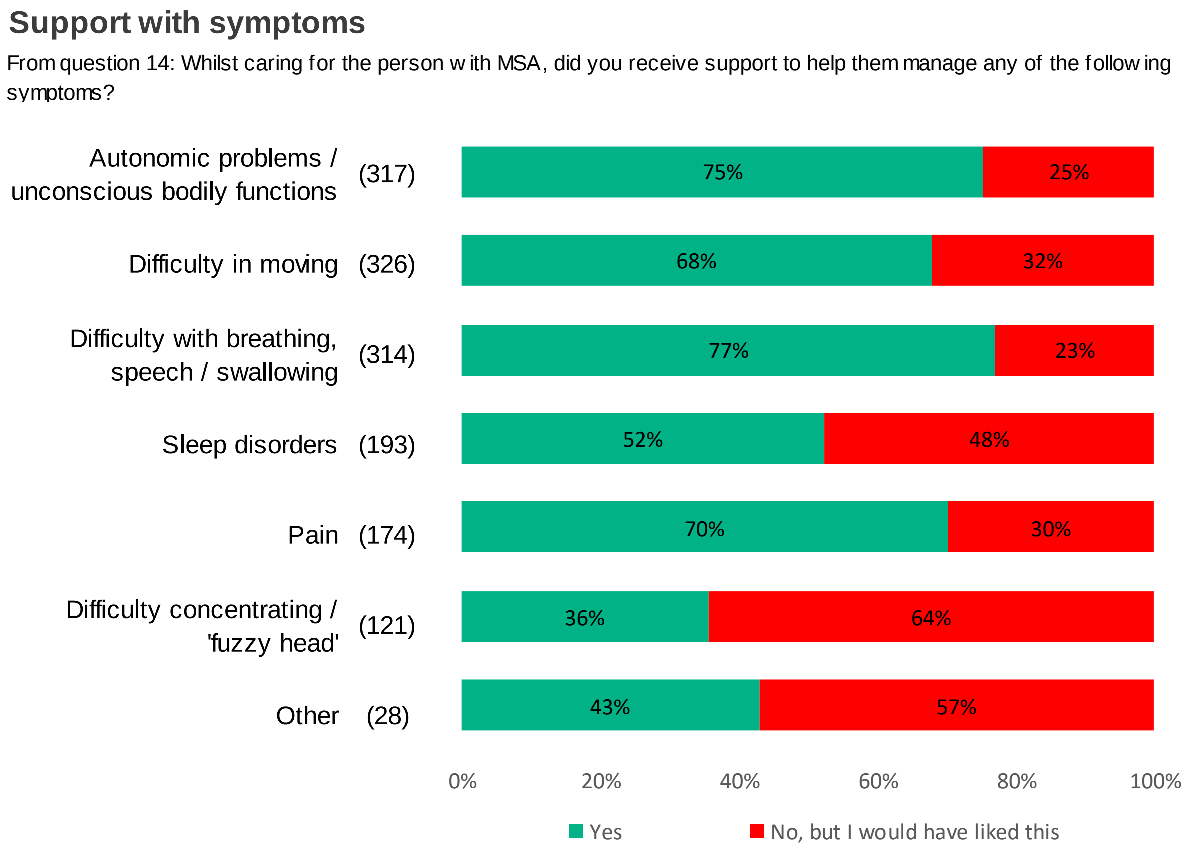
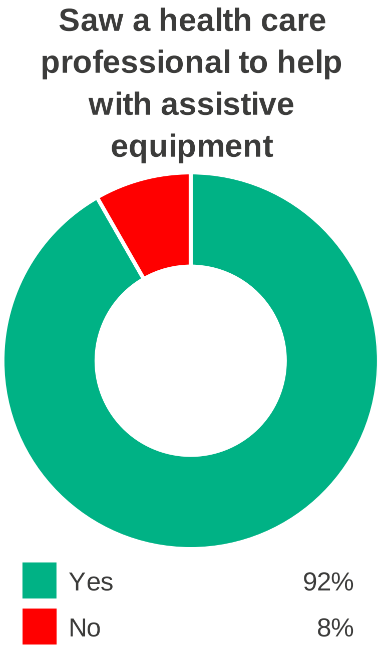


Fig 13. Support with symptoms

3.4.3 Help with assistive equipment

Encouragingly, the vast majority of former carers (92% n.332) who responded to the survey reported that the person living with MSA saw a therapist to help with assistive equipment.



From question 16: Did the person living with MSA see a therapist (or any other professional) to help with obtaining assistive equipment?

Fig 14. Help with assistive equipment

3.4.4 Conclusions

- Carers report finding it very difficult to manage issues surrounding mobility more than others. Following this, autonomic issues and speech and swallowing issues were reported by former carers to be difficult to manage.
- Carers are most likely to access support around speech/swallowing or breathing issues: this is perhaps unexpected.
- Carers are less likely to access support for sleep disorders and difficulty in concentrating.
- Encouragingly, the vast majority of carers report that they did see a health and care professional to help with assistive equipment. There is just a small proportion who did not.

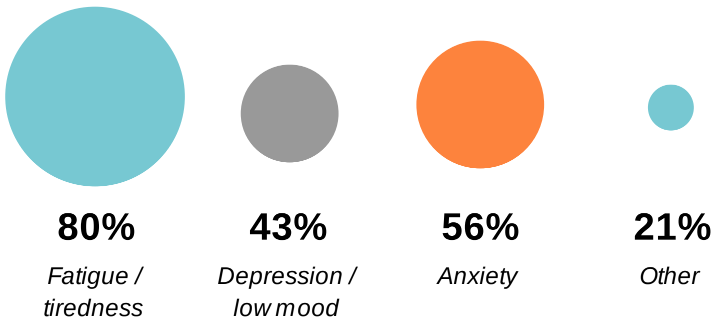
3.5 Emotional impact of caring for someone with MSA

3.5.1 Impact on mental health and wellbeing

The most commonly reported impact on the carer was fatigue/tiredness with 80% (n.297) of respondents experiencing this. Over half of respondents (56% n.209) experienced anxiety as a result of caring for someone with MSA. Just under half of respondents (43% n.161) experienced depression as a result of caring for someone with MSA. The results show a serious and damaging impact that caring for someone with MSA can have on the life of the person responsible for their care. This is further compounded by the rapid progression of the disease.

Health impacts of caring

From question 19: Did caring for the person living with MSA impact on your own health in any of the following ways?

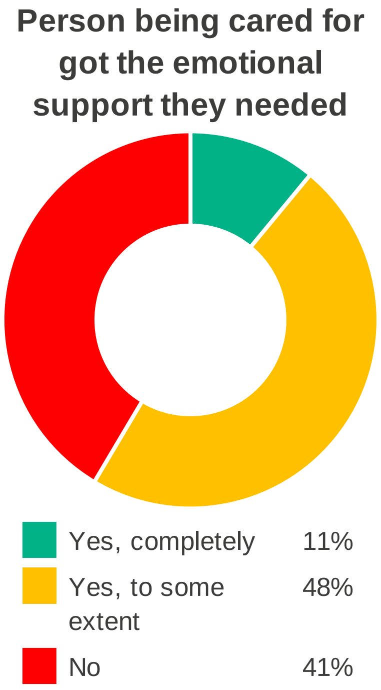


Based on 744 responses: 80% (297) answering 'Fatigue / tiredness', 43% (161) answering 'Depression / low mood', 56% (209) answering 'Anxiety', 21% (77) answering 'Other'.

Fig 15. Impact on mental health and wellbeing

3.5.2 Did the person being cared for get the emotional support they needed?

Overall, well over a third of respondents (41% n.143) reported that the emotional needs of the person living with MSA were not met. However, well over half (59% n.202) felt that the emotional needs of the person living with MSA were met, at least to some extent.



From question 20: Do you think the person that you cared for got the emotional support they needed?

Fig 16. Meeting the emotional and wellbeing needs of people living with MSA

3.5.3 Conclusions

- There is a significant impact on the mental and emotional wellbeing of carers when looking after someone living with MSA.
- Fatigue is most commonly experienced.
- Anxiety, depression and general low mood are also widely experienced.
- Most former carers feel there is also a significant gap in looking after the mental and emotional wellbeing of the person they were caring for.

3.6 Additional support

3.6.1 Support groups

The most commonly accessed support groups for carers were:

- MSA Trust support group (48% n.178).
- Hospice support group (22% n.82).
- Parkinson's support group (22% n.81).

However, almost a fifth of respondents (18% n.68) reported they didn't access any support groups because they couldn't physically get there suggesting additional provision for those most marginalised should be considered.

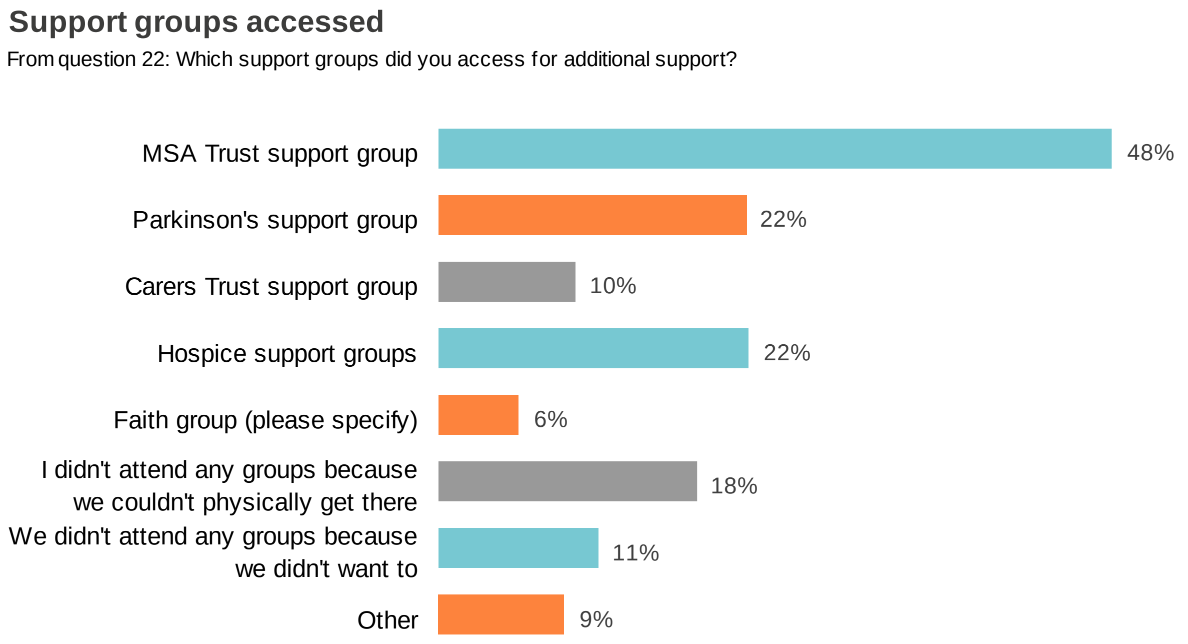
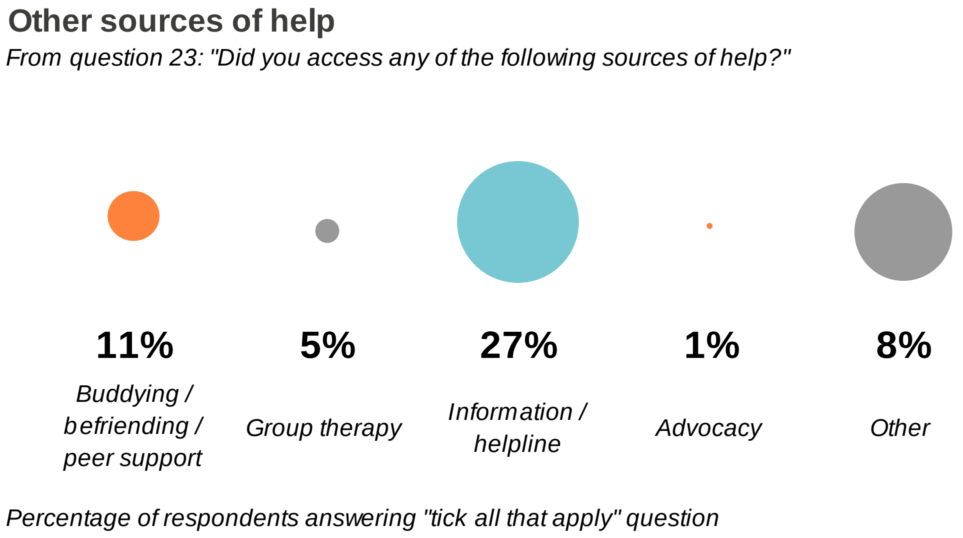


Fig 17. Support groups

3.6.2 Other sources of support

The majority of carers had not accessed this type of support. However, of those who did access this support, the most common other sources of support for carers were:

- Information/helpline (27% n.100).
- Buddying/befriending (11% n.41).
- Group therapy (5% n.20).



Other sources of help

From question 23: "Did you access any of the following sources of help?"

Percentage of respondents answering "tick all that apply" question

Fig 18. Other sources of support

3.7.2 Conclusions

- Carers are not accessing additional support in the numbers that might be expected, it would appear more can be done to highlight the support available to carers.
- Some carers struggle with attending support groups due to logistical issues.
- There is a lack of take up of services such as advocacy, peer support and group therapy – and these opportunities need additional promotion.

3.7 Impact on personal life

3.7.1 Other caring responsibilities

Most former carers who responded to the survey did not have additional caring responsibilities while caring for the person living with MSA. Of those who did:

- 13% (n.15) were caring for children aged 11 or under.
- 19% (n.22) were caring for children aged 12-17.
- Almost half of respondents (47% n.55) were caring for another family member at the same time as caring for the person living with MSA.

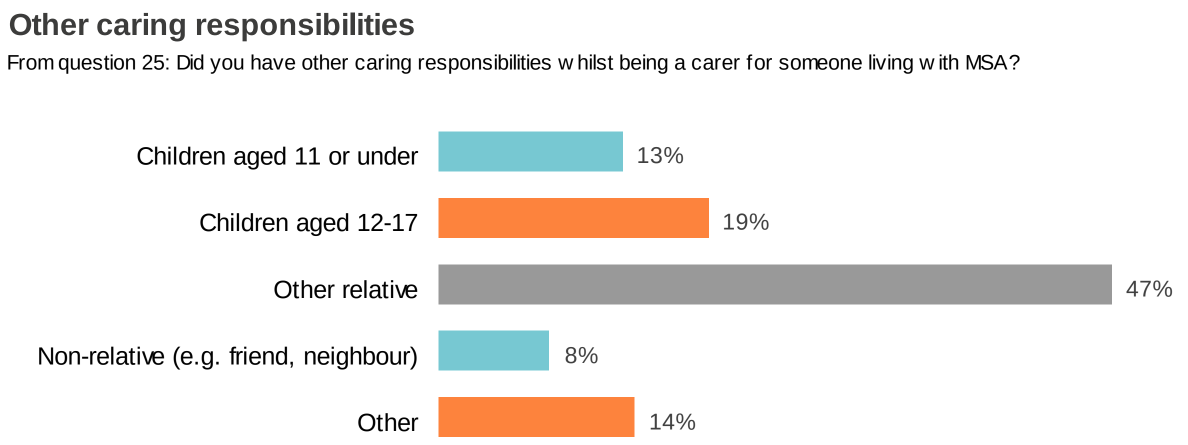


Fig 19. Other caring responsibilities[5]

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[5] Numbers in this chart are a subset of those that did have other caring responsibilities

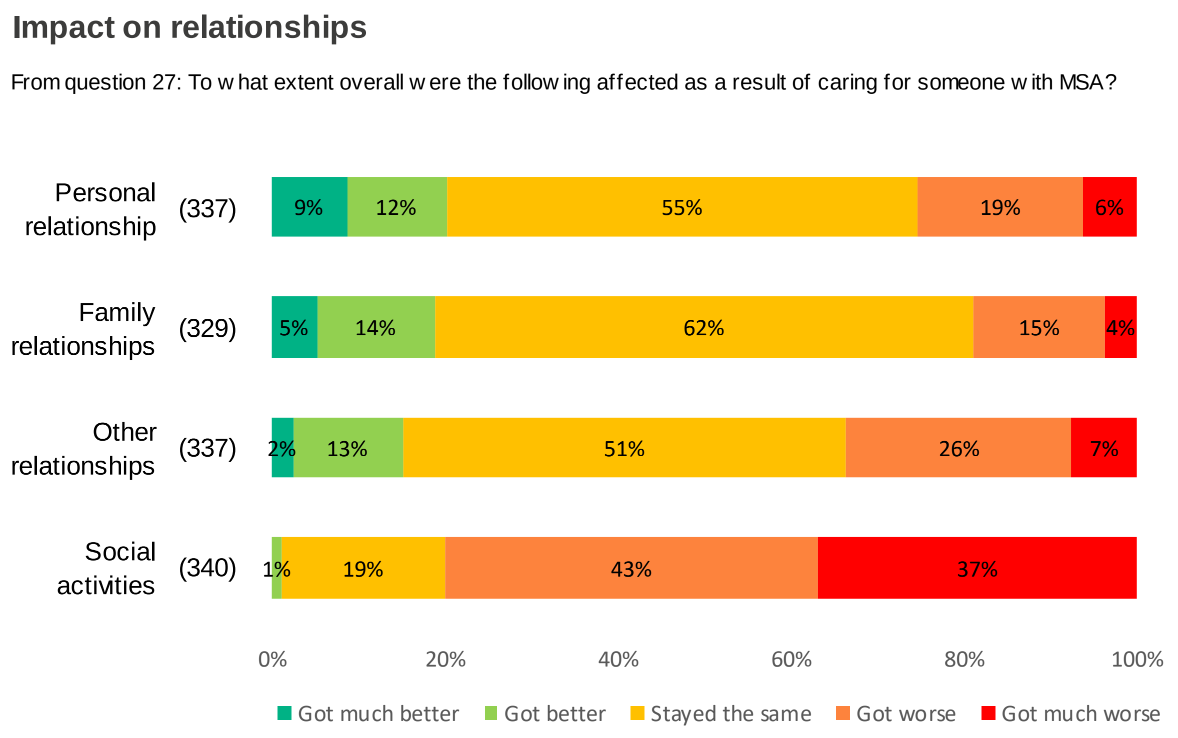
3.7.2 Impact on relationships

There were clear links between this survey and the person living with MSA survey in that the most affected area was the impact on social lives.

- **Impact on social life**
    - The majority (80% n.272) indicated that their social life got worse as a result of caring for someone with MSA.
    - Around a fifth (19% n.64) indicated that it stayed the same.
    - Only 1% reported that it got better.
- **Impact on other relationships**
    - Just over a third (34% n.113) indicated that their other relationships got worse as a result of caring for someone with MSA.
    - Just over a half (51% n.173) indicated that it stayed the same.
    - Just 15% reported that it got better.

In terms of the impact on personal relationships:

- Over a fifth (21% n.68) indicated that this improved.
- Over half (55% n.184) indicated that it stayed the same.
- A quarter (25% n.85) indicated that it got worse.



Impact on relationships

From question 27: To w hat extent overall w ere the follow ing affected as a result of caring for someone w ith MSA?

Fig 20. Impact on relationships

3.7.3 Conclusions

- Most former carers reported that they did not have additional caring responsibilities while caring for the person living with MSA.
- Of those who did have additional caring responsibilities, most were caring for an additional family member.
- Relatively few respondents reported caring for younger children at the same time as caring for the person who was living with MSA.
- Caring for someone living with MSA has a serious and damaging effect on relationships, in particular carers report that relationships with friends are most seriously affected. This mirrors the people living with MSA survey.

3.8 Financial impact

3.8.1 Receipt of benefits

The most commonly received benefits were a blue badge (79%, n.292), DLA (44%, n.164) and Attendance Allowance (36%, n.132). Just 3% of respondents (n.12) reported not being in receipt of any benefits while they were caring for someone with MSA.

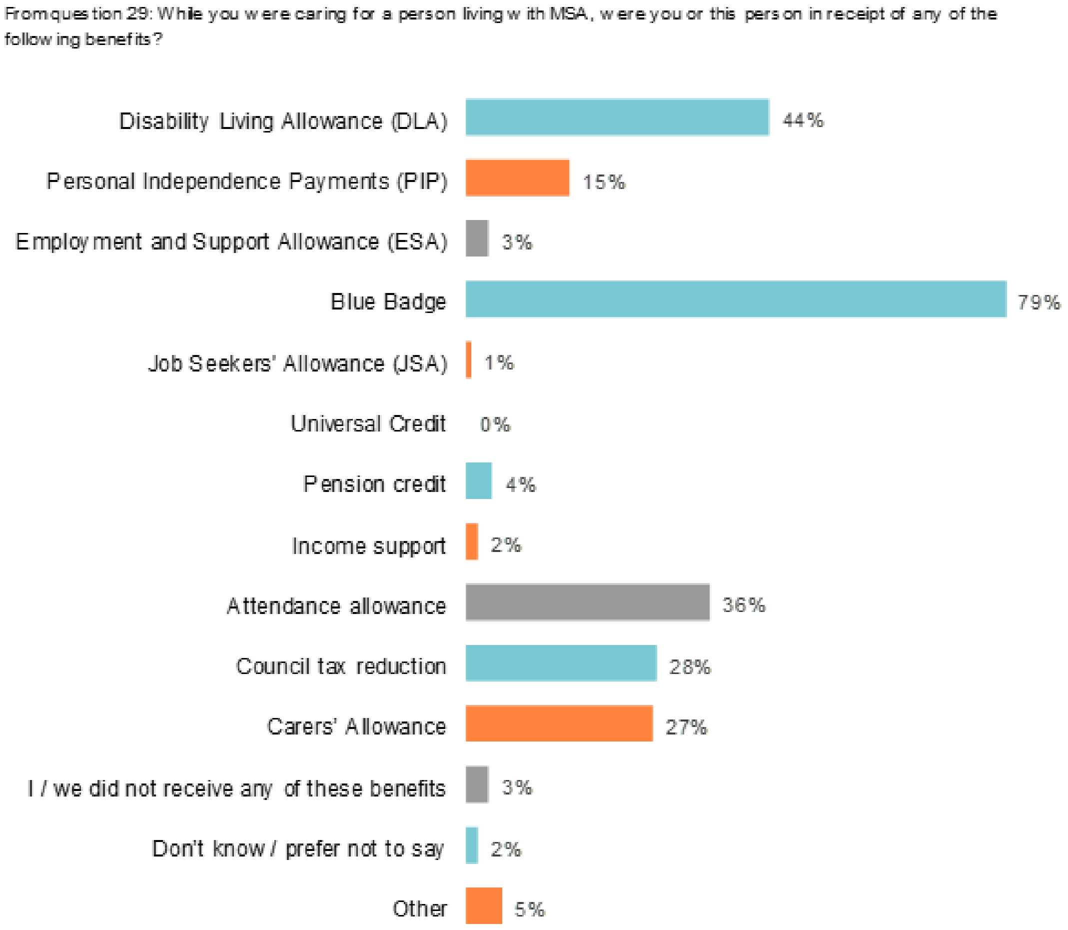
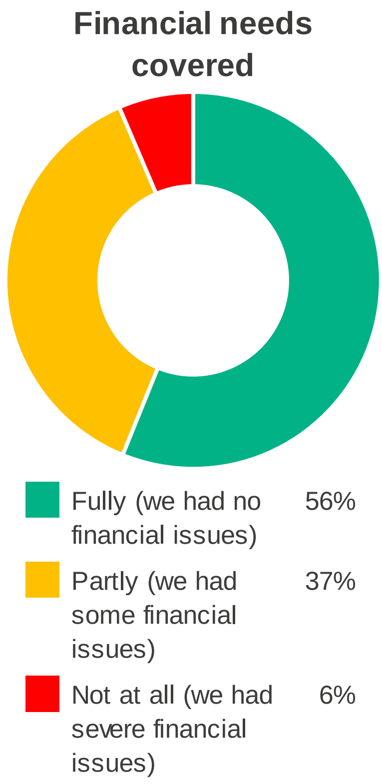


Fig 21. Receipt of benefits

3.8.2 Extent to which financial needs were met while caring for someone with MSA

The results here were unexpected with a working hypothesis that more carers would have experienced financial issues while caring for someone with MSA. Almost all respondents (93%, n.305) felt that their financial needs were covered at least to some extent during their time as a carer. This almost exactly mirrors the people living with MSA survey. Just 6% (n.21) of respondents reported having severe financial issues during their time as a carer.

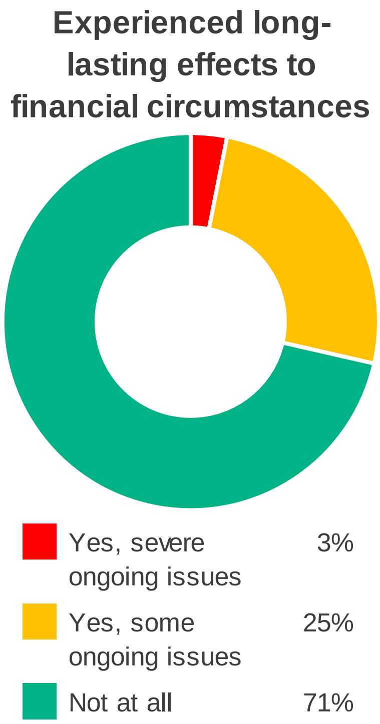


From question 30: To what extent were your financial needs covered during your time as a carer?

Fig 22. Extent to which financial needs were met while caring for someone with MSA

3.8.3 Long lasting effects to financial situation

In contrast to the last section, almost a third of former carers (28% n.92) reported having long-lasting effects to their financial circumstances as a result of having cared for someone living with MSA.



From question 31: Have you experienced long-lasting effects to your financial circumstances as a result of caring for someone with MSA?

Fig 23. Long lasting effects to financial situation

3.8.4 Conclusions

- Most respondents were in receipt of some kind of benefit. The most commonly received benefits were a blue badge, DLA and Attendance Allowance.
- 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. Just over a third reported having some financial issues. Just 6% of respondents reported having severe financial issues. This almost exactly mirrored the people living with MSA survey.[6]
- However, in contrast almost a third of respondents reported experiencing ongoing financial issues as a result of having to care for someone living with MSA.

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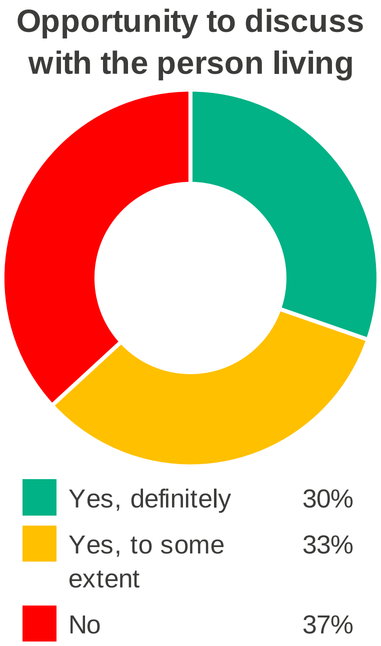
[6] It is important to point out that these findings could be influenced by the profile of respondents – many reported caring for someone with MSA over six years ago.

3.9 Palliative care / advance care planning

3.9.1 Discussion of end of life care

Almost two-thirds of respondents (63% n.223) had discussed with the person living with MSA what they wanted to happen towards the end of their lives. However, this means that over a third (37%, n.130) did not discuss with the person they were caring for what would happen at the end of their life. Similar to the results of the person living with MSA survey: this suggests more can be done in this area.

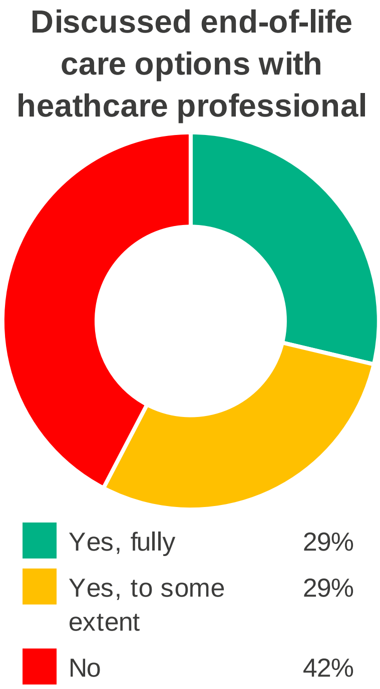


From question 32: Did you get to discuss with the person living with MSA what would happen at the end-of-their life?

Fig 24. Discussion on end of life care

3.9.2 Discussion of end of life care with a healthcare professional

Well over a half of former carers who responded to the survey (58% n.203) had discussed with their doctor the various end of life care options which were available at the time. This is a higher proportion than reported in the people living with MSA survey. However, 42% (n.149) had not had any discussion about end of life care with a healthcare professional suggesting there is an unmet need in this area.



From question 33: Did you discuss with a doctor or other healthcare professional the various end-of-life care options that would be available (e.g. hospice care, staying at home, sedation, refusal of life prolonging treatment)?

Fig 25. Discussion on end of life care with healthcare professional

3.9.3 How helpful was this conversation?

Overwhelmingly, those who had had this discussion found it helpful. 94% (n.173) of respondents found the conversation helpful.

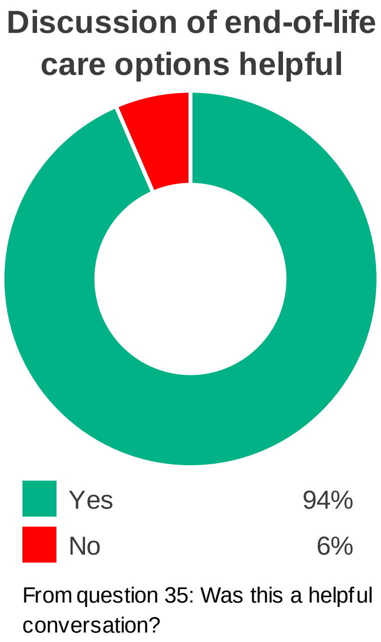


Fig 26. How helpful was discussion on end of life care with healthcare professional?

3.9.4 Formal planning for advance care

In terms of formal planning for advance care, the most commonly reported by former carers were:

- A will (85% of respondents had one in place).
- Lasting POA for property and finance (60% of respondents had one in place – exactly the same as the people living with MSA survey).
- Lasting POA for health and welfare (46% of respondents had one in place).

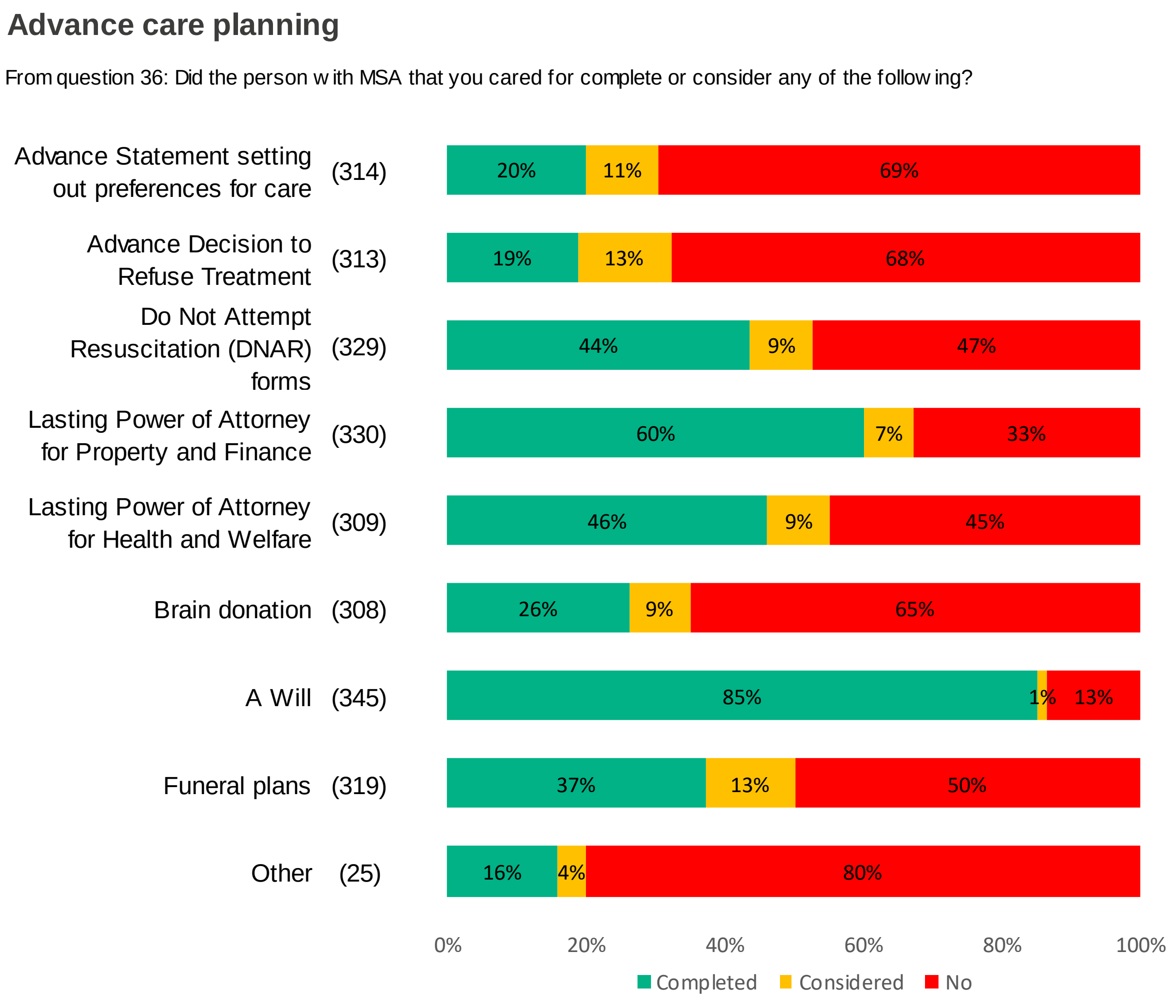
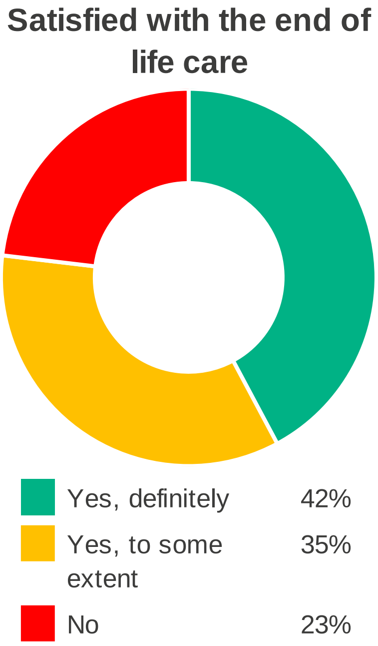


Fig 27. Advance care planning

3.9.5 Satisfaction with end of life care

Encouragingly, over three quarters of respondents (77% n.226) were satisfied with the end of life care the person living with MSA received at the time.



From question 37: Were you satisfied with the end of life care the person living with MSA received at the time?

Fig 28. Satisfaction with end of life care

3.9.6 Where did the person living with MSA die?

Over half of respondents (55% n.175) reported that the person living with MSA was able to die at a place of their choosing. However, this means that 45% (n.143) reported that the person they were caring for was not.

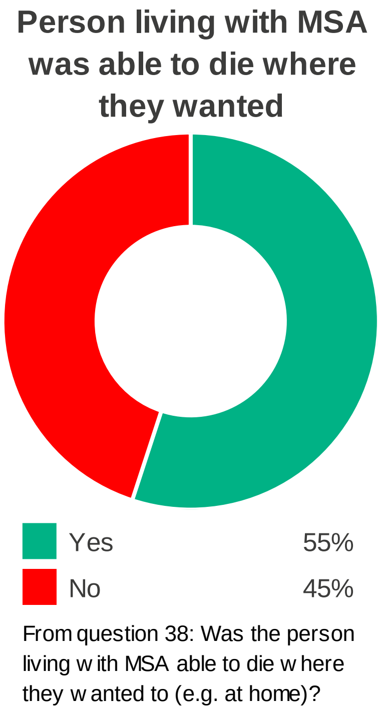


Fig 29. Where did the person living with MSA die?

3.9.7 Assisted dying

If assisted dying (with legal safeguards) was legal in the UK, just over two thirds of former carers (67% n.164) felt that the person living with MSA would have wanted this choice available to them. A third of respondents (33%, n.79) felt that the person living with MSA would not have wanted this choice.

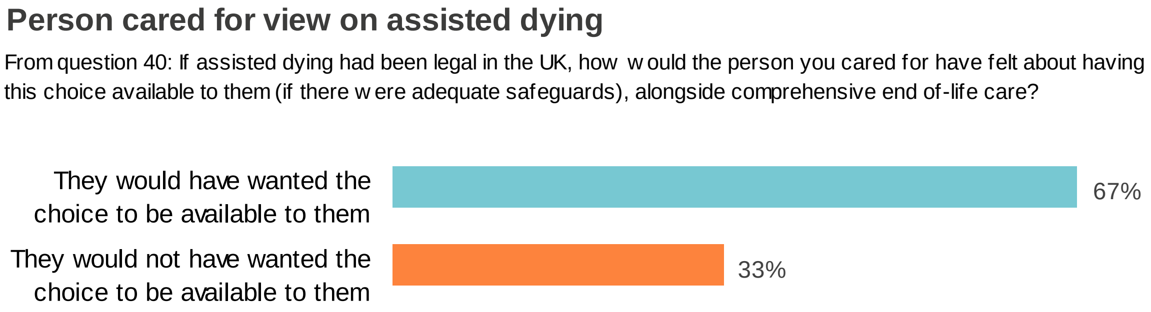


Fig 30. Assisted dying

3.9.8 Conclusions

- Almost a third of carers had not discussed end of life care options with the person who was living with MSA. This suggests more could be done to support carers to have these conversations at an early stage.
- The majority of respondents had discussed end of life care options with a healthcare professional at the time; however, over 40% of former carers reported having not had this conversation with a healthcare professional. Of those who had this conversation, the vast majority found it helpful. This suggests that carers 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. There were similar results in the people living with MSA survey.
- Generally, former carers were satisfied with the quality of end of life care the person living with MSA received at the time.
- Almost half of respondents reported that the person with MSA who they were caring for was not able to die at a place of their choosing, suggesting more could be done in this area.
- The majority of respondents felt that if the option of assisted dying (with legal safeguards) was made legal by parliament, the person who was living with MSA would have wanted this choice available to them. However, a third reported that the person living with MSA would not have wanted this option.

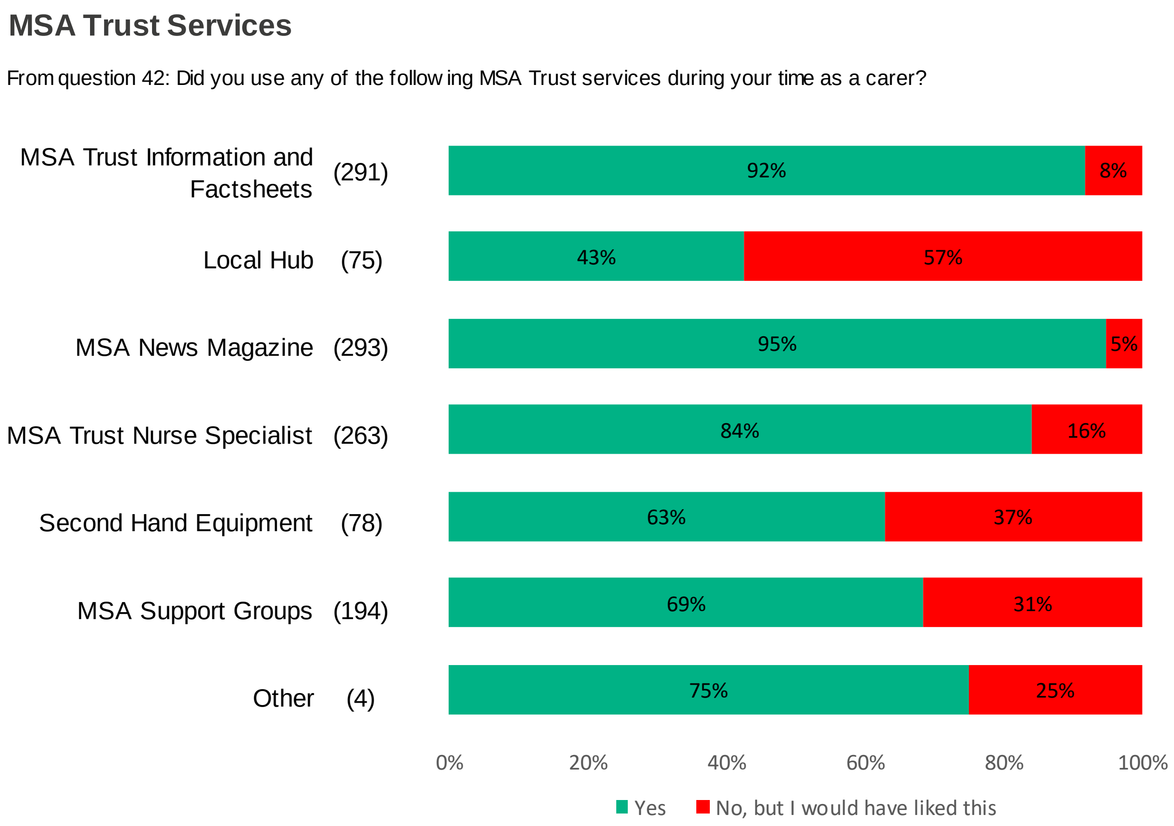
3.9 Overall including questions about MSA Trust

3.10.1 MSA Trust services

The most commonly accessed MSA Trust services reported by respondents who had previously cared for someone living with MSA were:

- MSA News Magazine (95%, n.278)
- MSA Trust Factsheets (92%, n.267)
- MSA Trust Nurse Specialists (84%, n.221)

MSA News Magazine in particular is rated highly by people living with MSA and is widely used.

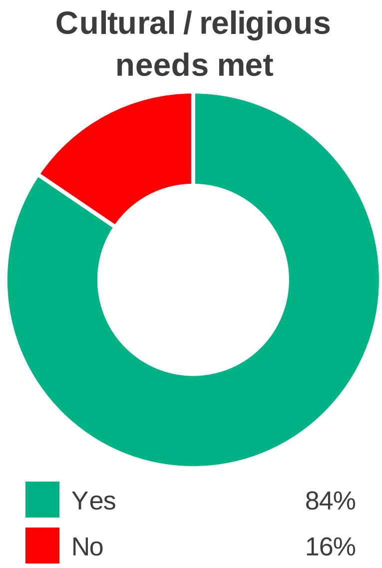

MSA Trust Services

From question 42: Did you use any of the following MSA Trust services during your time as a carer?

Fig 31. MSA Trust services

3.10.2 Cultural and religious needs as carers

Roughly half of respondents answered this question. Of those who answered it, the majority of respondents (84% n.136) felt that their cultural or religious needs were met during their time as a carer for someone living with MSA. Just 16% (n.25) felt that their cultural or religious needs were not met during their time as a carer.



From question 45: Do you feel your cultural or religious needs were met during your time as a carer for someone living with MSA?

Fig 32. Cultural and religious needs

3.10.3 Ongoing support for carers

The vast majority of respondents (92% n.322) are not receiving any support for issues which arose during their time caring for someone with MSA.

Almost the same amount (90% n.251) said they do not want any ongoing support for issues which arose during their time caring for someone with MSA.

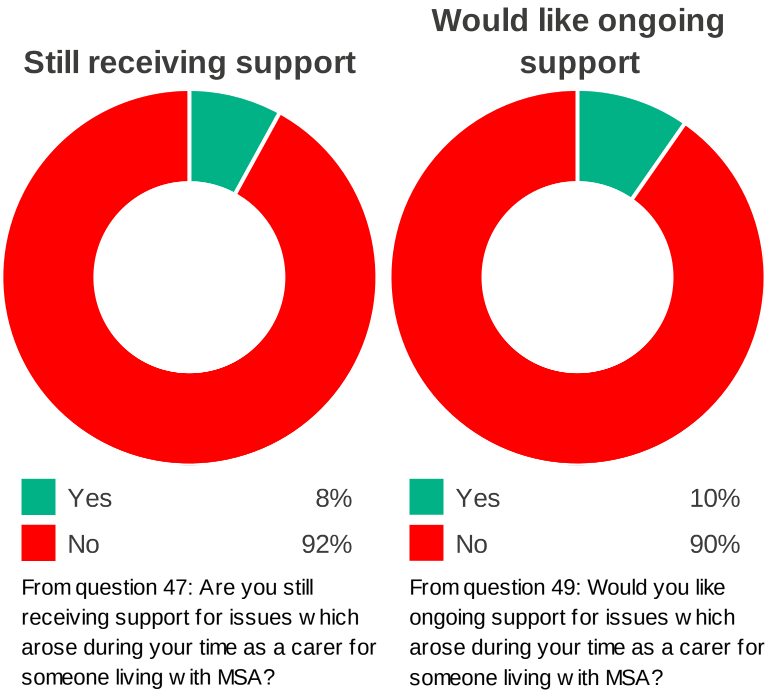


Fig 33. Ongoing support

3.10.4 Conclusions

- 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 carers of people living with MSA.
- Most former carers did not answer the question about cultural and religious needs – however of those who responded, the vast majority said that their cultural and religious needs were met during their time as a carer.
- The vast majority of respondents (>90%), reported that they are not receiving ongoing support following their experiences as a carer, and the same amount reported that they did not want support.

4. Data breakdown analysis

4.1 Key variables

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

- Year of death cross tabulated with:
    - Cause of death
    - Rating of MSA Nurse Specialist
    - MSA Support Groups
    - Effects to financial circumstances
- Age cross tabulated with
    - Other caring responsibilities
- How long ago did the person living with MSA die cross tabulated with
    - Would you like ongoing support for issues which arose during your time as a carer

4.2 Year of death

The data was cross tabulated by the year of death of the person living with MSA, and four key variables.

The most noticeable differences were as follows:

	Cause of death	Rating of MSA Trust Nurses	MSAT Support groups	Lasting impact on finances
Year of death 2019	MSA 58%	Excellent/good 95%	61%	Ongoing issues 34%
Year of death 2018	MSA 67%	Excellent/good 77%	65%	Ongoing issues 39%
Year of death 2017	MSA 81%	Excellent/good 88%	68%	Ongoing issues 22%
Year of death 2016	MSA 65%	Excellent/good 87%	56%	Ongoing issues 33%
Year of death 2015	MSA 50%	Excellent/good 81%	58%	Ongoing issues 17%
Year of death 2014	MSA 60%	Excellent/good 80%	65%	Ongoing issues 37%
Year of death 2013	MSA 67%	Excellent/good 89%	57%	Ongoing issues 30%
Year of death 2012	MSA 67%	Excellent/good 80%	33%	Ongoing issues 17%

- Most likely to have MSA recorded as cause of death on death certificate: 2018
- Most likely to rate MSA Trust Nurses as excellent or good: 2019
- Most likely to attend MSAT Support Groups: 2018
- Most likely to be experiencing ongoing financial issues: 2014

4.3 Age

This breakdown looked at the age range of former carers who had responded, cross tabulated with those who had additional caring responsibilities.

	Children under 11	**Children 12-17**	**Other relative**	**Non-relative**
Under 45	83%	0%	17%	0%
45-54	21%	53%	16%	0%
55-64	7%	15%	67%	0%
65-74	9%	14%	59%	5%
75-84	0%	12%	35%	29%
85+	0%	0%	33%	33%

- Unsurprisingly perhaps, younger respondents (under 45) were more likely to be caring for young children alongside the person who was living with MSA/
- Again, younger respondents (45-54) were more likely to be caring for older children alongside the person who was living with MSA.
- Former carers in the 55-64 age group were more likely to be caring for other relatives alongside the person who was living with MSA.
- Former carers in the oldest age categories were more likely to be caring for a non-relative in addition to the person with MSA that they were caring for.

4.4 How long ago did the person living with MSA die

This breakdown looked at how long ago the person living with MSA died cross tabulated with whether or not the former carer feels they would like additional support for issues which arose during their time as a carer.

	Yes – would like additional support	No – would not like additional support
Less than 6 months ago	44% (n.7)	56% (n.9)
6 months – 1 year ago	18% (n.4)	82% (n.18)
1-2 years ago	7% (n.2)	93% (n.26)
2-3 years ago	7% (n.2)	93% (n.27)
3-4 years ago	19% (n.5)	81% (n.21)
4-5 years ago	6% (n.1)	94% (n.16)
5-6 years ago	0% (n.0)	100% (n.18)
More than 6 years ago	5% (n.6)	95% (n.116)

- Perhaps unsurprisingly, those who had experienced a recent death of the person with MSA they were caring for are most likely to want additional support and this should be considered.
- Those who reported that there had been a longer amount of time since the death of the person they were caring for were less likely to want additional support.
- It is important to point out that there are a number of respondents who responded ‘don’t know’ to this question – which could mean they would benefit from additional support and this should be considered.

5. Conclusions and recommendations

5.1 Introductory questions conclusions and recommendations

- Most former carers report caring for their spouse or partner at home. The caring commitment can be long and demanding.
- A large proportion of people living with MSA are dying unexpectedly – that is at a time which is not considered to be at the end of their lives by a medical professional.
- Although a large number of former carers report having a carers' assessment, there remains a large proportion who report not having one.

Recommendations:

- Additional support should be considered for carers of people living with MSA around quality of life issues.
- MSA Trust to consider extending the offer of support groups and access to MSA Trust Nurse Specialists with a focus on carers.
- Consider additional information provision for carers with a detailed explanation of carers' assessments to improve uptake in this area.

5.2 Healthcare team conclusions and recommendations

- GPs fare poorly, this is not uncommon with rarer health conditions, but additional support should be considered. Former carers are however more positive than those living with MSA.
- 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.

Recommendations:

- Care planning for carers of 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.
- 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 and how carers in particular might access this information.
- Consider expansion of MSA Trust information service to fully meet the needs of all carers – to ensure they are empowered to seek the high-quality support offered by hospice care teams and MSA Trust Nurse Specialists.

5.3 Physical symptom management conclusions and recommendations

- Carers report finding it very difficult to manage issues surrounding mobility more than others. Following this, autonomic issues and speech and swallowing issues were reported by former carers to be difficult to manage.
- Carers are most likely to access support around speech/swallowing or breathing issues: this is perhaps unexpected.
- Carers are less likely to access support for sleep disorders and difficulty in concentrating.
- Encouragingly, the vast majority of carers report that they did see a health and care professional to help with assistive equipment. There is just a small proportion who did not.

Recommendations:

- Carers of people living with MSA should be able to support the person they are caring for to live dignified, fulfilled lives, maximising their wellbeing through:
    - Additional support for helping carers manage the physical symptoms of MSA;
    - Expansion of advice and guidance offered by MSA Trust Nurse Specialists to carers around physical symptom management;
    - Empowering those caring for someone 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.

5.4 Emotional impact of caring for someone with MSA conclusions and recommendations

- There is a significant impact on the mental and emotional wellbeing of carers when looking after someone living with MSA.
- Fatigue is most commonly experienced.
- Anxiety, depression and general low mood are also widely experienced.
- Most former carers feel there is also a significant gap in looking after the mental and emotional wellbeing of the person they were caring for.

Recommendations:

- Every person caring for someone living with MSA should have their mental, emotional and cognitive wellbeing effectively and systematically screened wherever they live. Caring for someone with a serious and progressive condition like MSA can severely impact on mental and emotional wellbeing.
- Access to counselling and psychotherapy for carers needs to be improved.
- Support groups focused on MSA and the negative effect on relationships should be considered for carers.

5.5 Additional support conclusions and recommendations

- Carers are not accessing additional support in the numbers that might be expected, it would appear more can be done to highlight the support available to carers.
- Some carers struggle with attending support groups due to logistical issues.
- There is a lack of take up of services such as advocacy, peer support and group therapy – and these opportunities need additional promotion.

Recommendations:

- Seek to expand the offer of support groups or consider support for carers to attend for those who are most isolated and marginalised.
- Take up of the advocacy service is low.[7] Continue active promotion of this service to new carers.
- Social isolation is widespread and damaging. Consider a service to better support carers around feelings of isolation – e.g. a befriending service.

5.6 Impact on relationships conclusions and recommendations

- Most former carers reported that they did not have additional caring responsibilities while caring for the person living with MSA.
- Of those who did have additional caring responsibilities, most were caring for an additional family member.
- Relatively few respondents reported caring for younger children at the same time as caring for the person who was living with MSA.
- Caring for someone living with MSA has a serious and damaging effect on relationships, in particular carers report that relationships with friends are most seriously affected. This mirrors the people living with MSA survey.

Recommendations

- Support groups focused on caring for someone with MSA and the negative effect on relationships should be considered.
- Consider additional support for those with young children so that people living with MSA and their carers are equipped with the skills to be able to talk to their children about the condition and lead fulfilled lives.

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[7] MSA Trust's Advocacy Service has only been running since 2017 so it is likely that many respondents would not have been aware of this.

5.7 Financial impact conclusions and recommendations

- Most respondents were in receipt of some kind of benefit. The most commonly received benefits were a blue badge, DLA and Attendance Allowance.
- 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. Just over a third reported having some financial issues. Just 6% of respondents reported having severe financial issues. This almost exactly mirrored the people living with MSA survey.
- However, in contrast almost a third of respondents reported experiencing ongoing financial issues as a result of having to care for someone living with MSA.

Recommendations:

- The benefits system must change to better serve its purpose in enabling people to get on with their lives in spite of their condition. MSA Trust to address issues around accessing benefits through an MSA Trust Social Welfare specialist.

5.8 Palliative care conclusions and recommendations

- Almost a third of carers had not discussed end of life care options with the person who was living with MSA. This suggests more could be done to support carers to have these conversations at an early stage.
- The majority of respondents had discussed end of life care options with a health and care professional at the time; however, over 40% of former carers reported having not had this conversation with a health and care professional. Of those who had this conversation, the vast majority found it helpful. This suggests that carers 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. There were similar results in the people living with MSA survey.
- Generally, former carers were satisfied with the quality of end of life care the person living with MSA received at the time.
- Almost half of respondents reported that the person with MSA who they were caring for was not able to die at a place of their choosing, suggesting more could be done in this area.
- The majority of respondents felt that if the option of assisted dying (with legal safeguards) was made legal by parliament, the person who was living with MSA would have wanted this choice available to them. However, a third reported that the person living with MSA would not have wanted this option.

Recommendations:

- Carers 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 healthcare 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.

5.9 Overall conclusions and recommendations

- 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 carers of people living with MSA.
- Most former carers did not answer the question about cultural and religious needs – however of those who responded, the vast majority said that their cultural and religious needs were met during their time as a carer.
- The vast majority of respondents (>90%), reported that they are not receiving ongoing support following their experiences as a carer, and the same amount reported that they did not want support.

Recommendations:

- It is particularly important that carers of 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 to new carers in particular.
- Consider follow up support for carers after the person living with MSA has died – but only immediately following death.

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.

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