2022 MSA Trust Needs Survey

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1. Introduction

Multiple system atrophy (MSA) is a rare, progressive, neurological disorder that affects adult men and women. It is caused by degeneration or atrophy (shrinking) of nerve cells in 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. Recent research suggests it affects about 4.5 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 210 people per 100,000. As we learn more about the condition, it has become easier to recognise, although for many people it can still take several years to reach a diagnosis.

MSA usually starts between the ages of 50-60 years of age, but it does also affect people both younger and older. MSA does not appear to be hereditary however current research is examining whether or not there is a genetic predisposition to develop the disease. The importance of environmental factors is also not clear and there is still much to understand through research 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).

Following on from the MSA Trust's first ever Needs Survey in 2019 the MSA Trust commissioned IQVIA to work with them on a new iteration. This 2022 MSA Needs Survey presents a comprehensive picture of the experiences of people living with Multiple System Atrophy, along with those of their carers and Former Carers.

In the absence of nationally collected MSA patient outcome measures, or social care data related specifically to MSA, this research provides much needed insights into how successfully health and care services are supporting people living with Multiple System Atrophy and those that care for them.

This report, authored by IQVIA on behalf of the MSA Trust, provides details of the design and development of the survey along with the subsequent findings. It accompanies a summary document, which presents a thematic discussion of the results in relation to the policy context, draws conclusions and makes recommendations for change to support improving outcomes for people living with MSA.

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

People living with MSA

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 Neurological Alliance Patient Experience Survey 2018 listed MSA as the 2nd most severe neurological condition.[1] 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. The help and support received for these physical health needs is rated poorly by respondents.
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. Sex life is directly affected because of MSA. People with MSA might be reluctant to talk about and it seems to be a neglected area and not raised by healthcare professionals.
7. The need for personalised care and care planning appears to be a significant issue as is the need for effective co-ordination of the range of complex support people will need.
8. 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.
9. Support Groups are very important to cope with a high-impact condition like MSA.
10. Impact on employment is severe and can be damaging both financially and emotionally due to the rapid progression of the disease.
11. Individuals living with MSA need additional support for end-of-life planning.

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

Current carers and Former Carers

1. Most carers and Former Carers report caring for their spouse or partner at home. The caring commitment can be long and demanding.
2. Although it is understood that MSA is life limiting, we find that a significant number of deaths are still unexpected when they actually occur.
3. All carers need to be empowered to obtain 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 and anxiety, depression and general low mood are also widely experienced.
7. Additional Support Groups for carers would be welcome, but logistical issues around location and leaving their loved one may prevent access to face-to-face Groups.
8. Caring for someone living with MSA can have serious and damaging effects on relationships, in particular carers report that relationships with friends are most significantly affected.
9. The current benefits system is not helping 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, compounded when the person dies unexpectedly or is not able to die in 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 a full range of useful and timely information.

2. Background and methodology

2.1 Background

This is the second MSA Needs survey run by the MSA Trust. The first survey, focusing on the needs of people with MSA and the experiences of Former Carers, was completed in 2019. In the current survey iteration design, we additionally included current carers' needs.

The MSA Trust engaged survey company IQVIA to undertake the research. The MSA Trust and IQVIA 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 17th August and 11th October 2022 and the survey received 520 responses.

2.2 Objectives

Besides the objective of producing a report about people living with MSA, carers and former carers, the survey had the objectives to collect data about the experience of the three groups in order to:

People with MSA

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. Raise awareness of the condition among healthcare professionals and where possible promote further research.

Carers and Former Carers

1. To better understand existing data about living with MSA by exploring the issues faced through the eyes of someone who cares 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 care or 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 carers and Former Carers of people with MSA to inform MSA Trust's strategic priorities and longer-term work. This entailed 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 people living with MSA, carers and Former Carers of people with MSA.

2.3 Methodology

The methodology for the 2022 survey included a dual method of data collection. Feedback was collected digitally from respondents via an anonymous online link and in a targeted way by sending the questionnaire to individual members online with a unique link.

The questionnaire was also sent by post to individuals living with a diagnosis of MSA as well as those caring for people affected by MSA and whose details were held on the MSA Trust’s CRM database.

This last 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. The paper copies did also contain a link to complete the survey online if that was the preference of the respondent.

A choice of response options aimed to maximise the overall number of responses in order to improve the reliability of the data.

A summary of the methodology is below:

- Three new questionnaires were developed based on the 2019 MSA Needs survey for people with MSA and Former Carers of people with MSA.
- The questionnaires were designed and developed between March and August 2022. The questions were thoroughly drafted, reviewed, tested and revised. IQVIA worked closely with the MSA Trust on designing and agreeing the final question sets.
- The questionnaires were developed alongside a project steering group that comprised MSA Trust representatives. This included MSA Trust Nurse Specialists, MSA Social Welfare Specialist, Neurologists, people with MSA, Palliative Care Consultants, Carers and Former Carers with direct experience of MSA.
- As a part of the process, cognitive testing was carried out with eight volunteers (four people living with MSA, two carers and two Former Carers to ensure the final questionnaires could capture the information required in the most straightforward and effective way. A number of changes and improvements were made as a result of these tests.
- Final questionnaires were produced in August 2022 in preparation for full rollout. These were produced as a paper copy.
- During this time a replica of the paper survey was produced as an online survey. IQVIA carried out User Acceptance Testing (UAT). UAT is the last phase of the software testing process.
- Both the online survey and paper survey were launched in August 2022 and ran until October 2022. The online survey was promoted to people via MSA Trust’s social media channels and other forms of communication.

- Of the Former Carers, the survey was only sent to those that remained as members of the MSA Trust as well as notifying the Trust of a bereavement in the last three years.

2.3.1 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 an interpretation of the data.

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.

2.3.2 Sampling and data

There was an anonymous link that was available to all respondents. The online survey and paper copies were sent to named individuals from the data sample shared by MSA Trust with IQVIA following stringent procedures regarding data protection personal data.

The sample was checked via DBS (Demographics Batch Service) to remove any deceased service users and the questionnaires were processed and sent out within 24 hours of this check. There was a system for anonymously tracking of responses.

IQVIA were able to provide over the phone form completion and in different languages for those who required this.

2.4 Timescales and fieldwork

The timescales were as follows:

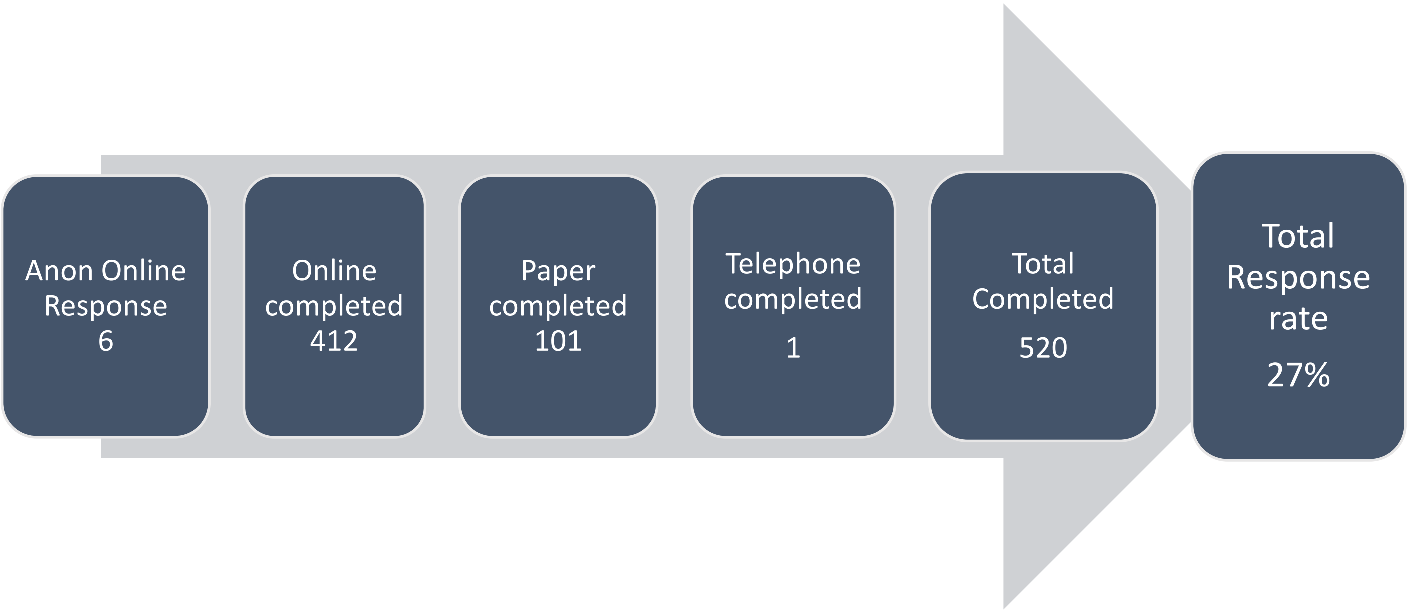
- **Development of question set:**
    - Steering group meetings and development of questions: March – June 2022
    - Cognitive testing of questionnaire: June 2022
    - Further refinements to questionnaire: July 2022
    - Questionnaire ready: August 2022
- **Full rollout:**
    - Survey START: 17 August 2022
    - Survey CLOSE: 11 October 2022

2.5 Response rate

The survey was sent to a sample of 1,955 (993 People living with MSA, 736 carers and 226 Former Carers) of which 520 were completed and returned.

We only surveyed people that accessed the MSA Trust services. Based on the final sample size, the response rate was 27% (see the detailed response rates on the next 2 pages). Given the demographic and nature of the condition, this means we can consider the results robust, which allow us to draw meaningful conclusions.

Total Response rate



Response rate per group

People living with MSA

Anon online response	Online completed	Paper completed	Telephone completed	Total Completed	Total Response rate
1	161	53	0	215	22%

Current Carers

Anon online response	Online completed	Paper completed	Telephone completed	Total Completed	Total Response rate
3	179	32	0	214	29%

Former Carers

Anon online response	Online completed	Paper completed	Telephone completed	Total Completed	Total Response rate
2	72	16	1	91	40%

3. Results of the questionnaires

3.1 Respondent characteristics

3.1.1 Who completed the questionnaire

Of the respondents completing the questionnaire for people living with MSA, just over three-quarters (76%, n=161) were people living with the condition, 15% (n=32) were family members or friends and a further 9% (n=20) were health or care professionals. Those answering the questionnaire on behalf of the person with MSA were instructed to respond from the point of view of the person, rather than their own point of view.

This is not typical of similar size survey programmes, where most individuals complete the survey themselves but is representative of the condition and its effects on individuals, especially as their MSA progresses. This option maximised the ability for people with more advanced MSA to still take part in the survey.

From question Person living with MSA 1: Who is filling in this survey?

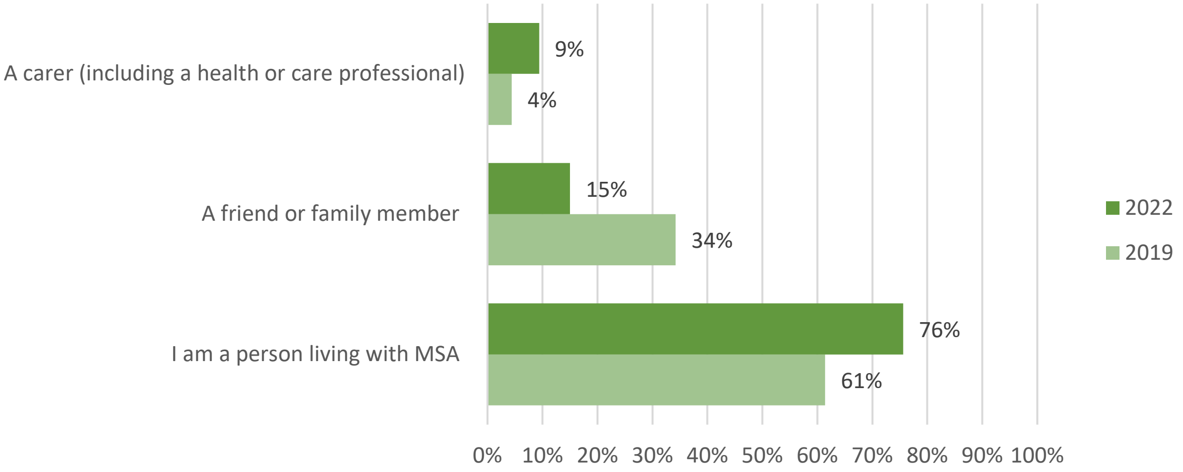


Fig 1. Respondents completing the survey

3.1.2 Age of people living with MSA

Of the respondents living with MSA none were under the age of 45. Given MSA is generally uncommon in younger people (diagnosis is not possible under 30), this is unsurprising and is in line with previous surveys and other literature. Only 6% (n=12) were aged between 45 and 54 and just over two thirds (69%, n=146) were aged between 55 and 74.

The age range for carers and Former Carers is broadly in line with that of people living with MSA. The vast majority of respondents were the spouse or partner of the person living with MSA and therefore it is more likely that they are of a similar age. The chart below breaks this down in more detail.

From question Person living with MSA 65/ CC 55/ FC 49: Your age band

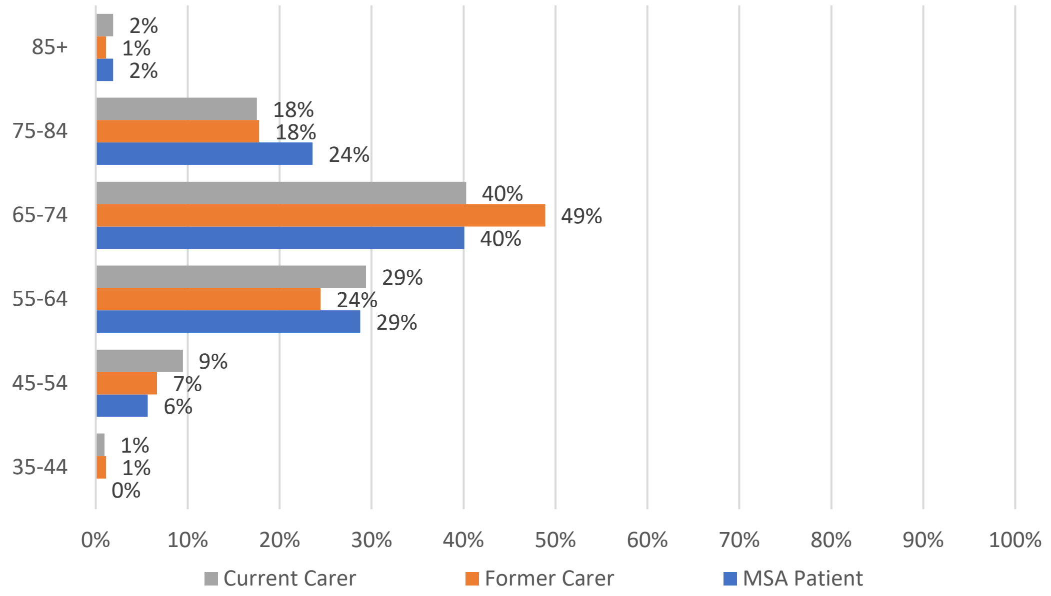


Fig 2. Age range of respondents with MSA, Carers and Former Carers

3.1.3 Ethnicity

Almost all respondents among the three groups (98%) identified themselves as 'White' (either English / Welsh / Scottish / Northern Irish / British, or Irish / other White background).

The numbers of those identifying themselves as any other ethnicity, was very low (just 2%). This compares poorly with the ethnicity of people resident in the UK where around 87% are white, with the remainder a mix of non-white ethnic backgrounds.[2] (UK population data 2022). These figures are in line with the results from the 2019 MSA Needs Survey.

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[2] https://populationdata.org.uk/uk-population/

Previous literature suggests that people from black and minority ethnic groups are less likely to respond to surveys than people that are white. It has been suggested that theories of literacy and language may be an explanations of low response rates in the national patient surveys.[3] To encourage engagement from across the breadth of ethnicities resident in the UK, IQVIA provided translation support to answer the questionnaire when needed.

3.1.4 Gender of respondents

There was an almost equal split between genders, with slightly more female respondents. 104 respondents (49%) identified themselves as male whilst just over half (51%, n=108) identified themselves as female. One individual preferred not to say.

Three fifths of the respondents (60%, n=127) among the carers are female and the remaining 40% (n.83) male*.* Almost mirroring the current carers ratio, 62%(n=56) of Former Carers are female and 38% (n=34) are male.

From question Person living with MSA 66/ CC 56/ FC 50: Which of the following best describes you?

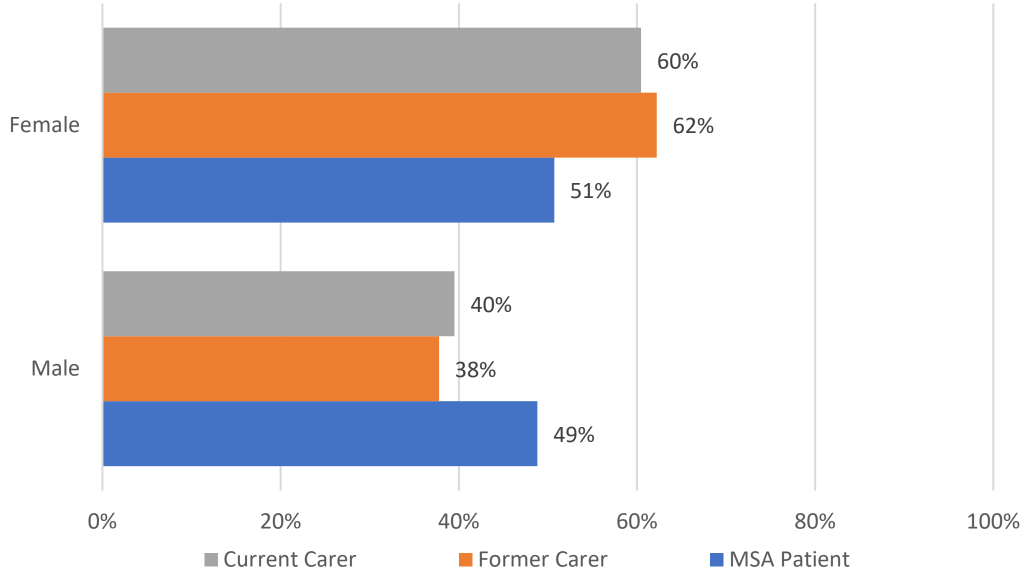

Fig 3. Gender breakdown

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[3] https://www.researchgate.net/publication/255650786_Increasing_response_rates_amongst_black_and_minority_ethnic_and_seldom_heard_groups

3.1.5 Information about carers

Most carers (97%, n=208) looking after a person with MSA were their spouse or partner, followed by their son or daughter (1% n=2) and an additional 1% (n=2) were other carers.

A similar split can be observed for the Former Carers where 96% (n=87) were spouse or partner, 2% (n=2) parents or guardian and an additional 2% (n=2) were sons or daughters.

Question CC 1/FC 1: What is your relationship to the person you care for who is living with MSA?

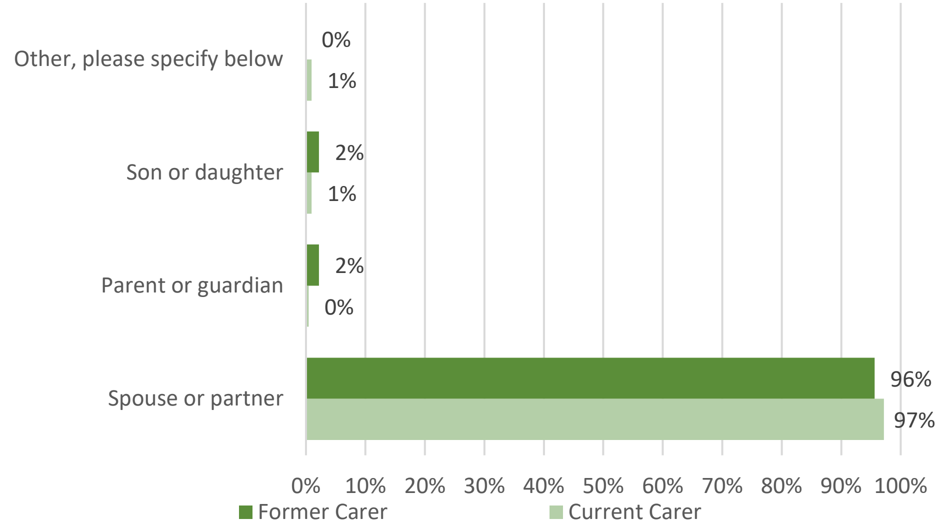

Fig 4. Carer and former carer relationship to the person with MSA

96% (n=204) of carers were the main and only carers of people with MSA. The percentage is slightly higher with Former Carers where nearly all of the respondents (99%, n=89) provided the majority of the unpaid care to their loved ones.

From question CC 2/FC 2: Are / were you the main / primary carer?

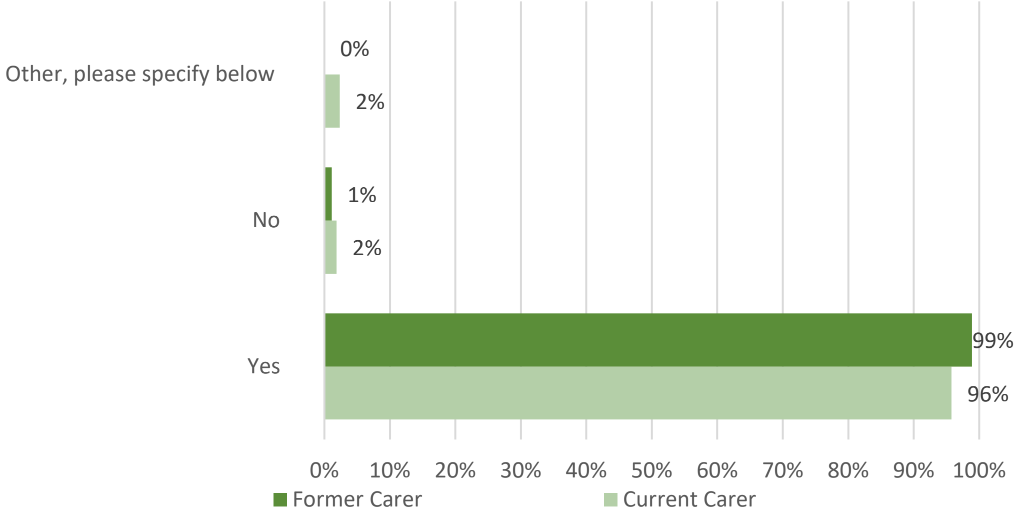

Fig 5. Primary Carer for people with MSA

3.1.6 Carers and former carers living arrangements

As the majority of the **carers** are the spouse or partner of the person with MSA, it's not surprising that 98% (n=206) live with the person they care for. The vast majority of **Former Carers** (88%, n=80) lived with the person they cared for until they died. An additional 9% (n=8) of Former Carers lived with the person with MSA until they were moved into a hospice or nursing home.

This correlates with the finding that the majority of carers are the spouse/partner of the patient but may also indicate the level of care required for patients here, particularly as the disease progresses. This may also highlight the time and effort required by a carer for someone with MSA.

3.1.7 Length of time providing care and support

59% (n=51) of Former Carers started providing the majority of support and care to the person affected by MSA in the last six years of their life with a further 23%(n=20) that provided care for more than eight years.

Among the carers nearly three quarters of respondents (73%, n=154) reported they had looked after a person with MSA in the last six years and only 15% (n=31) for the last eight years. The reason behind the discrepancy between carers and Former Carers is likely related to the later stage of MSA that Former Carers dealt with.

From question CC 4: How long have you been providing care and support to the person living with MSA?

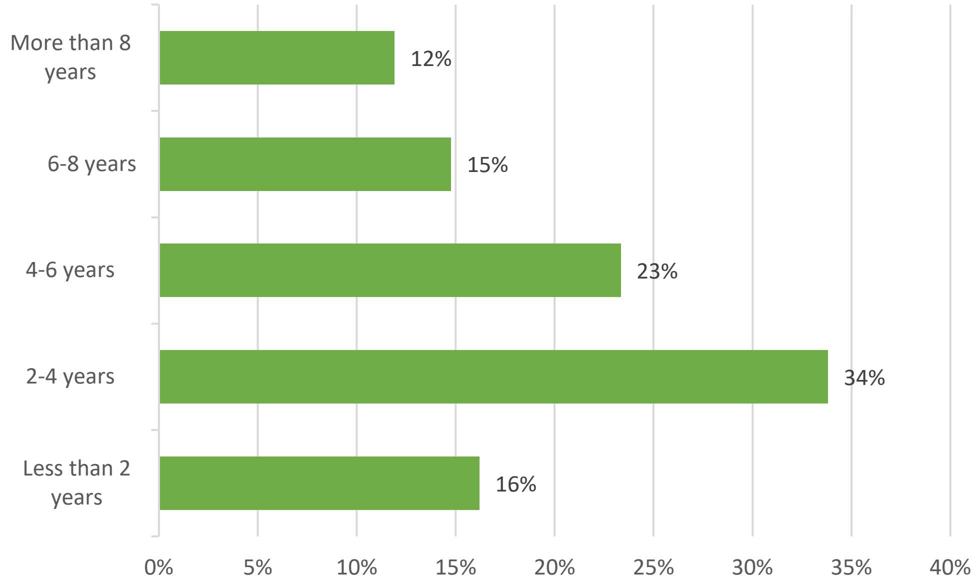

Fig 6. Length of care provided by carers

3.1.8 Living with other conditions

Over two-fifths of respondents with MSA (43%, n=90) were living with more than one chronic condition such as arthritis, asthma, or heart disease. This is not uncommon among the older segment of the population and is broadly in line with studies that show that by the age of 75 the likelihood of possessing two or more significant conditions is approximated to be 60%.[4]

From question Person living with MSA 4: Apart from MSA, do you live with any other chronic (long-term) conditions?

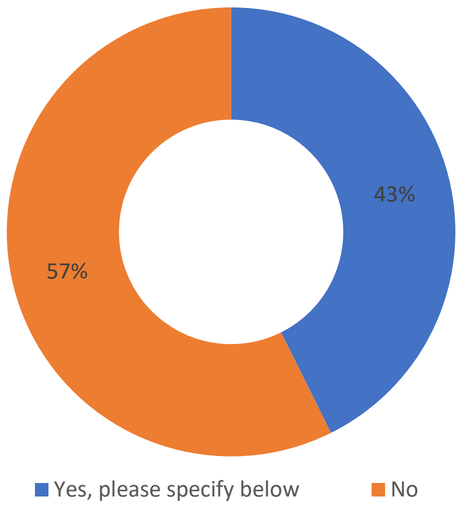

Fig 7. Respondents with additional chronic conditions alongside MSA

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[4] https://www.news-medical.net/health/Comorbidities-in-Older-Adults.aspx

3.2 Diagnosis

3.2.1 Length of time living with MSA since first symptoms appeared

As a rare condition, MSA can be difficult to diagnose as some symptoms can overlap with those of other conditions such as Parkinson's Disease.

Most respondents affected by MSA have been living with the condition for 10 years or less since first experiencing symptoms of MSA (86%) with 54% having the condition for less than five years. A small number of respondents (14%) reported that they had lived with MSA for over 11 years since the first symptoms appeared. The length of time discrepancy between those with MSA and former carers here will be due to the fact that people that Former Carers had cared for had passed away and therefore will have lived with MSA for a longer period of time.

From question Person living with MSA 2a/CC 3a/ FC 4a: How long do you think you have been living with MSA?

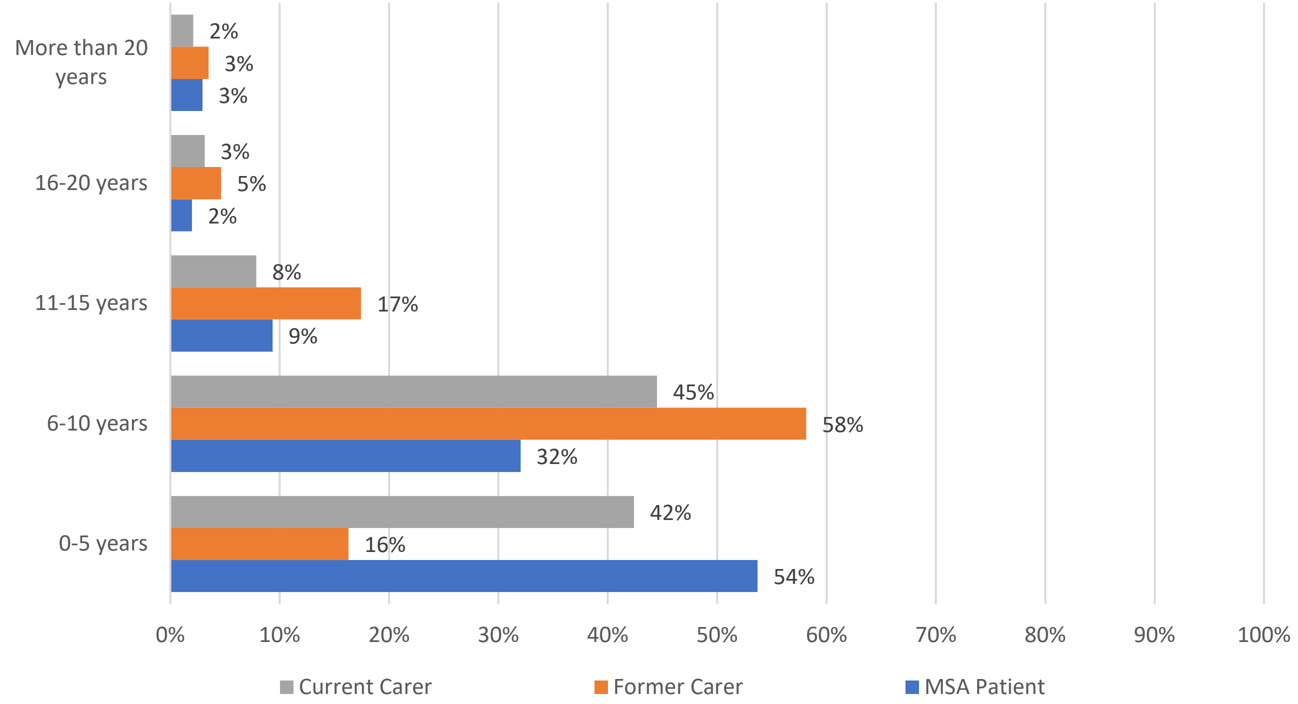

Fig 8. Length of time the person has been living with MSA

3.2.2 First symptom of MSA before diagnosis

Among the people living with MSA and carers, one of the first symptoms that prompt the person to seek medical help was issues with their balance. The chart below shows in more detail the most prevalent early symptoms.

From question Person living with MSA 3/CC 6: Perhaps even before diagnosis, what do you feel was the first symptom of MSA which caused you to seek medical help?

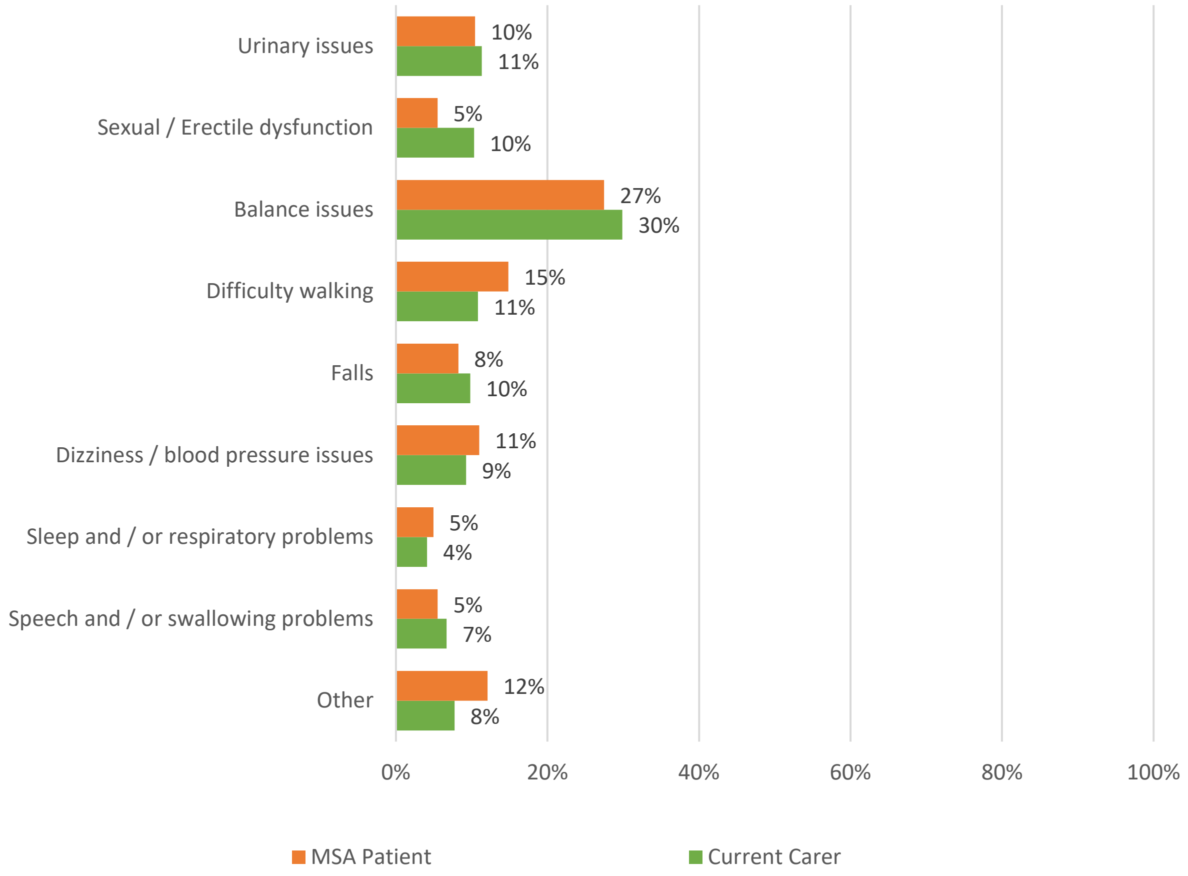

Fig 9. Early symptoms of MSA before diagnosis

3.2.3 Length of time between experiencing symptoms of MSA and diagnosis

When looking more closely at the data across all the surveys, it shows that only 5% of respondents received a diagnosis of MSA within one year of experiencing their first symptoms. Nearly a quarter of people with MSA reported it took one year to be finally diagnosed with MSA after their first symptoms appeared, with a further 49% reporting it took between two and four years to get an accurate diagnosis.

For the majority of respondents across the three groups, it took two years or more to be accurately diagnosed. This confirms the difficulty in obtaining an accurate diagnosis for MSA and the time lag to diagnosis that there is for MSA. Without a correct diagnosis, patients and their carers are unable to access the appropriate treatments, support services and care that they require and this could add to the physical, emotional and financial strain on them and their families. In addition, people will not be aware of the life-limiting nature of MSA, and the need to make the most of their lives, before their condition progresses.

Cross analysis from question Person living with MSA 2a/2b/ CC 3a/3b/FC 4a/b: Number of Years since first symptoms and Number of years since diagnosis

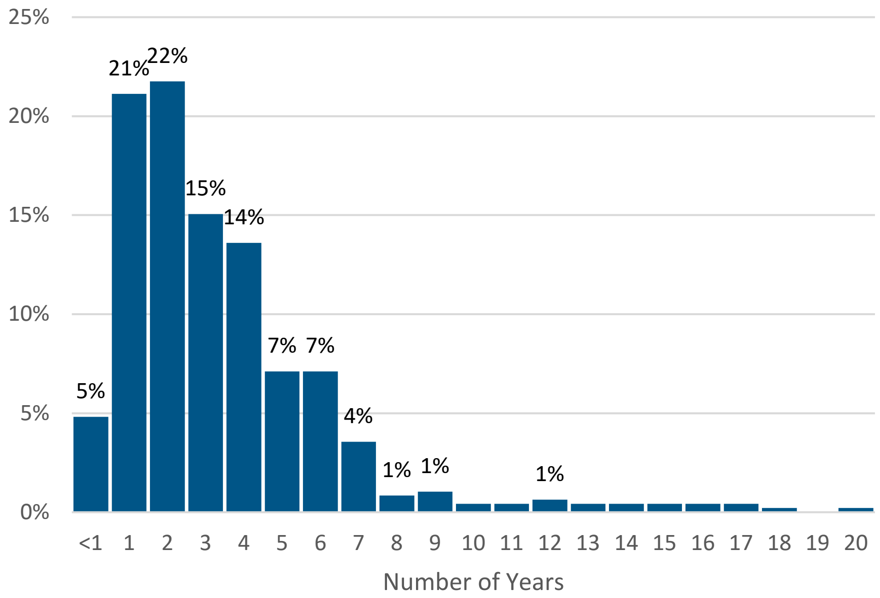

Fig 10. Length of time between when first symptoms appeared and diagnosis of MSA across the three groups

Cross analysis from question Person living with MSA 2a/2b: Number of Years since first symptoms and Number of years since diagnosis

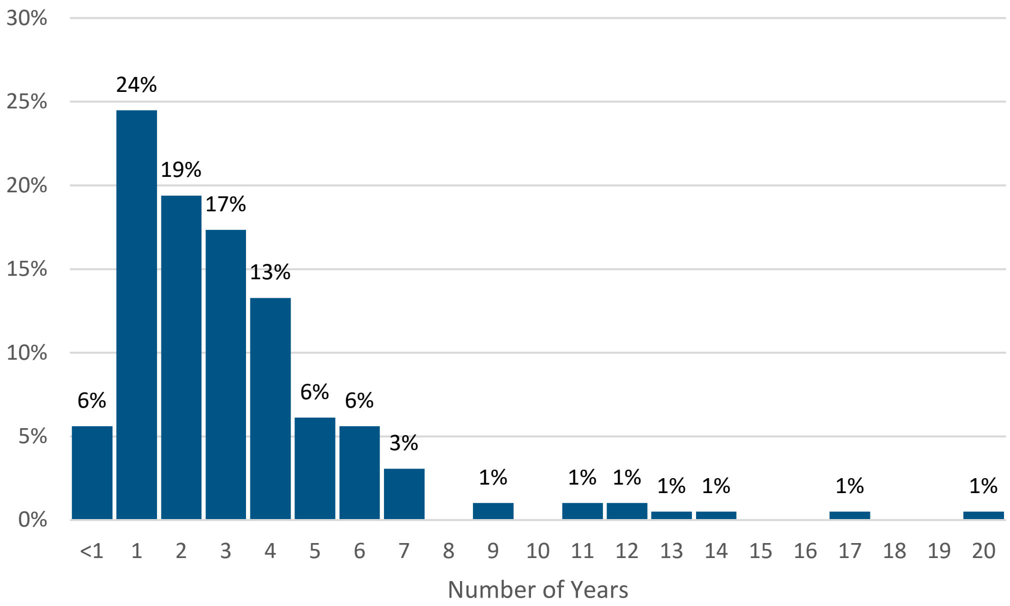

Fig 11. Length of time between when first symptoms appeared and diagnosis for people with MSA

Educating Healthcare Professionals on the symptoms of MSA could help to further reduce the length of time people affected by the condition need to wait for the correct diagnosis. This may include helping GPs to understand the importance of an early referral to neurology specialists for further investigations.

3.2.4 Diagnosis and late diagnosis of MSA

Respondents were asked if their MSA was initially diagnosed as something else. Less than a third of respondents (31%, n=65) were diagnosed with MSA as a first diagnosis. Given the challenging nature of the symptoms and overlap with other conditions, this is perhaps unsurprising. This is in line with the 2019 survey results.

Of those not diagnosed with MSA initially:

- 41% (n=84) were diagnosed with Parkinson's disease first
- 13% (n=27) were diagnosed with Ataxia first
- 6% (n=13) were diagnosed with Atypical Parkinson's first
- <1% (n=1) were diagnosed with Progressive Supranuclear Palsy (PSP) first
- 8% (n=17) were diagnosed with other conditions first, such as Vertigo or Epilepsy

From question Person living with MSA 5: Was your MSA initially diagnosed as something else?

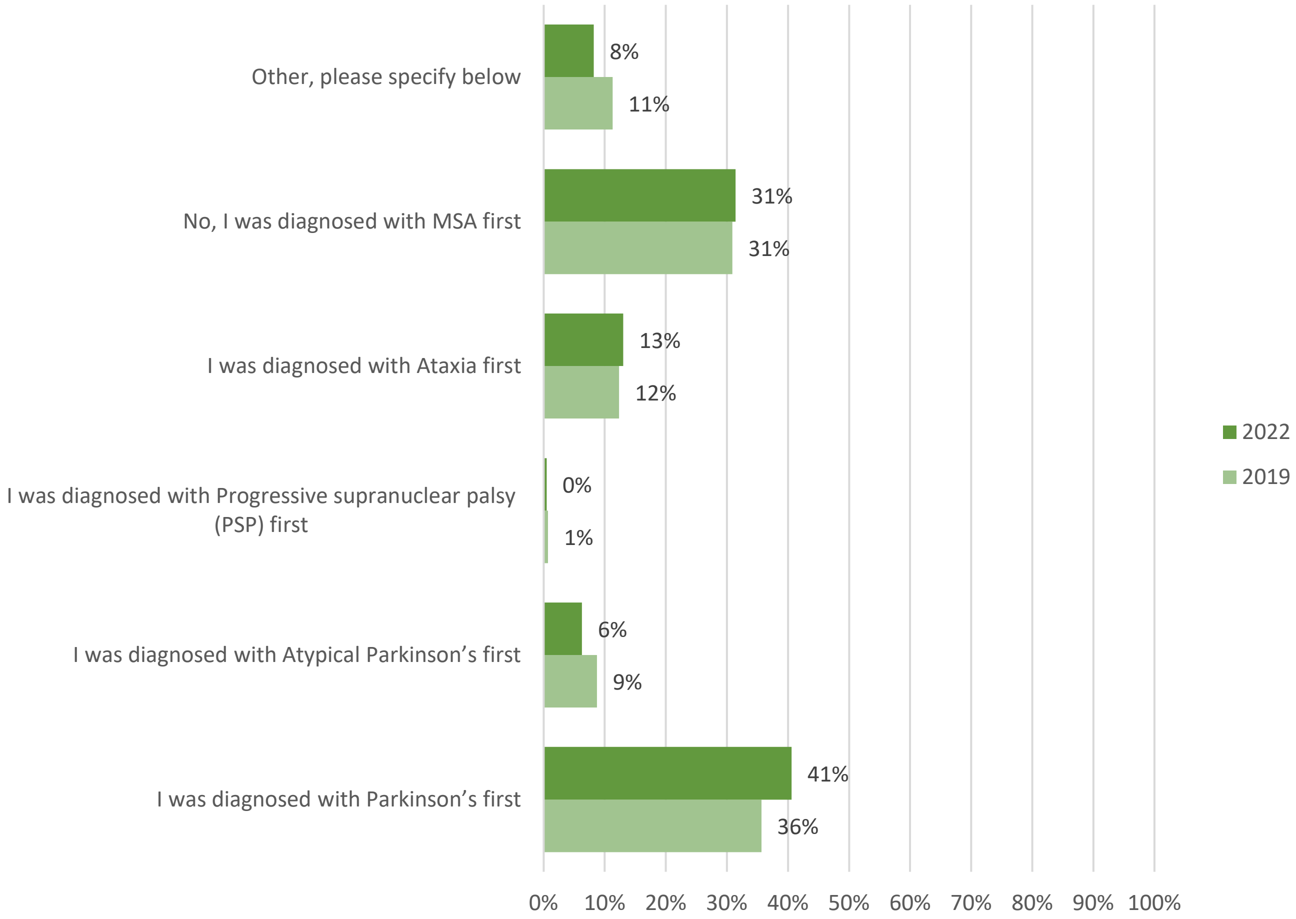

Fig 12. MSA diagnosis

3.2.5 Healthcare professional that gave the diagnosis

Considering the nature of MSA and the diagnosis profile described above, it's not a surprise that 85% (n=173) of the people with MSA received the diagnosis by a Consultant Neurologist. A further 5% (n=10) were given by an MSA Specialist and 4% (n=8) by a Movement Disorder Specialist with the remaining individuals diagnosed by a Geriatrician or by another specialist.

3.2.6 Information at diagnosis

41% (n=88) of the respondents with MSA were not given **any** information on what to expect from living with the condition on the day they received their diagnosis. 31% (n=66) of respondents stated that they received printed information produced by the MSA Trust with only 13% (n=29) stating that they received information from the NHS. More needs to be done to provide people at the time of diagnosis with information on MSA. Being given a rapidly progressive terminal diagnosis is obviously a huge shock for people, and truly disorientating. It should be part of the healthcare professional's role to sensitively support the person with printed information, not only on their MSA but also on the support available to help them manage their diagnosis and the progression of their condition both physically and emotionally. Ideally any information provided should be accredited by the PIF TICK to ensure it is accurate and reliable information (the MSA Trust holds this accreditation).

From question Person living with MSA 36: What information were you given on the day you were diagnosed about what to expect from living with MSA?

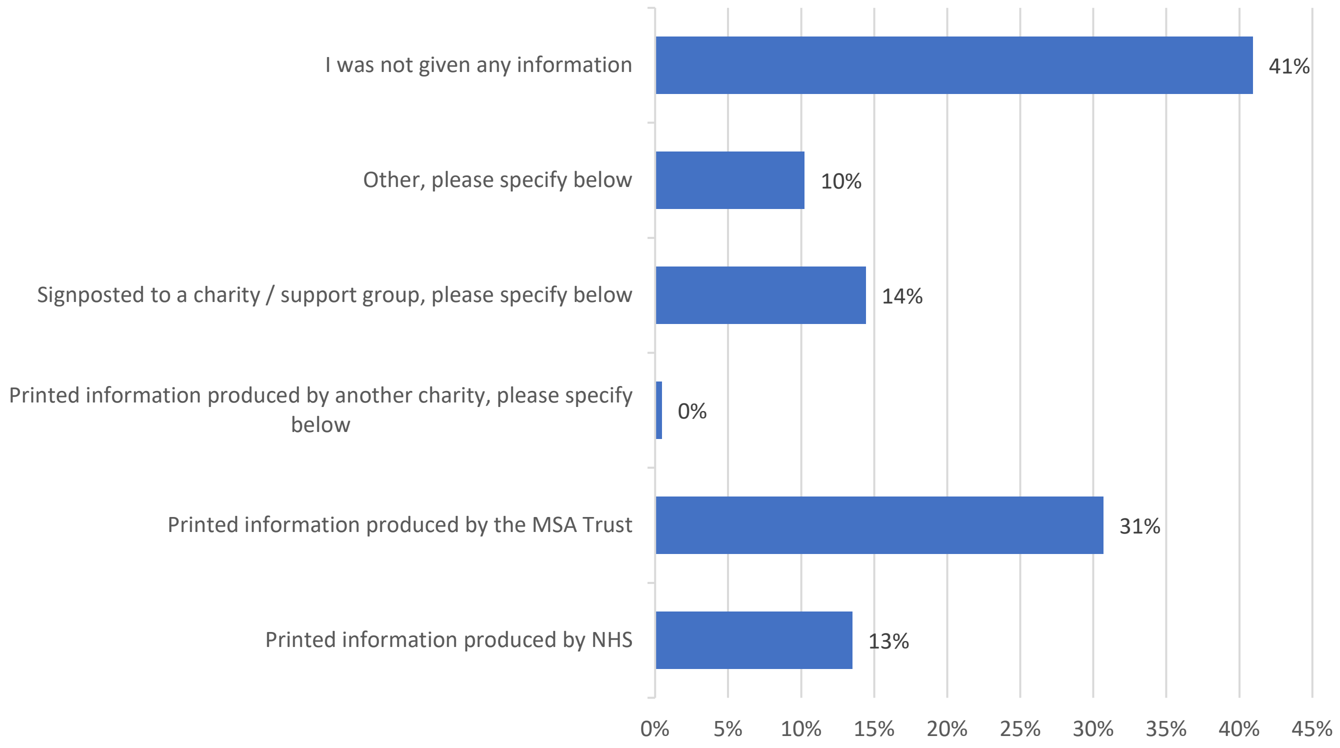

Fig 13. Information provided by healthcare professionals at time of diagnosis

3.2.7 Former Carers information at the time of diagnosis

Among the Former Carers that were looking after the person living with MSA at the time of the diagnosis, 36% (n=33) reported they did not receive enough information about MSA to prepare themselves for the months ahead. 18 respondents received the needed information and 42% (n=38) received partial information. Two individuals were not caring for the person at the time of the diagnosis.

"Consultant told both of us to go on the internet to find out more."

"No support about what to expect and limited advice on all aspects."

3.2.8 Quality of sources of information and support for MSA

The chart below shows how the respondents with MSA rated the sources of information and support received on MSA.

86% (n=176) of the respondents rated highly information from the MSA Trust versus only 9%(n=18) that highly rated the information and support from their GP Practice. As will be evidenced again later more should be done with GPs to increase their awareness of MSA and help them provide adequate information and support to those patients that require it.

From question Person living with MSA 37: How would you rate the following sources of information and support about MSA?

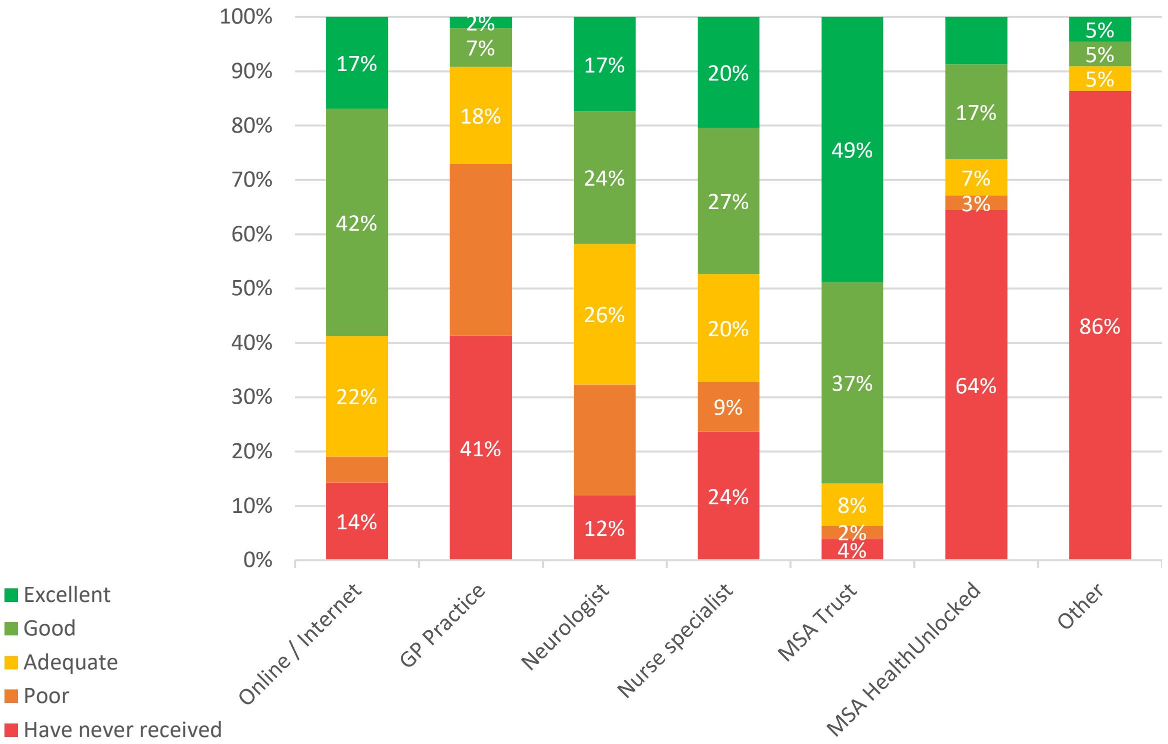

Fig 14. Quality of source of information

"Initially very good, useful information pack, but I think more could be done advertisement-wise."

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

“The information available in Ireland for me has been abysmal. I feel like I have been in a fog trying to get information. The last consultant I saw actually spoke to me as a person, not a patient and he discussed what MSA would eventually take away from me. This is the first real conversation I have had.”

3.2.9 What additional information would be useful

People with MSA were questioned about what information they would have preferred to have received.

- 43% (n=93) stated **Treatment options**
- 39% (n=84) **Research into MSA**
- 44% (n=95) would have liked information relating to **Help planning for the future**.

From question Person living with MSA 38: On which of the following, if any, would you like to be given more information about?

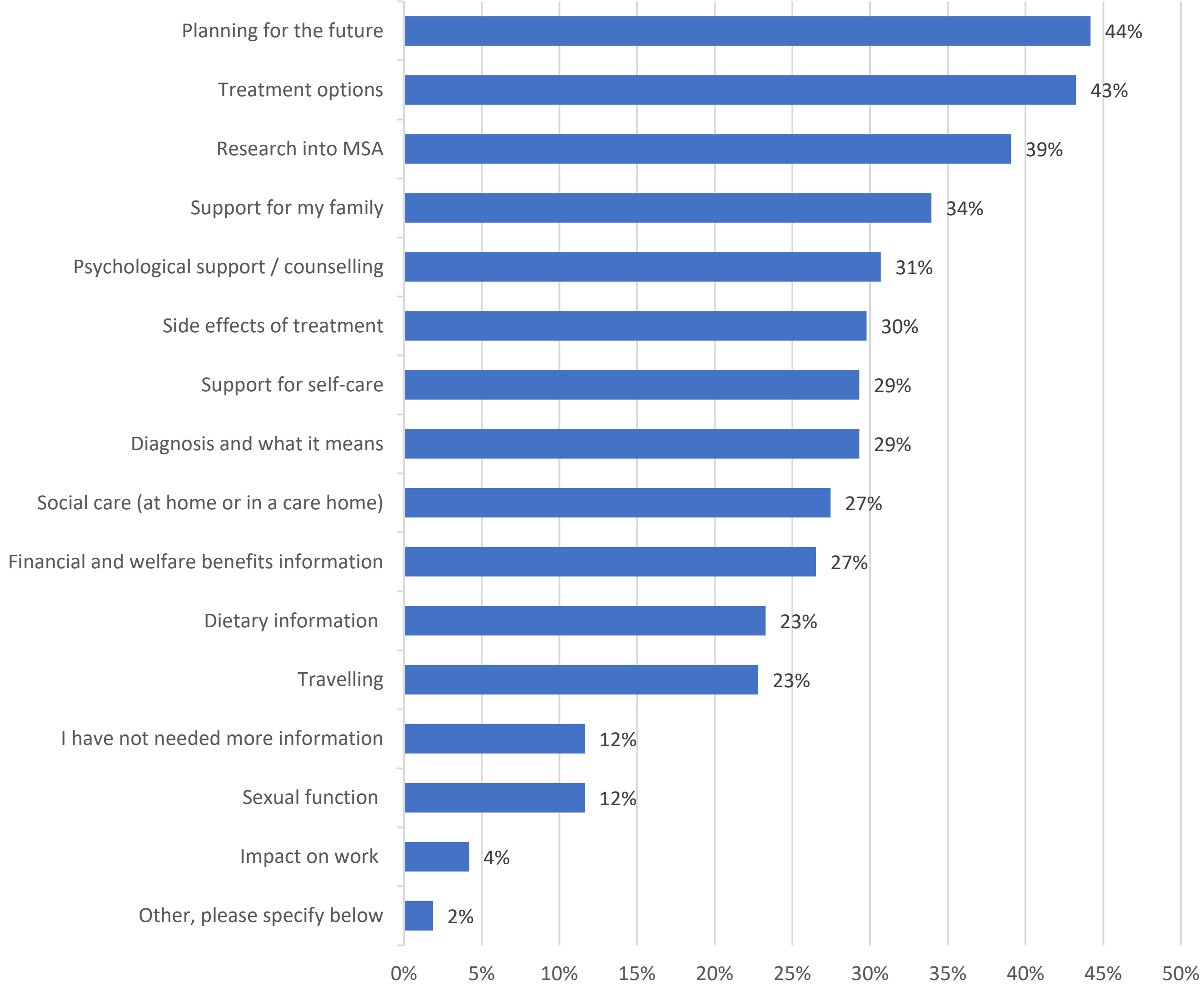

Fig 15. More information that would be useful

3.2. 10 Conclusions

People living with MSA

- The majority of respondents (86%) affected by MSA have been living with the condition for 10 years or less (since first experiencing symptoms), with just 14% living with MSA for over 11 years.
- Nearly one quarter of people with MSA reported it took one year to be finally diagnosed with MSA after the first symptoms appeared, with a further 49% reporting it took between two and four years to get an accurate diagnosis.
- Less than a third of respondents (31%) were diagnosed with MSA as a first diagnosis. This is unsurprising considering the challenging nature of the symptoms that overlap with other conditions, such as Parkinson’s disease.
- Understandably, due the nature of MSA, 85% of people with MSA received the diagnosis by a Consultant Neurologist.

Information and diagnosis

- Two fifths of respondents were not given information on what to expect from living with MSA on the day they received their diagnosis, this must have been very disorientating. Of those that received information, one third received printed information from the MSA Trust.
- The MSA Trust rated highly as a source of information and support among the respondents, whilst GP Practices fared poorly.
- Being a rare condition, people with MSA would benefit from access to more information on treatments and research.

Current Carers

- In line with results from those with MSA, current carers have stated that the person they care for has been living with the condition for 10 years or less (since first experiencing symptoms of MSA).
- Issues with balance was one of the first symptoms that prompted the individual they care for to seek medical help.
- Responses from current carers correlates with those from people living with MSA; it took two years or more for the person they cared for to receive an accurate diagnosis.

Former Carers

- A higher percentage of Former Carers reported that the person they looked after experienced symptoms of MSA for more than 11 years (14%). We can understand that this is due to most former carers having to care for individuals living with MSA for a longer time in comparison to current carers.

Information

- More than one third of Former Carers confirmed that at the time of the diagnosis they did not receive enough information about MSA to prepare themselves for the months ahead.

3.3. Care by Healthcare professionals

3.3.1 Healthcare professionals' attendance at clinics

Of the respondents with MSA attending clinic appointments 59% (n=126) said that they had a consultant present.

The chart below breaks down in more detail the different healthcare professionals attending regular clinic appointments and the knowledge people feel they have of MSA.

From question Person living with MSA 7: Please provide your feedback on the following healthcare professionals.

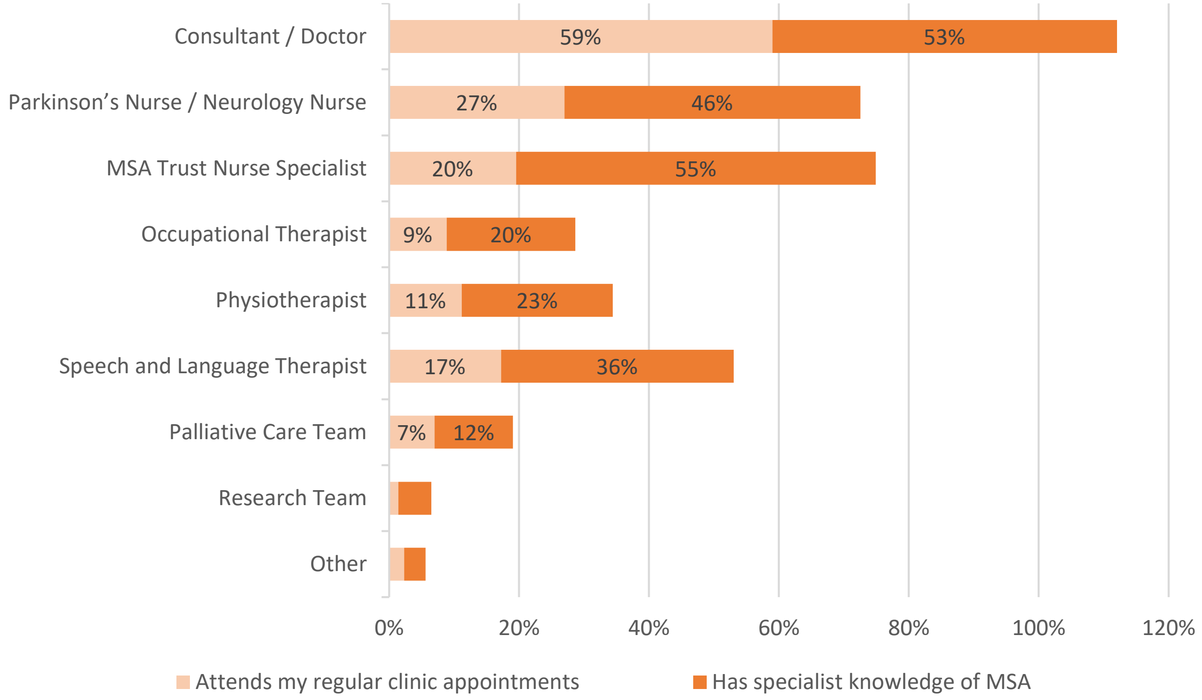

Fig 16. Healthcare professional attending appointments

3.3.2 Clinic and local service co-ordination

Only 29% (n=57) of people with MSA confirmed their clinic coordinates their local service support versus 71% (n=137) of respondents that reported this was not the case.

Over three quarters of respondents affected by MSA (78%, n=111) stated that **no one coordinates their care locally**. This result may reflect the current economic situation coupled with the repercussions of the COVID 19 pandemic that has affected the resources available to local services. However, improvement in this area is a central aim of the UK Rare Disease strategy so it seems COVID19 is by far the only barrier to co-ordination.

"No unless my wife calls them, I used to have a MS nurse but it was stopped due to COVID-19."

"Me! GP has made referrals to physio, speech therapy and occupational health on my request."

3.3.3 Satisfaction with clinic appointments

Three fifths of people with MSA on a scale of 1 to 10 are moderately to very happy with their experience of clinic appointments. The chart below breaks this down in more detail.

From question Person living with MSA 10: On a scale of 1 to 10, overall, how happy are you with your experience of your clinic appointments?

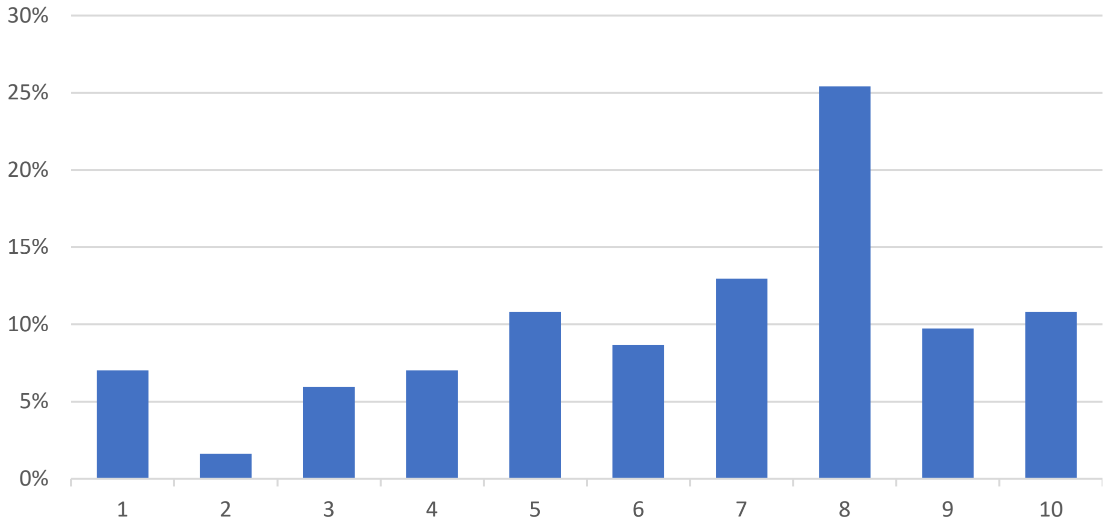

Fig 17. Clinic appointments satisfaction

3.3.4 Improvement of clinical appointments

When the respondents with MSA were asked how their clinic appointments could be improved, 139 out of 215 (65%) explained in their own words.

An analysis was carried out and the comments were organised into four main themes:

1. Access and frequency of appointments

Access to regular appointments would help to monitor the progression of the condition and timely adjustments to treatments.

"*Access to clinician every time would be useful."*

"More regular checks to see how disease is progressing and more help with medication."

"I have no regular/scheduled clinic appointments. It would improve co-ordination of treatment of my symptoms if there were regular clinic appointments."

2. Coordination of appointments

There is a desire for people with MSA to have access to multidisciplinary appointments where the patients are treated holistically. This approach would also be more time efficient for both patients, carers and healthcare professionals. The appointments could be done in person or as a blended approach using in person and remote online technologies.

“I think that the clinic appointments can be arranged with different health care professionals at the appointment with the consultant neurologist and would cover the appointment 360 degrees and would make it bit of fun too. Some of the health professionals like GP, pharmacist or dietician can attend the clinic via video link. Video link can solve space and time issues as well and produce a really comprehensive and coordinated treatment strategy.”

“All services attending doing a 'case study' type appointment.”

“I am fortunate to have access to a multi-functional range of professionals. I don't have a clinic as such but have individual regular appointments.”

3. More time and better information at the appointments

Due to the mobility and speech problems experienced by people with MSA, there is a desire to not be rushed during appointments and to have time for questions and discussions.

“My first clinic appointments were very rushed and completely without empathy. More time could have been spent explaining the nature of this illness and I could have been given a little more information on paper. I was only told I could end up using a wheelchair. I left my first appointments dazed and my wife had to do all the research and groundwork herself to find out about MSA and this is how she found your organisation.”

“Also, it would help if we had more time with the doctor/neurologist rather than being a 20-minute consultation.”

“Not enough time to explain how I feel. No real explanation or plan of care. I always leave feeling dissatisfied”.

4. Better knowledge of MSA

The lack of knowledge of MSA among healthcare professionals is often commented upon by people affected by the condition and is a source of frustration.

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

“Having doctors etc. know more about MSA. Also waiting 6 months for each consultation”.

“Someone who is an expert in area of MSA/Parkinson's rather than geriatric care. Face-to-face appointment and to have daughter present for support and background knowledge as memory isn't good.”

3.3.5 Support from health care professionals

Because MSA affects a small portion of the population and it’s not well known among healthcare professionals, it’s very noticeable from the data that people with MSA feel mainly supported by Neurologists (85%, n=147), followed by the MSA Trust Nurse Specialists (82%, n=128) and then Speech Therapists (80%, n=127).

More than half of the respondents (53%, n=90) have never been offered support from their GPs, this is very likely due to the lack of understanding GPs have of the condition. Similar, to GPs, 85% (n=94) of respondents have not been offered support by a Multidisciplinary Team. This is something to consider as patients really value a coordinated, well-informed response from their healthcare team as we have seen from the previous comments.

Similar results can be observed for carers and Former Carers. The chart below shows in more detail the support provided or never offered by different healthcare professionals.

From question Person living with MSA 13: Which of the following health care professionals offer you valuable support for your MSA?

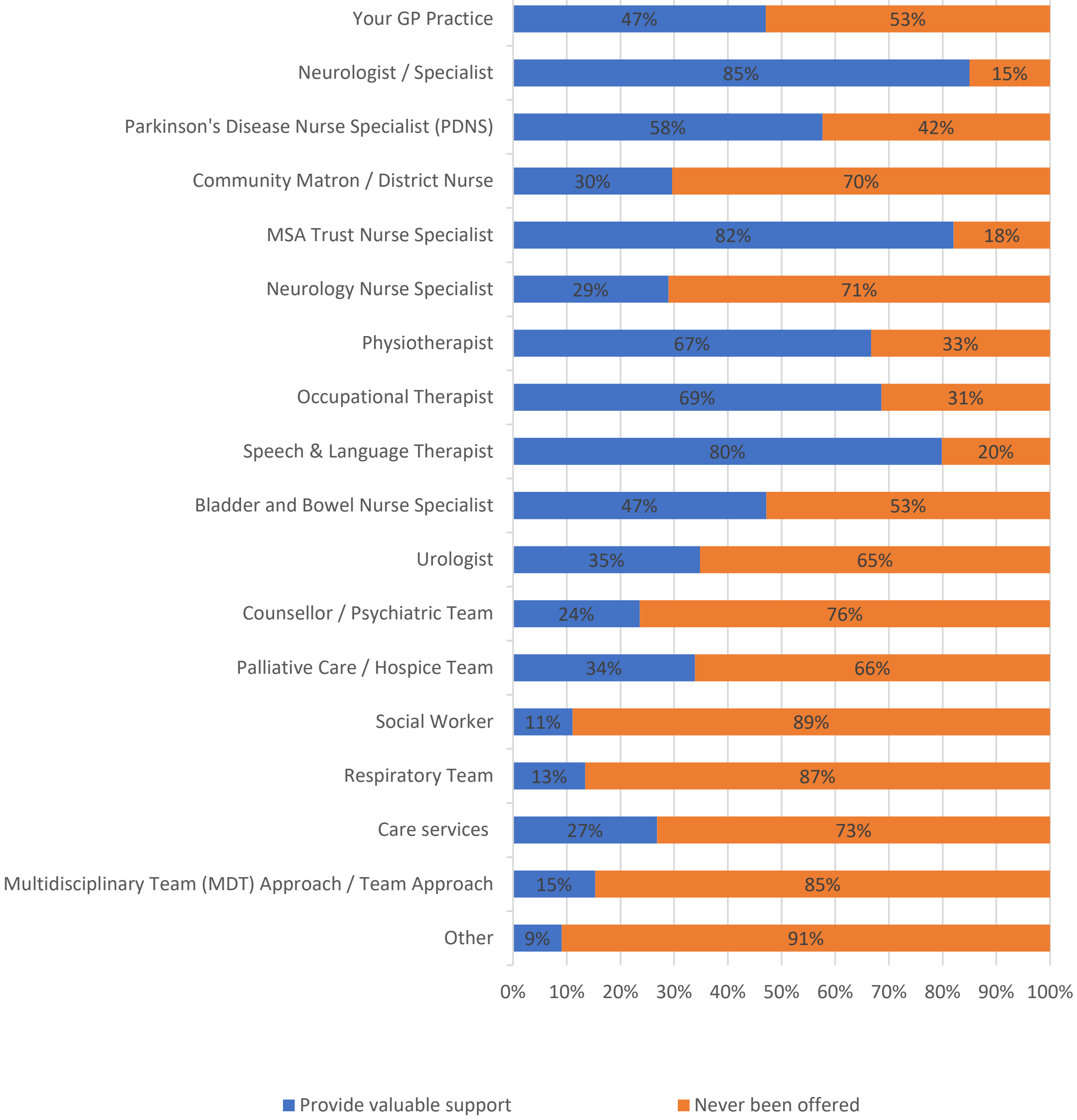

Fig 18. Healthcare professionals offering valuable support to people living with MSA

3.3.6 GP Practice provision

Among people living with MSA and carers it's very evident how unsupported they feel by their GP Practice, their first point of contact when MSA manifests itself. The GP is often the point of contact for other points across their MSA journey particularly in areas where there is a lack of coordinated specialist support.

Nearly three fifths of people with MSA (56%, n=120) don't think their **GP Practice** understands MSA, which may explain why half of the people with MSA surveyed do not feel they receive valuable support by their GPs.

From question Person living with MSA 14: Are you confident that your GP Practice understands MSA?

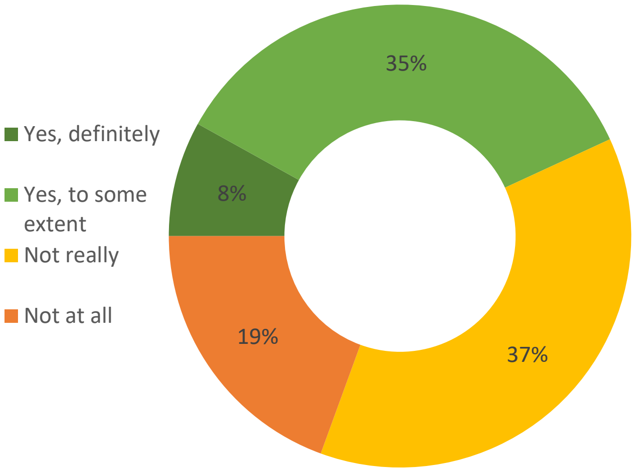

Fig 19. GP's understanding of MSA

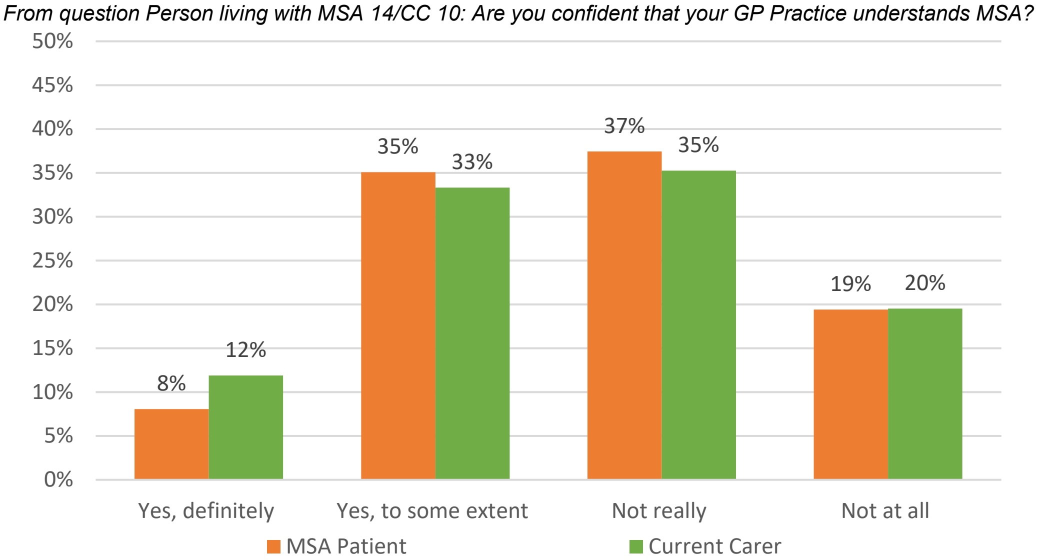

Fig 20. GP's understanding of MSA compared to current MSA patients and carers

This is reflected in some of the comments made by respondents:

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

"My GP provides everything that is asked of him to ensure that I can be treated in my own home. There is not a lot of proactive support, probably because of his limited experience of the condition."

40% of respondents (n=85) report not feeling supported or supported only to some extent. When it comes to contact with their GP Practice over one third of the people with MSA (35%, n=74) find it fairly or very difficult to contact them. Similar data have been reported by carers of people with MSA.

From question Person living with MSA 15: Are you well supported by your GP Practice?

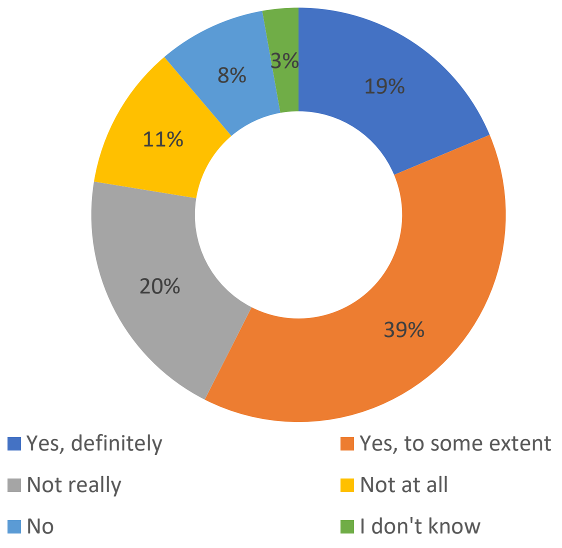

Fig 21. People living with MSA- support from GP Practice

From question Person living with MSA 15/CC 9: Are you well supported by your GP Practice?

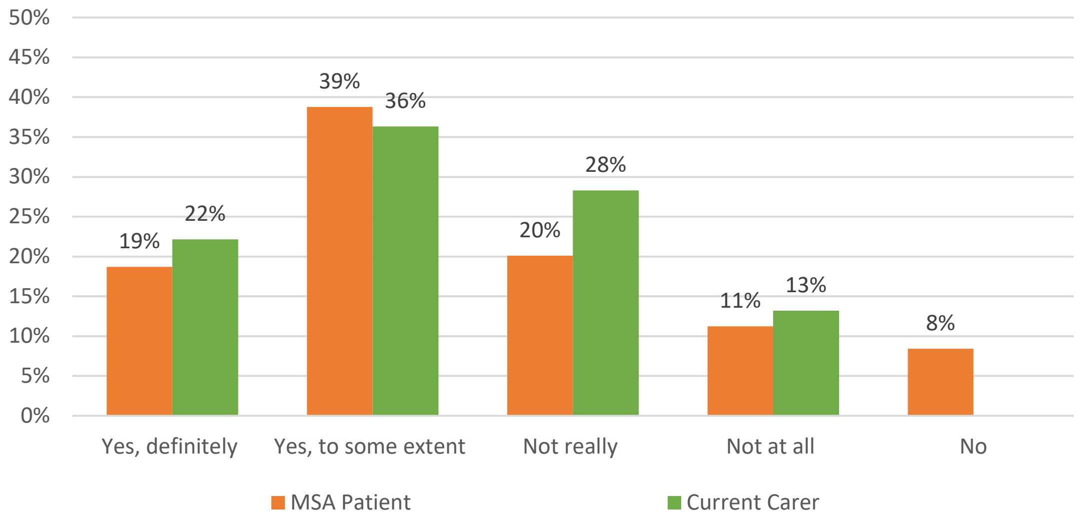

Fig 22. Support from GP Practice, comparison between people with MSA and carers

From question Person living with MSA 16: How easy or difficult do you find it to contact your GP Practice?

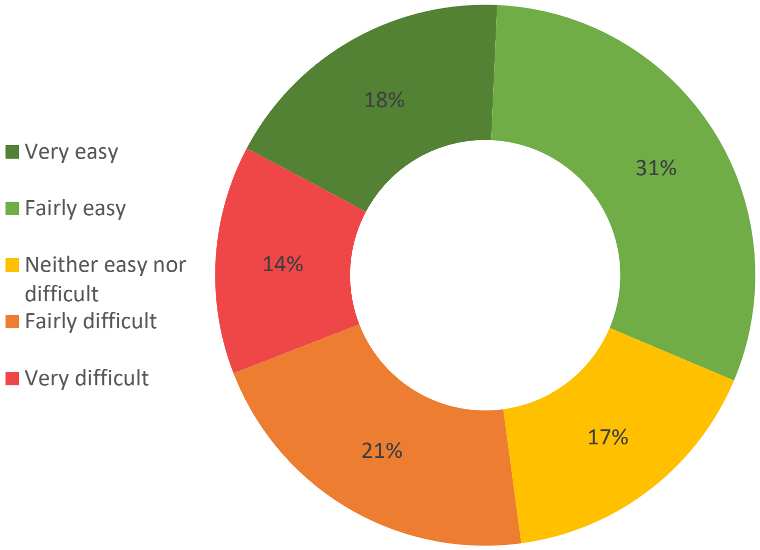

Fig 23. People living with MSA - contacting GP Practice

From question Person living with MSA 16/ CC 11: How easy or difficult do you find it to contact your GP Practice?

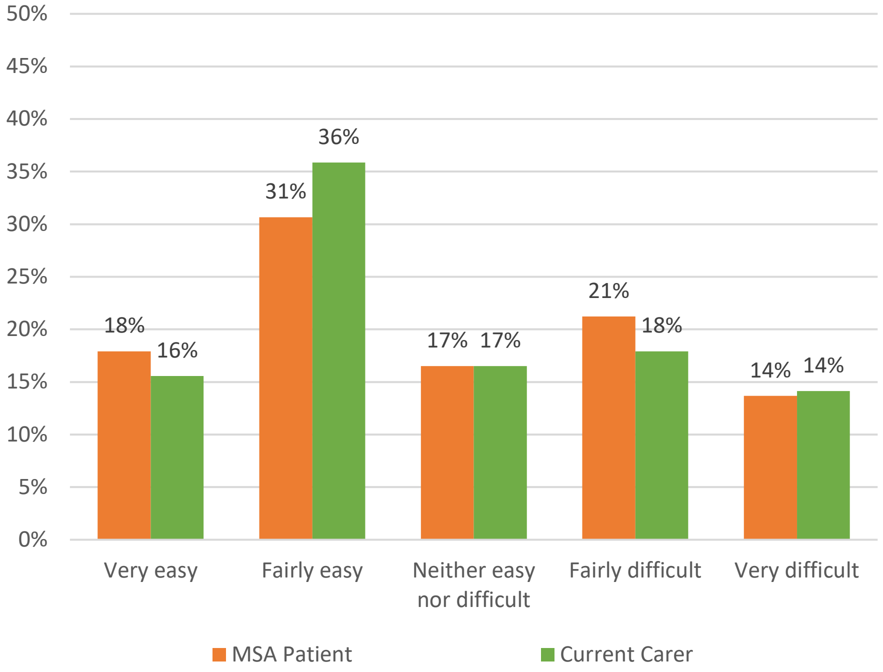

Fig 24. Contacting GP Practice, comparison between people with MSA and carers

3.3.7 Access and challenges getting to medical appointments

Knowing the impact MSA has on the mobility of people affected by the condition, it was important to look into the challenges people with MSA and their carers face when attending medical appointments.

Only 7% (n=14) of the respondents with MSA find it **very easy** to get to their various healthcare appointments. Another 29% of respondents find it fairly easy and more than a quarter (26%) find it neither easy nor difficult to attend appointments. 38% of the respondents find it **fairly difficult or very difficult** to get to the appointment, this is likely due to an advanced stage of MSA.

These results appear similar for carers, with only 8% (n=18) of respondents finding it easy to get to their various MSA healthcare appointments and 35% finding it difficult or very difficult.

From question Person living with MSA 17/ CC 15: How easy or difficult is it to get to your various healthcare appointments for your MSA?

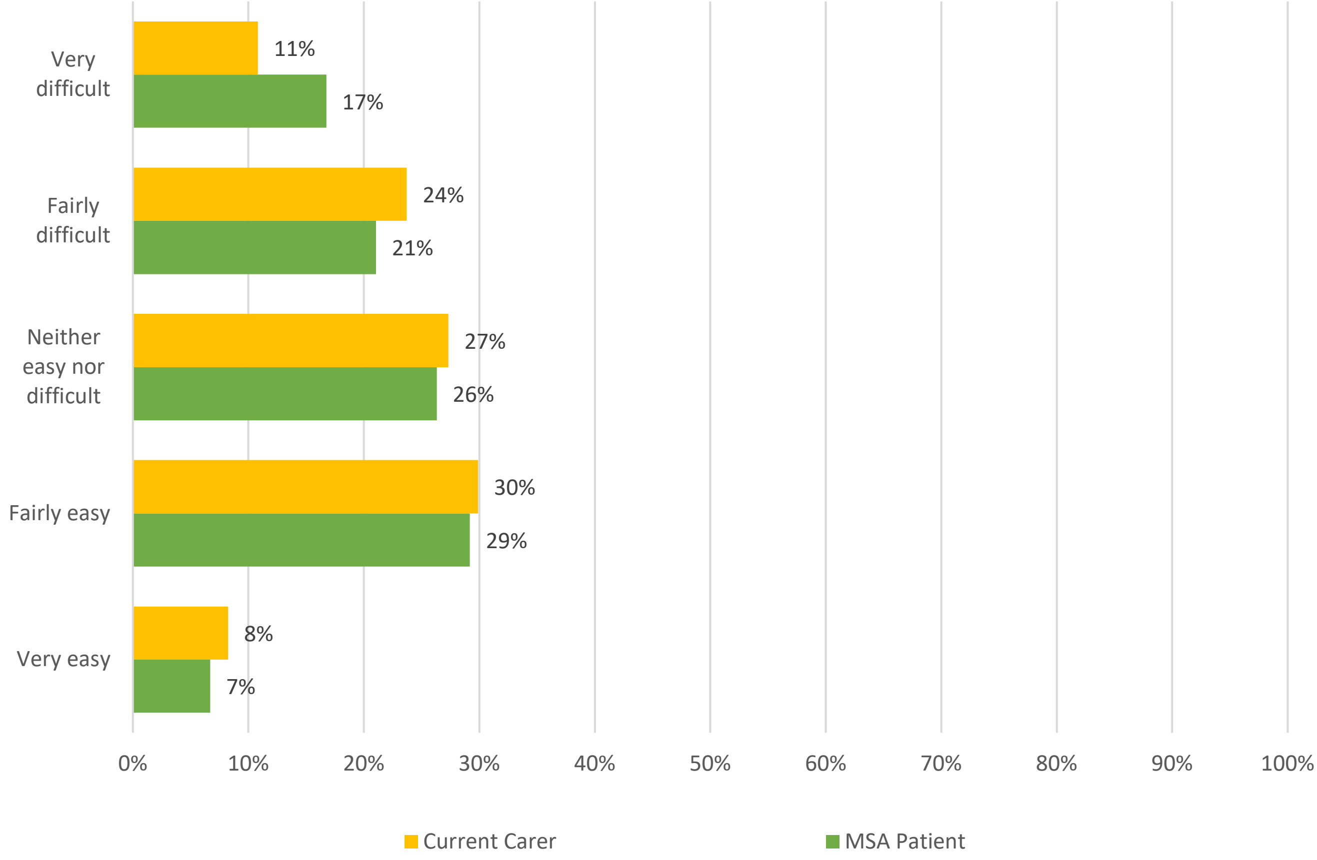

Fig 25. Getting to healthcare appointments

3.3.8 Mobility issues and access to medical appointments

The responses to this survey clearly show that one of the challenges that people with MSA face when going to medical appointments is connected to their level of mobility.

From question Person living with MSA 17/23: How easy or difficult is it to get to your various healthcare appointments for your MSA? and What is your level of mobility?

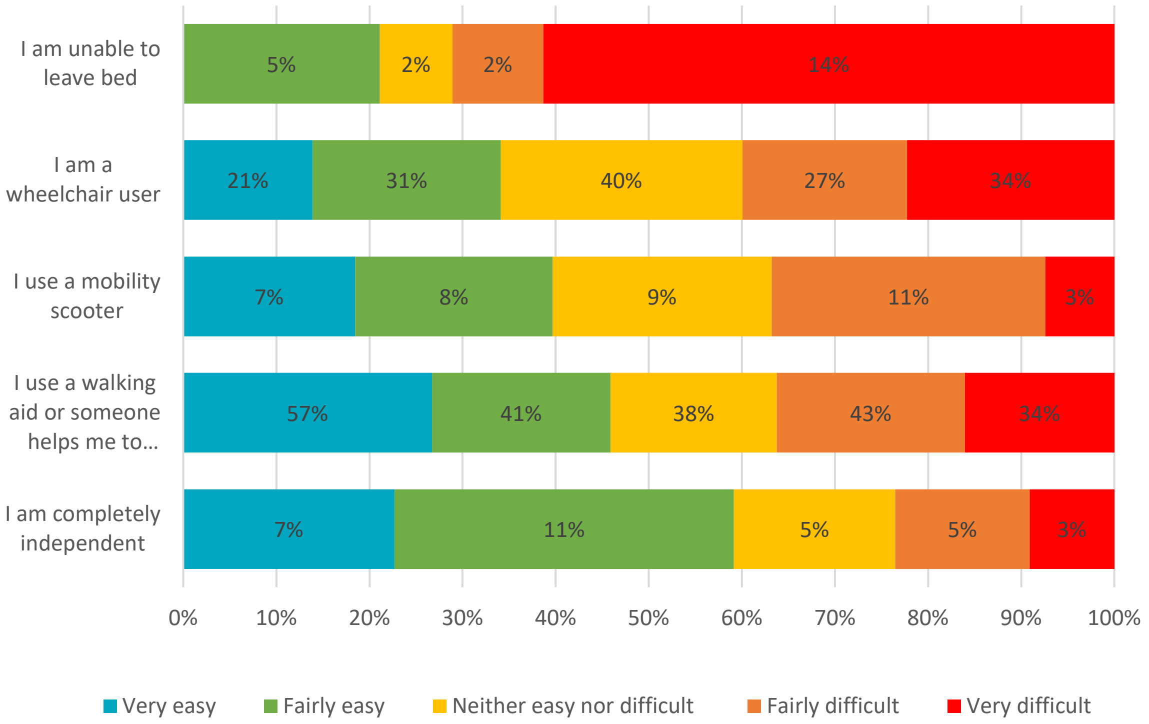

Fig 26. Cross analysis between access to medical appointments and level of mobility

3.3.9 Additional challenges to access medical appointments

When looking at the reasons why people with MSA and carers have challenges with their medical appointments, 97 respondents with MSA (45%) and 69 (32%) carers reported in their own words the issues that they face.

An analysis was carried out and the comments were organised into four main themes:

1. **Lack of or delayed appointments**

People commented how long they need to wait to get a medical appointment and how sometimes they don’t get an appointment at all. This seems to be a challenge across the UK health service in general, particularly after the difficulties presented as a result of the COVID-19 pandemic. However, given the range of appointments that people with a complex condition like MSA need this is clearly an area where effective co-ordination and support would be useful.

“I had to wait a long time to be able to see my incontinence nurse, but she has been very helpful since she has seen me.”

"I don't get appointments."

"It can be fairly difficult as you don't have control over the times of the clinics."

2. Issues with transport

Experiencing mobility problems and fatigue, people with MSA often cannot take public transport. They need to rely on family and friends or other private transport options to go to their medical appointments. There are many challenges related to this such as cost and the length of time taken.

"If I can't get someone to take me I have to get taxi, very expensive."

"My husband has to take me as I cannot drive, use public transport or otherwise travel on my own."

"I have to rely on friends to take me. Patient transport takes a long time and is very tiring."

"Just getting my husband up and dressed presents a challenge which is exacerbated when we have time constraints with appointments, especially if he needs to go to the toilet. Also having to order ambulance transport when I am unable to manoeuvre him into our own car."

3. Mobility barriers

Even with the help of a carer, when MSA is more advanced it becomes challenging to access medical appointments.

"I can't afford a carer in the day, so it can be very difficult to get on my mobility scooter. Occasionally I can't actually do it and have had to cancel the appointment."

"I'm in an electric wheelchair and the ambulance have changed their contact, it is a nightmare trying to order one and I only have to go every 6 months."

"No mobility, require hoist to reposition. Would need stretcher service to attend an appointment."

"My dad can no longer travel, it's too much for him to get into the car so if we want to attend any appointments in Dublin (one hour away from home) we need to get a very expensive taxi, so my dad has stopped attending his appointments in Dublin."

4. Parking

People often complain that disabled parking spaces are insufficient or too far away for them to use.

"More disabled parking!"

"Better/allocated disabled parking spaces."

"Car parking and distance."

"It's a struggle now to get my husband in the car. If I park on the road he can hardly navigate making sure foot is on the pavement as he tries to stand and turn to sit in the wheelchair."

3.3.10 Hospital staff awareness of MSA

Not surprisingly, over two thirds of respondents with MSA (77%, n=104) that have been admitted to hospital for an emergency or planned procedure, have reported that the hospital staff do not understand MSA or the needs a person with MSA can have. More should be done to raise awareness of this condition among the hospital staff so people with MSA or their carers are not forced to explain their condition continually when attending for a procedure and their needs can be more easily met.

3.3.11 Remote medical appointments

Due to the COVID-19 pandemic, remote appointments have become much more prevalent. Respondents were asked about their experiences of remote appointments.

43% of people with MSA reported that they prefer to have in-person appointments. This could be explained as people with MSA who experience subtle changes in their symptoms would struggle to show the progression of their condition in a remote appointment. Speech impairment is another reason why some people with MSA would find it challenging to explain themselves in a remote appointment. Communication is often easier in-person.

However, a further 38% would be open to consider a remote healthcare appointment depending on what the appointment was for. People with MSA face different challenges in accessing medical appointments, such as mobility barriers or issues with transport and attending in person is much more tiring than attending online.

Similar percentages can be observed for the carers of people affected by MSA.
The chart below breaks this down into more detail between the two groups.

From question Person living with MSA 19/CC 17: More health and care appointments are now being delivered remotely (this could be by telephone or video technology). How do you feel about it?

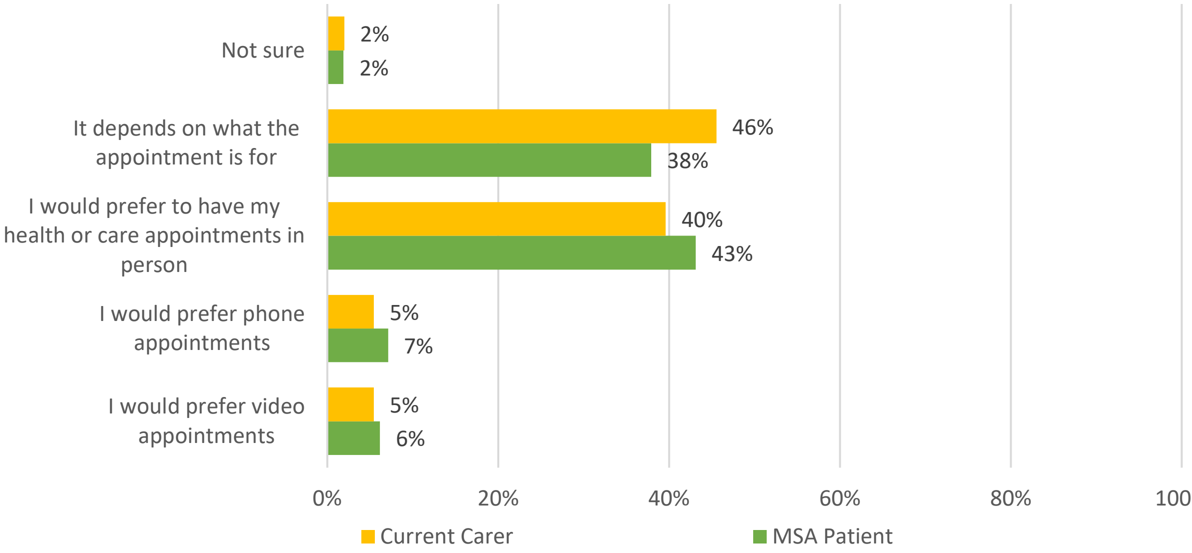

Fig 27. Remote appointments

Some respondents commented on these issues:

“Some issues are minor and can easily be fixed over the telephone, others are more complex and it would be easier to show and be seen.”

“I prefer face to face appointments as I find it difficult being on the telephone due to my speech which isn't always very clear.”

"I am for telephone or video appointments, but sometimes you need face to face appointments too."

"As my husband has bilateral hearing loss and even with hearing aids it is difficult for him to hear so face to face is easier also it gives the clinician an overall view of health issues."

"The changes in my husband's health can be subtle but very significant, for this reason we have requested one to one appointment very recently."

3.3.12 Carer needs recognition at MSA clinics

When attending healthcare appointments with the person with MSA, more than half of the carers (52%, n=106) reported that their needs are not considered and discussed at the clinics.

Only 20% (n=40) of respondents reported that their needs were considered and a further 28% (n=58) replied that they didn't know. Healthcare professionals should consider and support carers' needs at medical appointments by taking into account the impact that caring for a person with MSA can have, both physically and emotionally.

3.3.13 Culture and religious needs recognition

Interestingly, when people with MSA, carers and former carers were asked if their cultural or religious needs had been met by their healthcare professional team, 57% across the three groups noted that it was not applicable or preferred not to say. The reason for this is unclear however some of the respondents reported that they haven't been asked about their religious or cultural needs.

3.3.14 Respondents' comments on the help received

115 carers (54%) and 63 Former Carers (69%) reported in their own words on what is/was particularly good about any help that they receive in connection with MSA. A further 126 carers (59%) and 69 Former Carers (76%) commenting on what can be improved about the help they receive/received and what they feel is missing from their support*:*

An analysis was carried out on what is/ was good about the help carers and Former Carers received. The comments were organised into four main themes:

1. **Home visits and respite care**

With the progression of MSA and increased mobility problems, home visits and respite care become essential for carers.

"I have 2 carers to get him dressed and to put him to bed. I can do everything else etc, I just can't turn him by myself."

"We now have carers to help wash and dress and will soon have carers to come in to prepare lunch although this is something that we have to pay for."

"Carers getting up my husband, washing, dressing and putting to bed."

"I had 2 carers in 3 times a day which I found to be good for the social aspect."

"My home help gives me time to get out and not be restricted to my home."

“S A Hospice have been a god send, they go above and beyond for me and my husband.”

“C S Hospice provided respite care at times, they also provided a day-care centre once a week.”

2. Specialist support

The progression of symptoms requires extra support by specialised healthcare professionals to help carers with the increased needs that the person with MSA has.

“MSA nurse very supportive and good to know she is there if we have any queries. She was very helpful in getting us referred to an MSA specialist.”

“The clinicians and support staff across the board are generally very good indeed. We've certainly had access to the full range of diagnostic testing available.”

“Our very recent experience of help we received from the occupational therapist and speech and language therapist has been excellent. What made it such a positive experience was the initial assessment was in depth, a plan was made going forward and actions were followed through with.”

“Speech therapy, he is now banking his voice on a computer. 2 carers, 4 times a day to help with toileting, showering, dressing.”

“All of our key therapists, specialist nurses etc. have left no stone unturned to try to find answers and to make Richard as comfortable, independent and safe as possible.”

“The occupational therapy team are a godsend. I would not have coped without them.”

“We were given CHC funded care which was organised by our neurologist expert which gave up to four visits a day to help with care. Local GP was always on hand for advice when needed.”

“Couldn't fault all the care my husband was given from all that were involved with his care.”

3. Equipment

Suitable equipment to help with mobility issues, lifting or general care are often commented on by the respondents.

“We have received good wheelchair and home instalments for chair lift, etc. I think these things are put in place to keep my dad at home for as long as possible, which is a real strain on the whole family.”

“The physio's get the right equipment for us, like lifting equipment, transfer chairs etc.”

“The NHS has provided so much help for us. Wheelchairs, Electronic Assistive Technology, slip sheets for the bed as well as care and medicine.”

“Equipment for my husband.”

“W… provided excellent wheelchairs, including electric model.”

4. Information and the MSA Trust

The MSA Trust is considered to be a source of reliable information and support by people with MSA and their carers.

“The MSA Trust are very supportive and we're glad that we've got involved with them.”

“I was also able to find out information about financial help through the MSA Trust.”

“Having the Trust to help is very reassuring, knowing you have always got a nurse specialist who will be able to help you and advise, and the zoom calls are excellent.”

“Being 'successful' with MSA depends on putting in a lot of effort to find out information and advocate for the seriousness of the condition. The MSA Trust are an invaluable resource.”

“It's all a bit haphazard and dependent on that person who goes the extra mile. MSA is an unmagical mystery tour and requires input from a myriad of sources and often you don't know what or whom you need. Enter The MSA Trust who are there for you at whatever level you want. In particular, the MSA nurse is your support and guide through the horrible MSA maze.”

An analysis was carried out on what can improve /could have improved the help carers and Former Carers received. The comments were organised into four main themes:

1. Lack of information and practical advice on MSA

Respondents commented on the lack of information available on MSA and training or guidance on issues that arise daily.

“Think the illness needs to be explained more.”

“More of an understanding of MSA and all the issues and healthcare needs.”

“Hard to know where to begin. I need help and guidance in helping my wife's movement especially at night. It would be good to have someone to talk to about issues that arise daily.”

“Some training in the practical aspects of caring would be helpful. Lifting, dressing, helping with personal needs etc.”

“The actual day to day care required is rarely discussed, yet this is the major part of both of our lives.”

“There is no continuity. No information is provided I have had to google for information and argue or fight for everything.”

“I need some training. I have injured my neck and back lifting and pulling my partner. I have asked if there is a course or if someone can teach me how to do it safely without hurting myself and I was told to look at YouTube. I don't think this is satisfactory. I wish someone would take the time to show carers how to do things without causing yourself damage.”

2. Specialist services and HCP knowledge of MSA

Frustration was expressed by the respondents on the lack of MSA knowledge healthcare professionals have when supporting a person affected by the condition.

“We feel that the Ambulance Service needs to have a greater awareness of the problems of MSA and to give a higher priority to any calls made”

“More contact with the neurologist who specialises in MSA - we have had no contact since MSA diagnosis. We have many questions to ask but despite all contacts for an appointment we have not been given one and this has been going on for 4 months!”

“GP doesn't understand MSA.”

“The services need a greater understanding of the condition. Instead of me telling them what it's about.”

“MSA is a rare condition. I don't think our overworked neurologist consultant had any knowledge of MSA. He did not distinguish it from Parkinson's and did not prepare us for how the disease would progress. It took

around 6 months to get even basic information about Parkinson's after initial consultation, by which time I was already aware of the likelihood of MSA."

3. Benefits and respite information and support

Lack of respite care was often brought up by the respondents which, even when available, is often self-funded. Also, it was commented on the lack of clarity around how to access financial help.

"What I would like in an ideal world is occasional respite care for my husband. As he is only young, going into a care home with elderly people would not suit. It would also be good for him to get some mental or physical stimulation. I would just love to go to bed when I want to, without all the time spent getting him ready and put into bed. Not being woken up at night. To get up when I want not when the bed is wet or he is getting frustrated. I'd also occasionally like to eat more normal food as I normally cook very soft food. On a day-to-day basis it would be wonderful if you were able to book a two hour time slot for a carer depending on your needs on a certain day. E.g., Going to the dentist, haircut, they are not on a regular weekly basis but just an occasional need."

"We only wanted limited help with care because of cost and too much would have broken the bank to soon. The total bill for one carer 3x a day (total 1 3/4 hours) for 6 1/2 years £110,000 so far in money."

"Currently 4 hours care. More hours of care but can only be resolved when deputyship is given (COP)."

"Opportunities for respite care"

"More advice on Financial support and where to get help and look for help."

4. Carer physical and emotional needs.

It's clear that caring for a person with a progressive condition like MSA has a huge impact emotionally and physically on the carer.

"Mutual Carers conference call is a good idea. Could I further suggest from experience that if you are going to form sub-groups the attendees within each stay the same throughout. Over time the initial reticence to share thoughts and concerns lessens as individual's familiarity with each other within the sub-group grows and deeper held feelings are sometimes revealed. I have experienced this first hand."

"I need help to get a little more rest and to deal with the emotional issues that we both face."

"I feel the need for couple counselling as this is the biggest issue to affect our relationship. I was given the details of the Rare Minds organisation which has offered counselling."

"I need to have someone to talk to about how I feel and how I am coping.

"For someone to look after him for a couple of hours a week to give me a break."

3.3.15 Conclusions

People living with MSA

Specialist Support

- Except for Neurologists, and MSA Trust Nurse Specialists, there appears to be a significant issue surrounding the lack of specialist support offered to people affected by MSA across the healthcare profession.
- GPs, in particular, appear to have a lack of knowledge and the ability to provide appropriate support for people living with MSA and their carers'. This is not uncommon with rarer health conditions.
- Hospital staff are also rated poorly when managing patients affected by MSA. Training should be considered to make the patient's stay as comfortable as possible.

Healthcare appointments

- Three fifths of people with MSA are moderately to very happy with their experience of clinic appointments.
- However, knowing the impact MSA has on the mobility of people affected by the condition, we looked at the challenges people with MSA face when attending physical medical appointments. Only 7% of the respondents found it very easy to get to their various healthcare appointments. Lack of, or delayed, appointments, issues with transport, mobility barriers and parking were the main problems reported.
- When asked what could be improved, the most common response was better coordination, frequency of appointments, and better access to clinics. Additionally, there is a desire from individuals with MSA to not be rushed during appointments, due to mobility and speech problems.
- Following the COVID-19 pandemic, remote appointments have become common practice. 43% of people with MSA reported that they prefer to have in-person appointments. This could be due to people with MSA having subtle changes in their symptoms and thus would struggle to show the progression of their condition in a remote appointment. However, a further 38% would be open to the prospect of a remote healthcare appointment depending on what the appointment was for.
- A high percentage of respondents did not answer when asked if their cultural and religious needs were met by the healthcare professionals. One reason reported was that respondents were not asked by the HCP. We feel that HCPs should be encouraged to ask about their patients or carers' cultural or religious needs so they can be met.

Current Carers

Specialist support and GPs practices

- Broadly in line with the results of people living with MSA, current carers confirmed they are mainly supported by Neurologists and MSA Trust Nurse Specialists but not so much by their GPs.
- Carers reported GPs having a lack of knowledge and the inability to provide support for them and for people living with MSA. This is, again, typical with rarer health conditions.

Healthcare appointments

- Similarly, carers face the same challenges when helping the person they care for to go to healthcare appointments with only 8% (n=18) of respondents finding it easy to access them. Relying on others, mobility issues, delayed appointments, and access to premises, were the main issues experienced by carers.
- Remote appointments have become common practice due to the COVID-19 pandemic. Like people with MSA, a similar percentage of carers prefer to have in person appointments. Interestingly more than two fifths would be happy to have a hybrid approach when the condition allows.
- In healthcare appointments it is vital that the needs of carers are considered alongside the needs of the person affected by MSA. Unfortunately, more than half of carers (52%, n=106) reported that their needs are not considered, nor discussed, at the clinics.

Additional support received and unmet needs

- Carers reported how invaluable the support they receive from healthcare professionals is. Home visits, respite care, specialist support, suitable equipment, and the vital help from the MSA Trust, can make a huge difference to the day-to-day life of carers.
- When asked what could be improved in the support received by healthcare professionals, respondents commented on the inadequacy of information available on MSA, training to remedy the lack of knowledge some health professionals have of the condition, the lack of respite care available and the lack of consideration for the carer's physical and emotional needs.

Former carers

Clinical support, GPs practices and hospital staff

- Similarities can be drawn between the information that what was reported by people with MSA, carers and Former Carers. Former Carers confirmed they were mainly supported by Neurologists and MSA Trust Nurse Specialists at the time of caring for the person with MSA - but not so much by their GPs.

Healthcare appointments

- Broadly in line with people living with MSA and carers, a high percentage of Former Carers did not respond when questioned whether their cultural and religious needs were met by healthcare professionals.
- Carers reported on GPs having a lack of knowledge and their inability to provide support for them and for people living with MSA. This is again not unusual with rarer health conditions.

Additional support received and unmet needs

- As with current carers, Former Carers praised the support they received at the time of caring for their loved one. Home visits, respite care, specialist support, suitable equipment, and the help from the MSA Trust were regarded highly.
- Broadly in line with what was reported by current carers, Former Carers confirmed the scarce information available on MSA, healthcare professionals' lack of knowledge on

the condition, insufficient respite care available and the lack of consideration for the carer’s physical and emotional needs.

3.4 Physical Impact

3.4.1 Impact of symptoms before and after diagnosis

Due to the nature of MSA, and its effect on the autonomic functions of the body, multiple symptoms are experienced by those with the condition.

We looked at how symptoms affected people before diagnosis and afterwards. Problems with mobility were most widely reported, especially before diagnosis with this worsening post diagnosis. The chart below breaks this down in more detail.

Every person living with the condition had experienced mobility issues and 96% had experienced difficulty with breathing and swallowing/speech. Out of all of the symptoms discussed, pain seemed to be the least often experienced with 29% only experiencing pain since diagnosis and a further 28% had never had pain.

It's not a surprise that carers and Former Carers experienced great difficulty with helping the person with MSA to manage their symptoms before and after their diagnosis. Mobility problems, falls and problems breathing were reported as the most difficult to handle. The difficulties were higher among the Former Carers. This is likely due to Former Carers supporting people a later stage of the condition than many of the carers surveyed.

From question Person living with MSA 22a: Before diagnosis, how affected were you by the following symptoms?

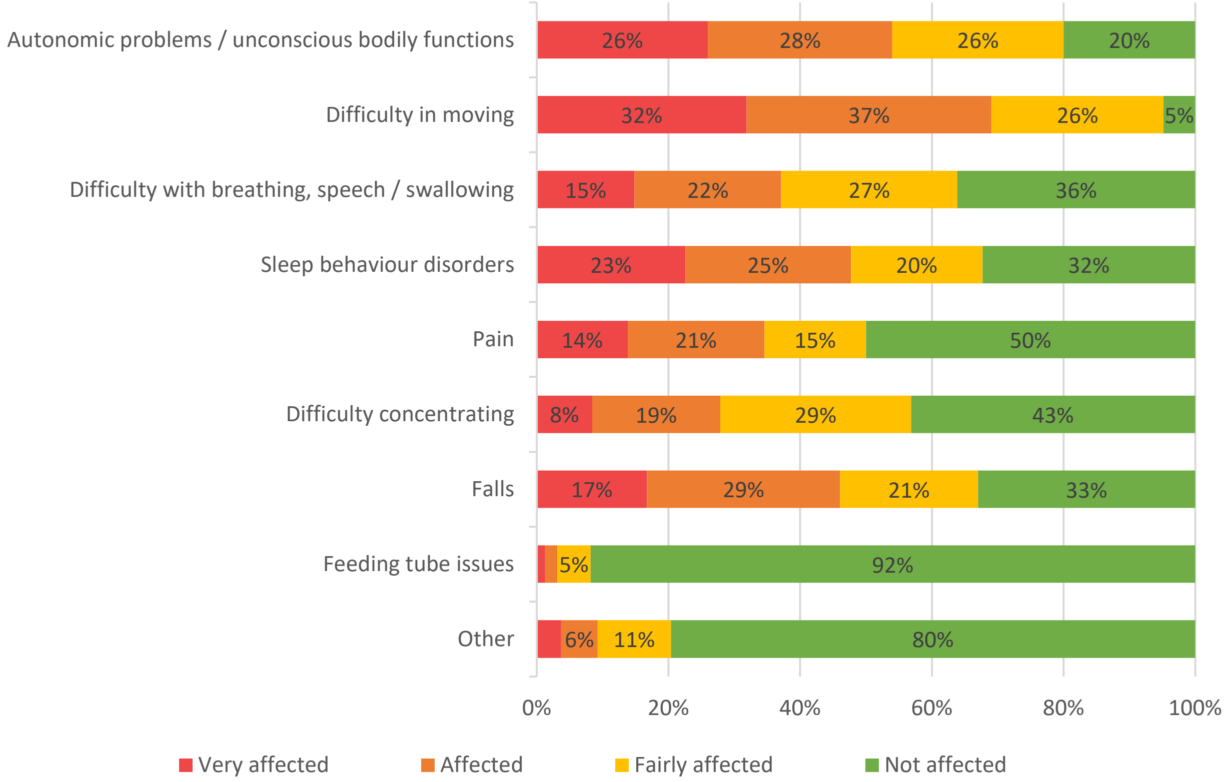

Fig 28. Impact of symptoms before diagnosis

From question Person living with MSA 22b: After diagnosis, how affected are you by the following symptoms?

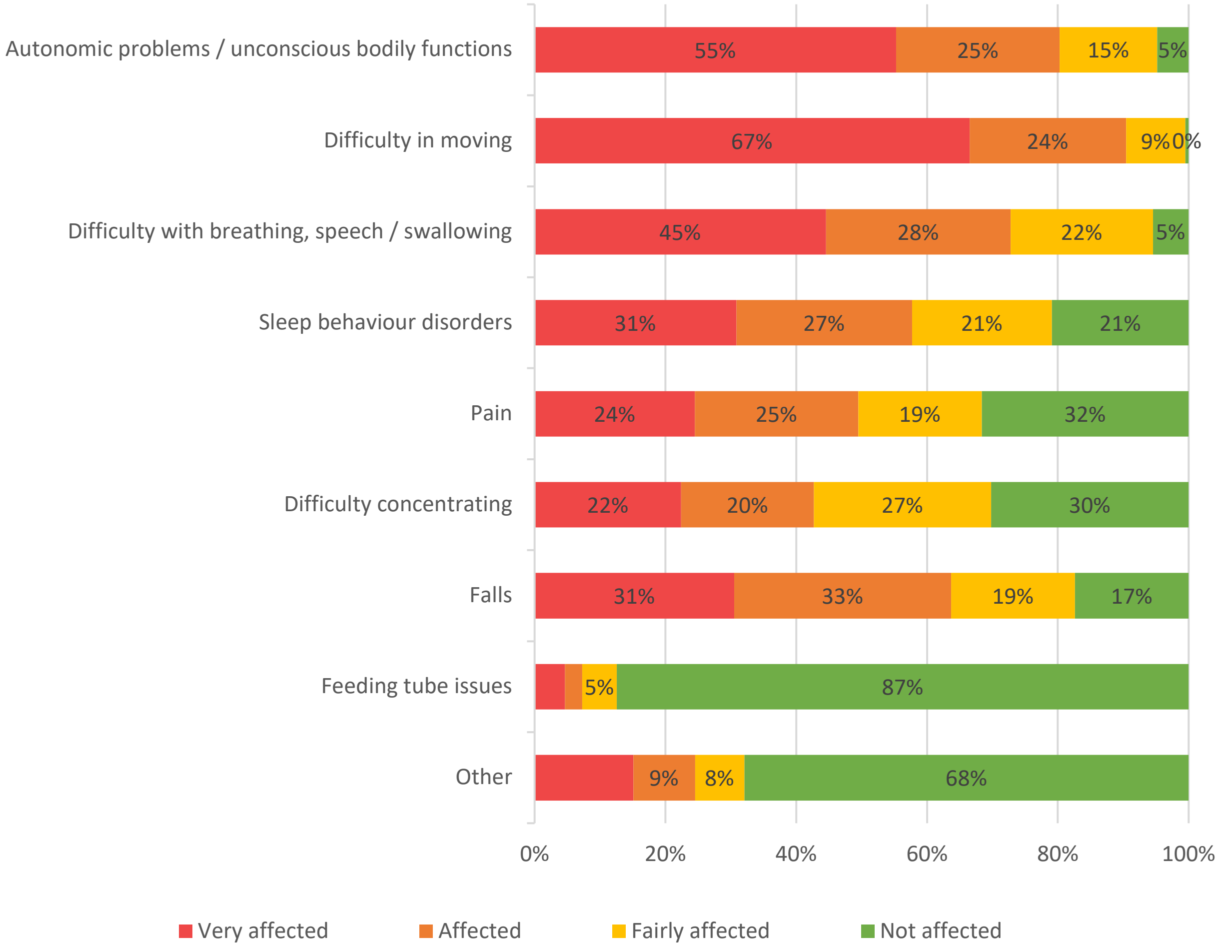

Fig 29. Impact of symptoms after diagnosis

3.4.2 Levels of mobility

The data clearly shows the significant negative impact living with MSA has on the level of mobility of the respondents and the deleterious effect on their quality of life.

Only 8% of respondents with MSA reported being completely independent. The vast majority (87%, n=174) need a walking or mobility aid to move around, depending on the stage of MSA they are at. A further 6% are unable to leave bed.

From question Person living with MSA 23: What is your level of mobility?

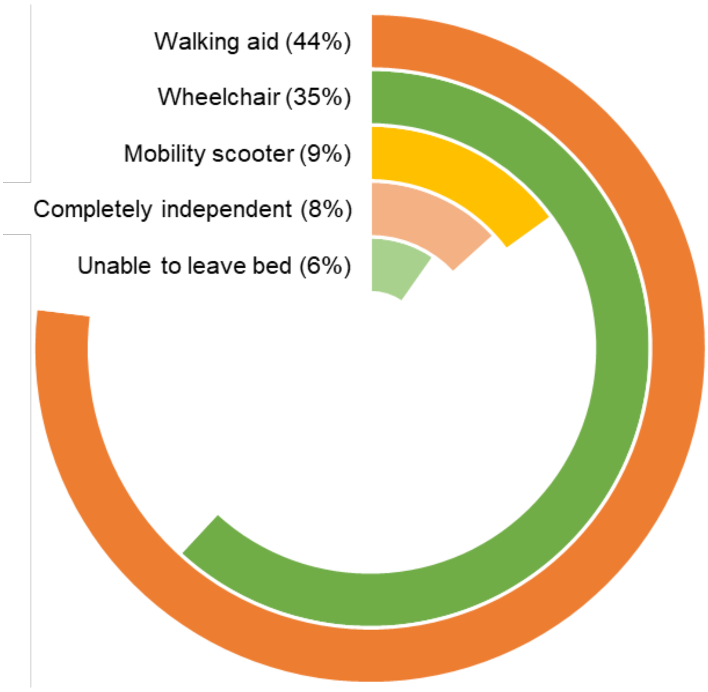

Fig 30. Level of mobility

A further analysis was carried out on the level of mobility of the respondents and the support received from the local council to support their needs. Sadly, even when the respondents' mobility had declined and they were using a wheelchair, 34% reported they were still not eligible for any funded care.

From question Person living with MSA 23/41: What is your level of mobility? and Has your local council / social services assessed your care and support needs to see if you are eligible to receive funded care or support?

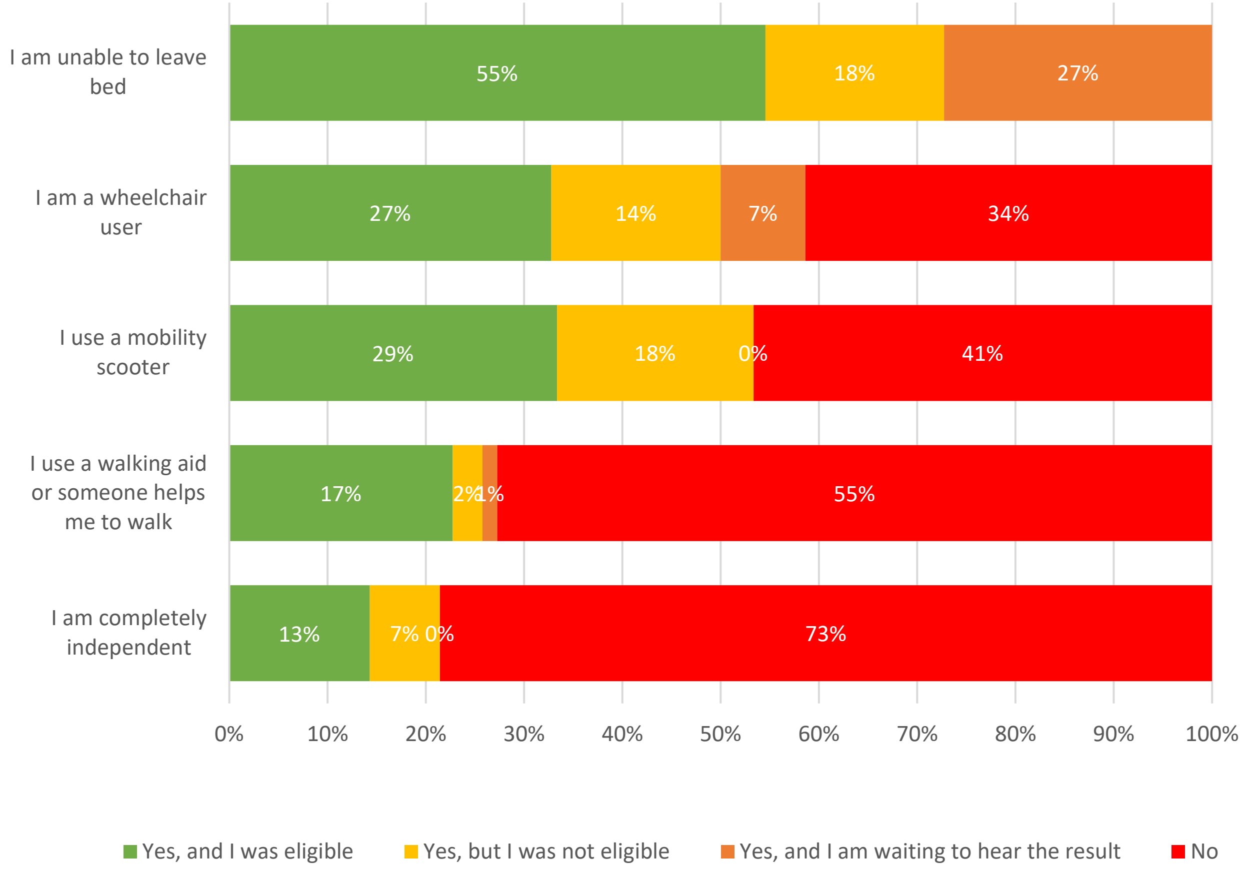

Fig 31. Level of mobility versus local council assessment

3.4.3 Length of time between first symptoms and impact on mobility

This survey provides a challenging picture around the speed it takes from the first appearance of MSA symptoms to the significant impact on the mobility of the person affected.

Only 22% of respondents reported being completely independent in the first two years since the appearance of the symptoms. The percentage decreases drastically to just 4% after six years. After seven years half of the respondents are using a wheelchair, 42% use a mobility scooter and 8% are unable to leave bed. When we consider the length of time people have symptoms before diagnosis and the fast progression of the disease this must be a challenging and emotionally draining time for people and their carers.

From question Person living with MSA 23/2a: What is your level of mobility? and Number of years since symptoms

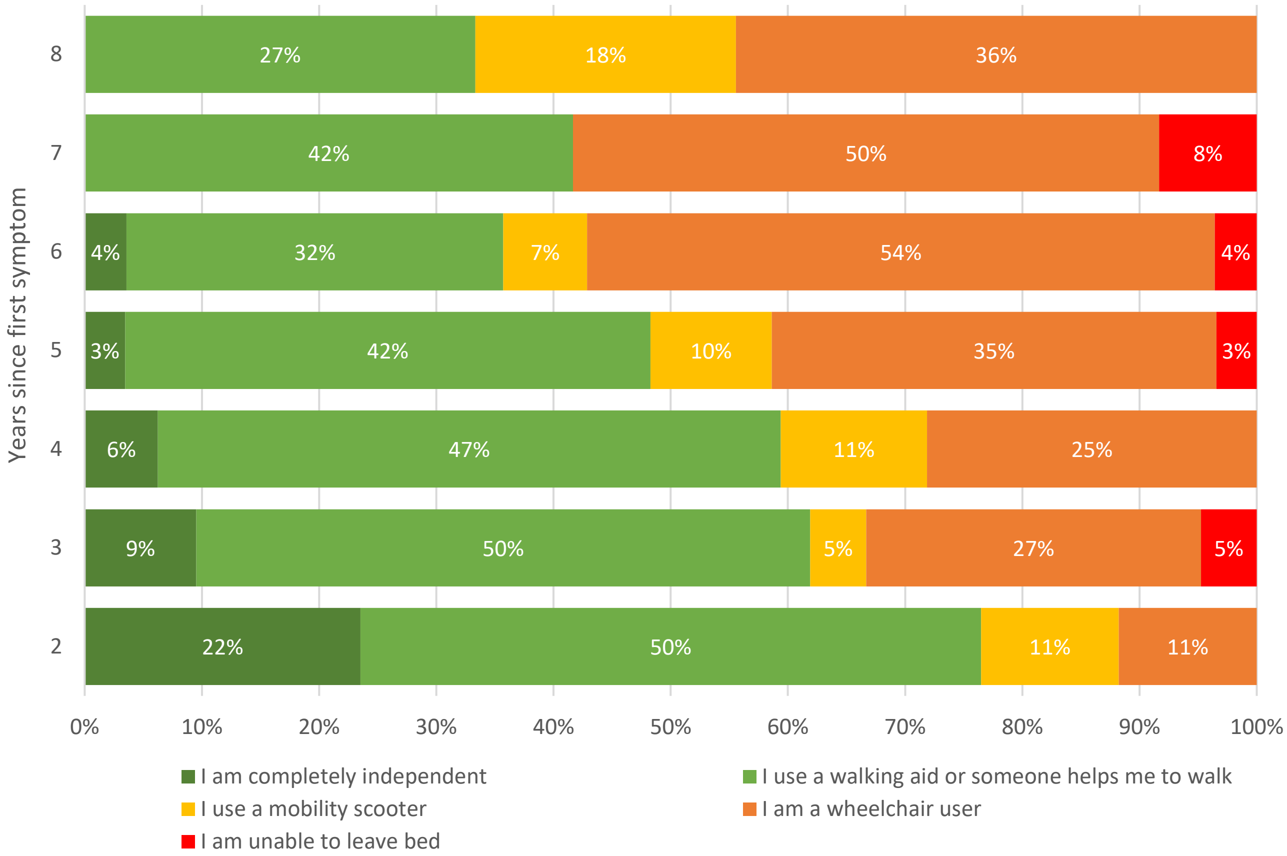

Fig 32. Cross analysis of number of years since first symptoms appeared and impact on mobility

3.4.4 Age band and impact of mobility

When comparing the age of the respondents with MSA to their level of mobility, there are not many significant differences that can be seen regardless of the age band. The only exception is people that are unable to leave bed, which is more prevalent at an older age.

From question Person living with MSA 23/65: What is your level of mobility? and Your age band

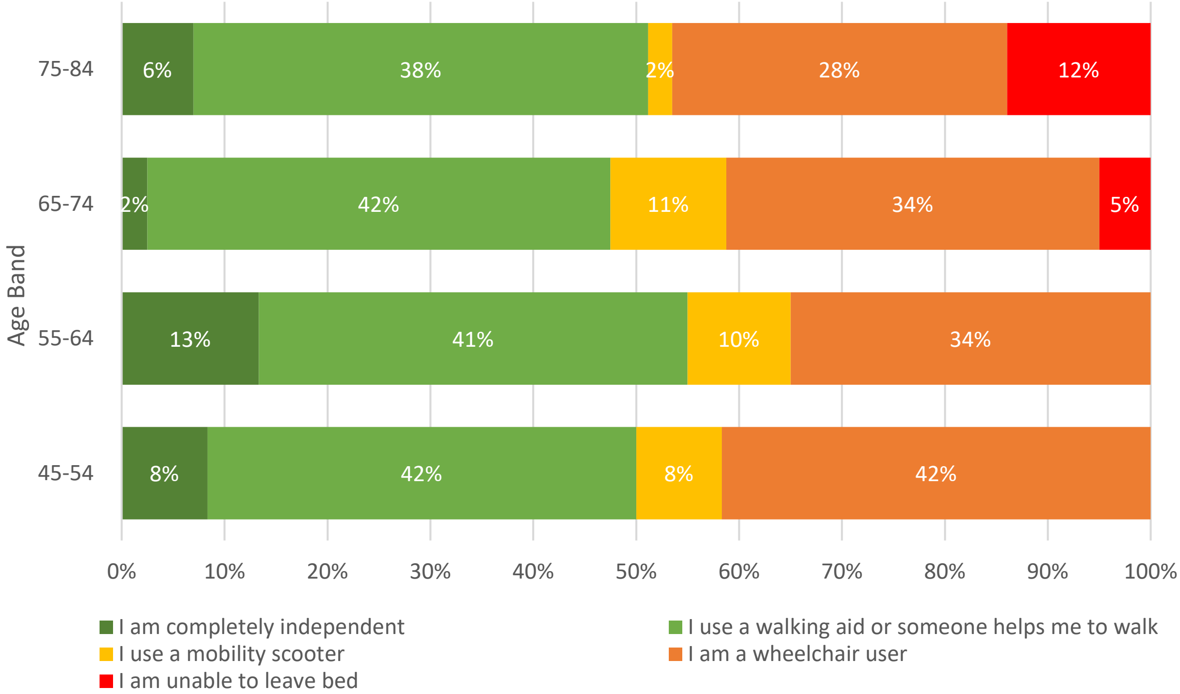

Fig 33. Cross analysis between age band and impact on mobility

3.4.5 Level of independence and quality of life of people with MSA

Due to the nature of MSA, only 5% (n. 10) of the respondents stated they were completely independent, whilst 19% (n. 39) were restricted to a bed or chair.

All respondents taking part in this survey stated that their quality of life had been affected by the condition. Most people (73%, n.157) reported that their quality of life was impacted severely by MSA. Just 5% (n.11) of the respondents reported that MSA affected their quality of life only slightly. The results are broadly in line with those seen in 2019.

From question Person living with MSA 39: How would you describe your current level of independence?

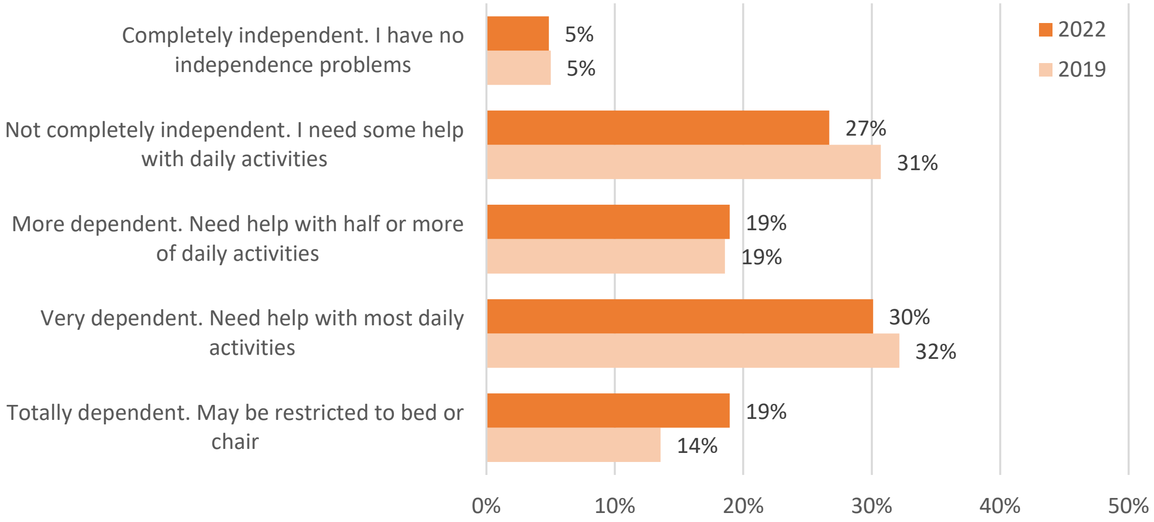

Fig 34. Current level of independence

From question Person living with MSA 40: To what extent does having MSA impact on your overall quality of life?

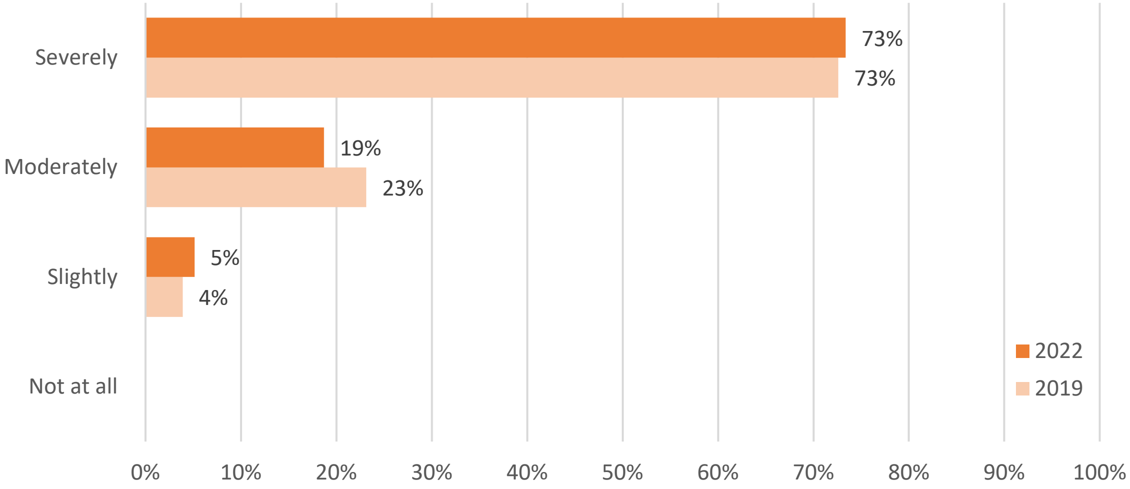

Fig 35. MSA impact on quality of life

64 respondents (30%) with MSA commented further as to what extent MSA has impacted on their quality-of-life.

“Can't do household chores, frustration levels through the roof.”

“Social life no longer exists. Very experienced ballroom dancer and now unable to visit grandchildren and great grandchildren.”

“It affects every aspect of my life, from the second I wake up I constantly think about it. I can't ever forget about it as it affects everything from trying to turn over and get out of bed as it's difficult to move, my speech, my swallowing, my walking, my balance and coordination and it has made me incontinent. It is just going to get worse, but the worst thing is that it is making my family suffer too which is extremely difficult.”

“My granddaughter has forgotten what fun we had. I can no longer drive. I used to be a brownie leader - I can no longer do that. My hobbies of walking and gardening I can no longer pursue.”

3.4.6 Treatments to help with MSA symptoms

Of the main treatments to help with symptoms associated with advancing MSA, urinary catheters were the most reported (31%, n=61). 12% of the respondents (n=22) used some kind of ventilatory support and a further 7% (n=13) used a feeding tube. 1% (n=2) had a tracheotomy.

From question Person living with MSA 24: Do you currently have any of the following medical aids?

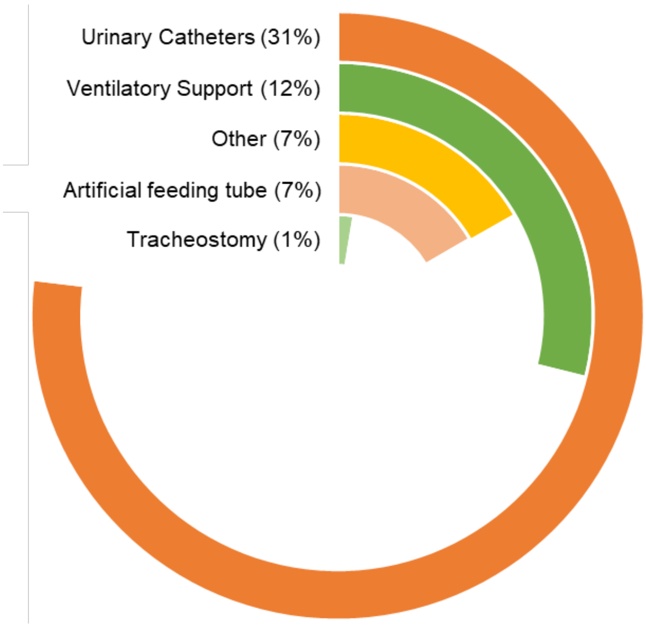

Fig 36. Main treatments to help with symptoms associated with MSA

3.4.7 Support received for physical needs

When asked to rate the help they receive for their physical health needs, 44%(n=87) of the respondents with MSA reported that the help they received was poor to very poor (rated 5 or below). This is of real concern as we have seen how dramatically affected the physical health of people with MSA is.

3.4.8 Support received by carers to help with MSA physical needs

When asked if carers receive support managing some of the physical symptoms experienced by the person they are caring for, the chart below demonstrates the lack of support that many receive. In particular, over one third reported a lack of help in moving and managing the falls of people with MSA. The chart below breaks this down in more detail.

From question CC 22a: Do you receive support to help the person with MSA manage any of the following symptoms?

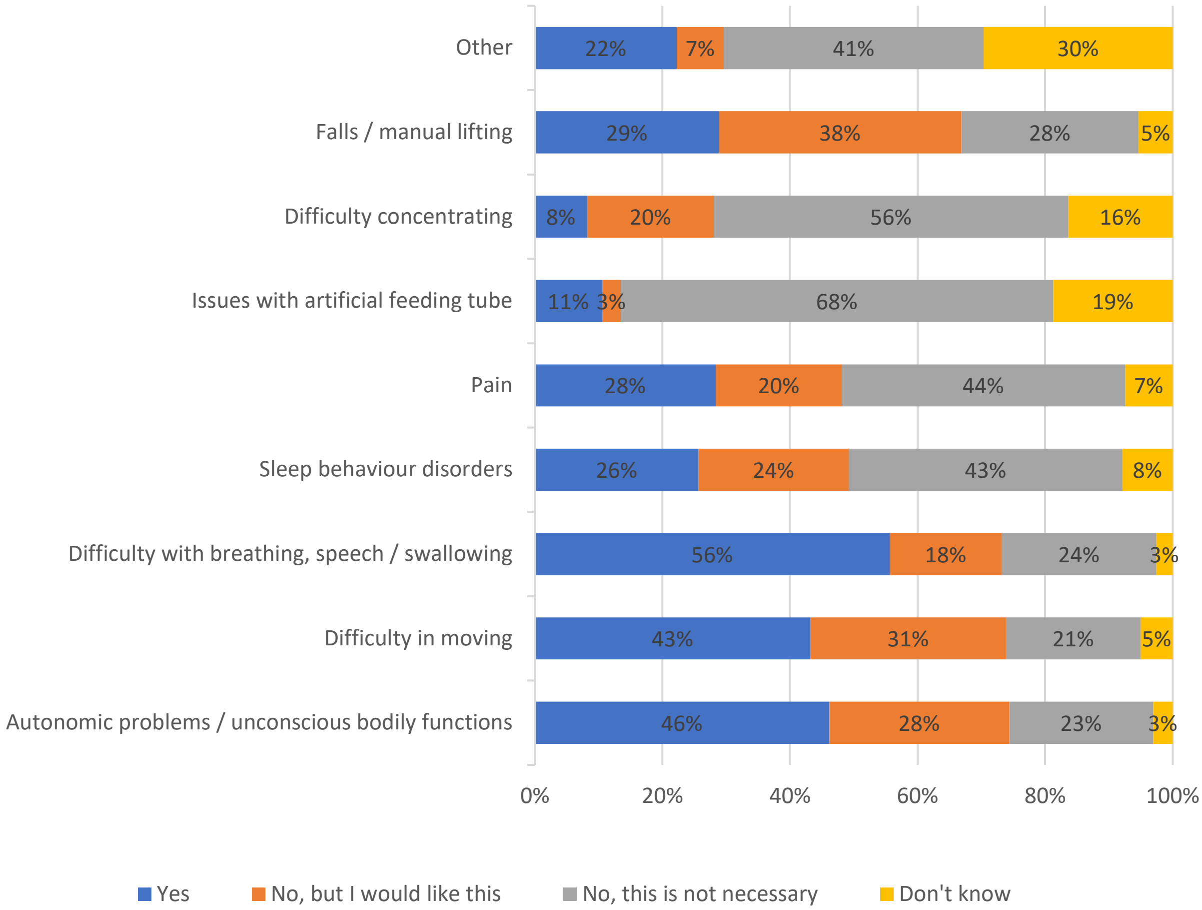

Fig 37. Support received by the carer to manage physical symptoms

3.4.9 Support received by Former Carers to help with MSA physical needs

Little over half of the Former Carers (54%, n=45) stated that they received sufficient support when they found some MSA physical symptoms difficult to manage. However, 36% (n=30) of the Former Carers didn't feel supported with some of the physical needs the person with MSA experienced such as bowel and bladder problems, choking episodes and lifting/falls.

"My husband gained weight due to his inactivity which made lifting him very hard."

"Falls/ fainting where he would end up on the floor having no easy access to help get him up."

“I had great difficulty at times trying to manage my wife's choking episodes especially during the night. She often declined to go to A&E Department as they were not familiar with MSA.”

3.4.10 Physical impact of MSA on carers and Former Carers

Most of the respondents have clearly been physically affected by the impact of looking after a person with MSA. Almost all (89%) reported experiencing **Fatigue/ Tiredness**.

The most common other symptoms were: **Physical Inactivity** 43% and **Back Pain** 41%.

From question CC 23/FC 18: Does caring for the person living with MSA impact on your own physical health in any of the following ways?

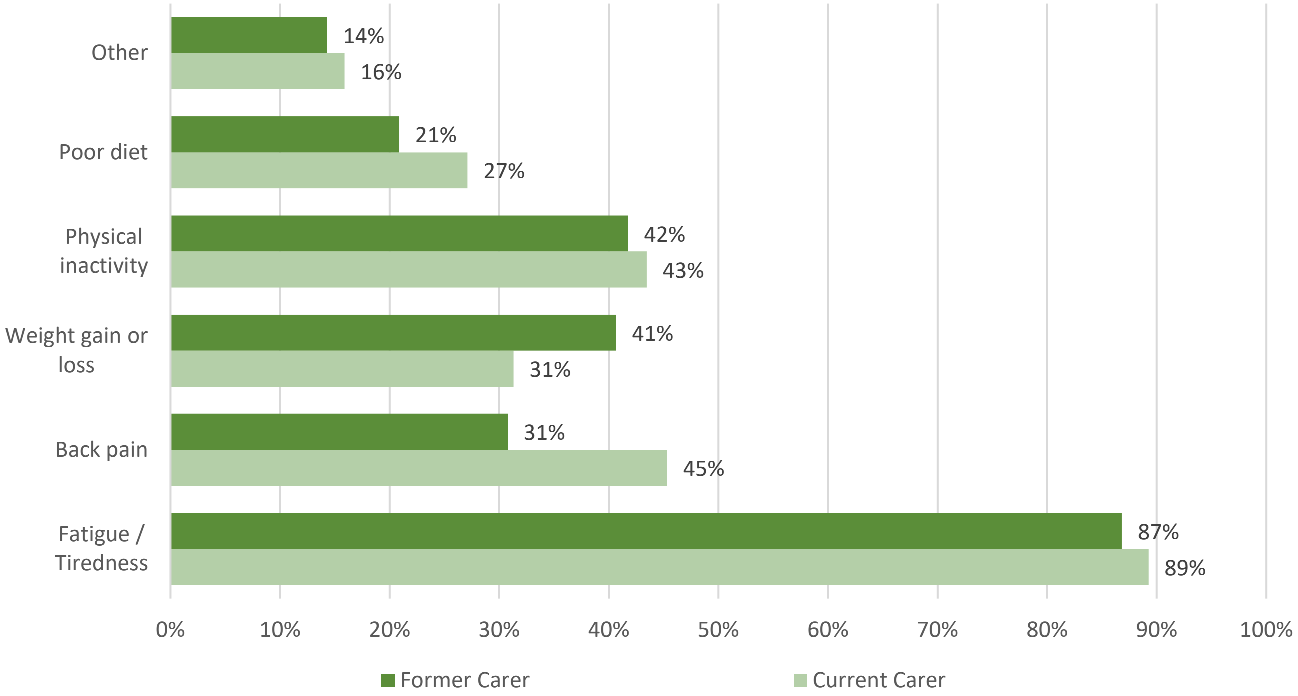

Fig 38. Impact on carers’ physical health

Current carers and Former Carers commented on the issues in their own words, split below into three themes:

1. Physical impact of MSA on carers

Looking after a person with MSA is exhausting, often causing physical injuries.

“The extreme tiredness of coping with being 'on call' 24 hrs a day, even with twice daily input from carers, is debilitating.”

“Physical manual handling has caused injury to shoulders. Exhaustion is causing huge problems with our personal relationship.”

“Doing the same tasks day after day does impact greatly of my health as I can't get out for exercise and feel very trapped and concerned that my health has deteriorated. Just try not to think about it.”

“Super hard. He is very heavy. He drives all his weight into me just to help him transfer. Getting him out of bed, lifting his legs, everything is super hard and I'm realising I am less patient now because it hurts me and I'm tired.”

2. Increasing physical demands at a later stage of MSA

As MSA progresses, carers and Former Carers experience increased physical demands that are often overwhelming and worrying. The most difficult tasks reported were: lifting a person with MSA after a fall, getting in and out of bed and physically moving the person around the house coupled with the worries on how to handle choking fits.

"The main issues I worry about dealing with are primarily falls and breathing/choking issues. Broken sleep and fatigue are a secondary issue."

"Every day is a challenge and get more challenging with time. Most difficult thing is lifting wife up from floor after falls. And her total inability to keep herself safe. My mind can't or won't compute that she simply can't think safely first. This is getting worse. I'm frightened that my health will deteriorate one day and I won't be able to cope with her."

"It's becoming more difficult for me to be the only person caring for my husband. I dress him, help him on and off the loo, feed him. Catheterise him day and night it is exhausting. I feel isolated something."

"It is very hard to get my wife into and out of bed. Also cleaning her is a real problem."

3. Concerns on how to cope

The progression of MSA inevitably brings concerns on how they might be able to cope later with the increased needs*:*

"I am currently just about managing to cope with my husband's physical issues but I know these are going to get worse, I worry that as the condition progresses I will not be able to cope."

"I worry about how we will cope later on when the symptoms are much worse."

"Currently we have private carers for about 25 hours per week. I need more help however, private carers are very expensive. Also the carers have limitations in what they can provide."

This suggests that not only does MSA have a progressive impact on the person with the disease but there is a progressive worsening impact on their carer as well, both in terms of their physical but also their mental and social wellbeing.

3.4.11 Conclusions

People living with MSA

Disease progression, level of mobility, and level of independence

- As MSA advances, so do problems with mobility and autonomic functions of the body. Multiple symptoms can be experienced, with subsequent need for physical support, such as walking aids or wheelchairs often progressing until the respondent is unable to leave their bed.
- This survey provides a challenging insight into the length of time it can take from the first appearance of MSA symptoms in the individual until significant impact on their mobility. After seven years, half of the respondents needed a wheelchair and a further 8% were unable to leave bed.
- With the progression of MSA, the individuals' level of independence is greatly impacted, with an increased need for support from carers and a range of healthcare professionals, and a deterioration in quality of life.
- Sadly, two fifths of people with MSA reported the help they receive for their physical health needs is poor.

Current Carers

The demands of care and the future progression of the disease

- Current carers experienced difficulty helping the person with MSA to manage their symptoms. Mobility problems, falls and problems breathing were reported as the most difficult to handle.
- Unsurprisingly, looking after a person with MSA, particularly at an advanced stage, has a detrimental physical effect on carers with many reporting a number of physical effects on their health and wellbeing.

Support received

- The support received by carers to manage the physical needs of the person they are caring for they feel is generally poor. In particular, over one third of carers reported a lack of help in moving and managing the falls of people with MSA.
- The future demands of caring is a big concern for carers, especially regarding how they will cope physically and financially with the increasing needs of the person that they are caring for.

Former Carers

The demands of care

- The difficulties experienced by Former Carers were greater when helping the person with MSA to manage their symptoms. This is likely due to Former Carers dealing with people at a later stage of the condition than many of the current carers surveyed.

Support

- More than one third of Former Carers stated that they didn’t get sufficient physical support when looking after the person they cared for.

3.5 Emotional impact

3.5.1 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, the effects of living with a rare neurological condition, or as a direct result of being given a terminal diagnosis. However, with the previously documented impact of the physical symptoms of MSA, it is likely that this is at least a partial cause of psychological distress.

Unsurprisingly, fatigue is experienced by 89% of the respondents living with MSA with 72% experiencing times of low mood/depression, 58% experienced anxiety and a further 55% reported experiencing stress. The chart below shows in more detail how people with MSA suggest that they have been affected.

From question Person living with MSA 26: How affected are you by any of the following issues

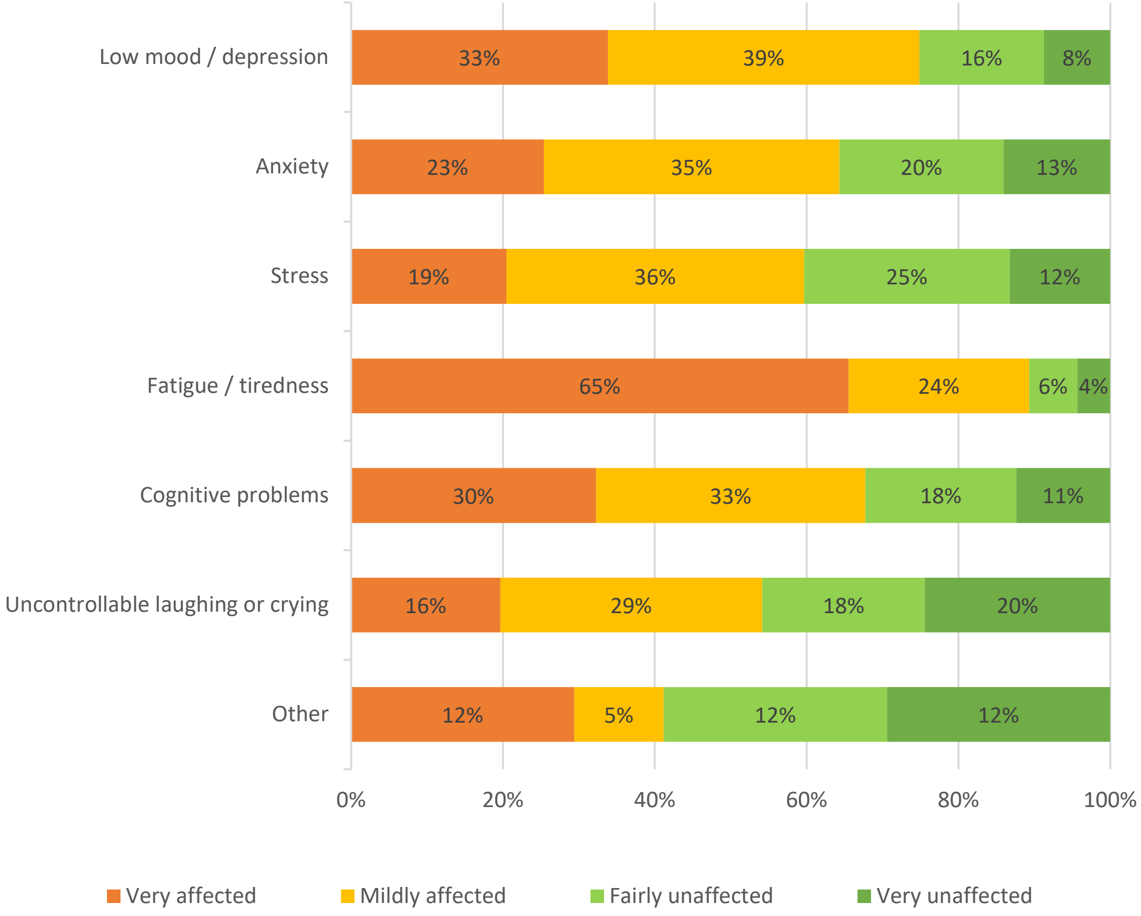

Fig 39. Impact of MSA on emotional wellbeing

A further analysis was carried out to identify at which point during their journey psychological issues had been experienced. Unsurprisingly, people with MSA have reported that they experience low moods, depression, or feeling hopeless, throughout their condition with 50% of respondents experiencing this feeling even before diagnosis. The majority of people reported a significant impact on their mental wellbeing at diagnosis (77%) and in particular when their symptoms worsened (85%).

*From question Person living with MSA 26/32: How affected are you by any of the following issues (**low mood, depression**) and When would you have most valued support for your mental wellbeing?*

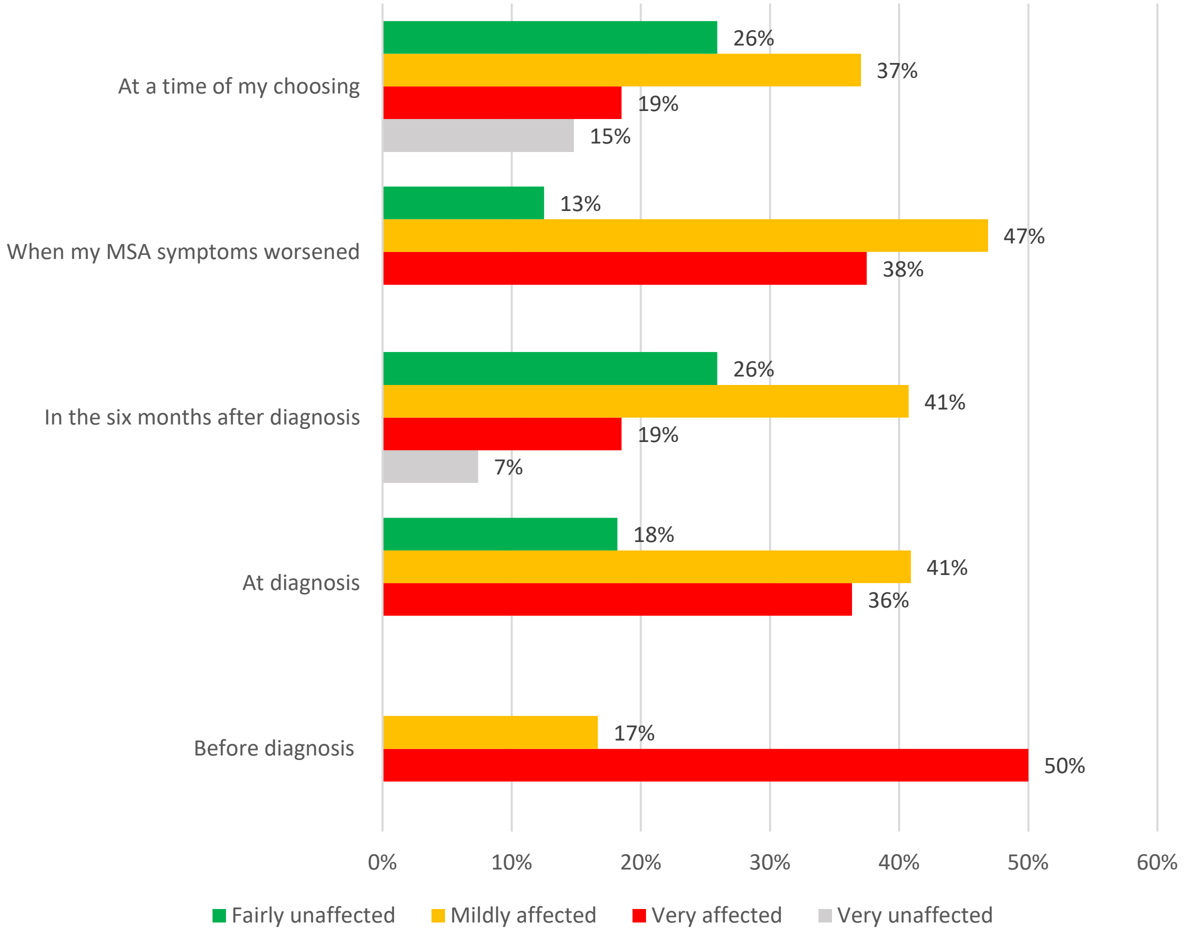

Fig 40. Low mood/ depression experienced throughout the patient's journey

3.5.2 Timing of support for mental wellbeing

Of the respondents with MSA 26% (n=52) reported they would most value the support for their mental wellbeing **throughout** the different stages of MSA. Only 17% (n=35) said that they didn't need it.

From question Person living with MSA 32: When would you have most valued support for your mental wellbeing?

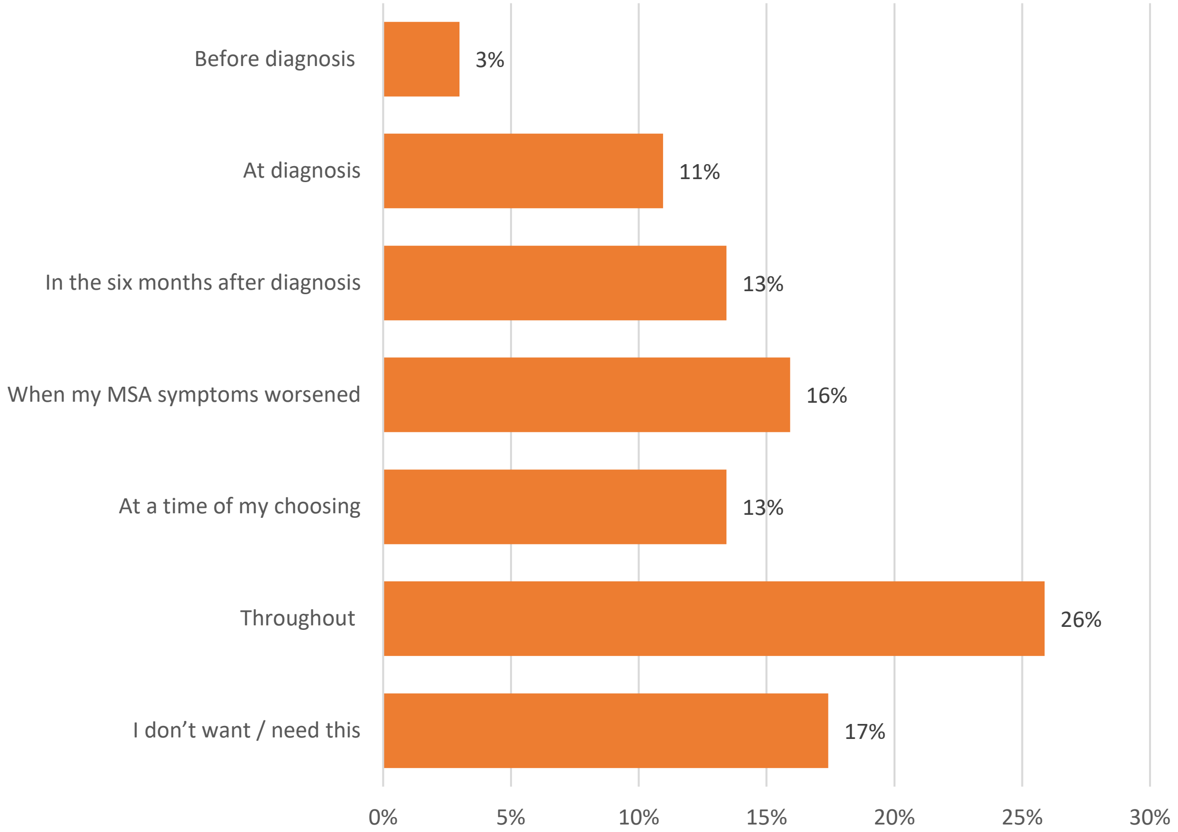

Fig 41. Desired mental wellbeing support throughout person's MSA diagnosis

3.5.3 Rating of the help received by people with MSA for their emotional needs

Not surprisingly considering the answers to the previous sections, of the respondents with MSA taking part in the survey, 63% (n=125) rated the help that they have received for their emotional needs as poor (rating the help as 5 or below out of 10).

From question Person living with MSA 33: On a scale of 1 to 10, how would you rate the help you receive for your emotional needs?

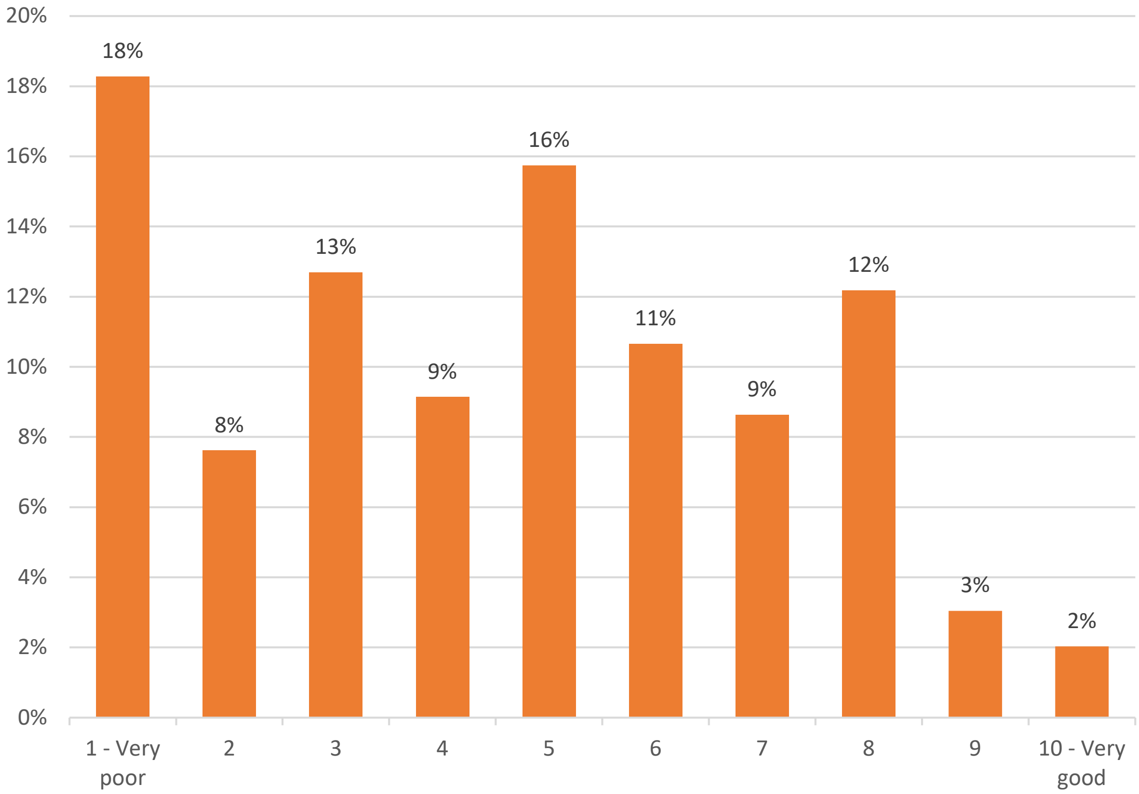

Fig 42. Rating of support for emotional needs

3.5.4 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 also shows serious impact). Over one third of respondents (35% n=72) reported that their relationships with their friends were negatively affected with 80% (n=164) of respondents reporting their contact with others deteriorated contributing to their feeling of isolation.

With all the listed relationships, at least some respondents reported these getting better. This is the case for some personal and family relationships. The reason is not clear from this survey however it could be related to relationships getting closer in the case of adverse events and spending much more time together focused on their MSA journey.

The chart below shows in more detail the impact of MSA in personal relationships, with the data broadly in line with results from 2019.

From question Person living with MSA 27a: To what extent do you feel the following are affected as a result of living with MSA? Personal relationship (e.g., partner / spouse)

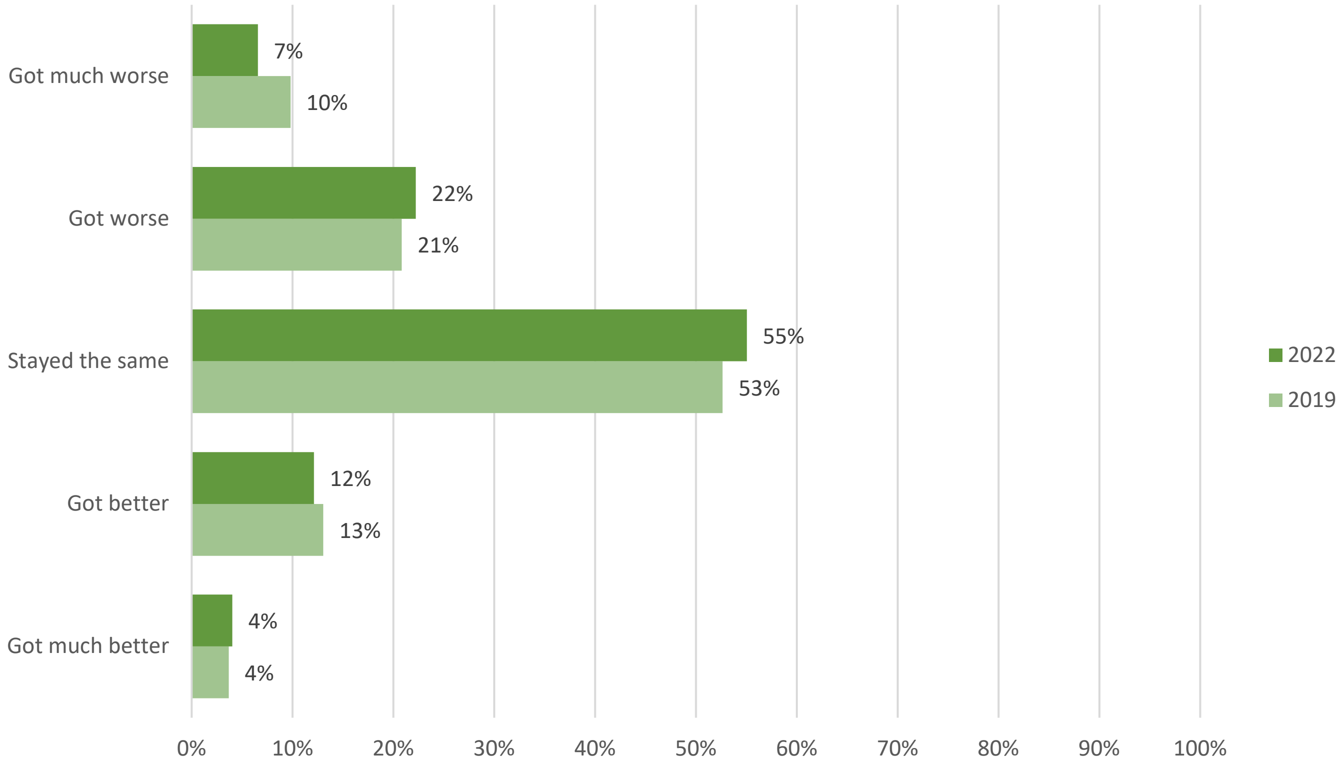

Fig 43. Changes in personal relationships

3.5.5 The impact of MSA on relationships and quality of life

To understand the impact MSA's progression has on relationships and the quality of life for people living with MSA and their carers, further analysis was carried out.

In line with the aforementioned results, personal and family relationships appear to remain stable regardless of the deteriorating quality of the life of the person with MSA. However, **relationships with friends and social activities** were greatly affected as their MSA progressed, increasing the feeling of isolation and abandonment people affected by the condition have.

From question Person living with MSA 40/27d: To what extent does having MSA impact on your overall quality of life? and To what extent do you feel the following are affected as a result of living with MSA?

Social activities / reduced contact with others

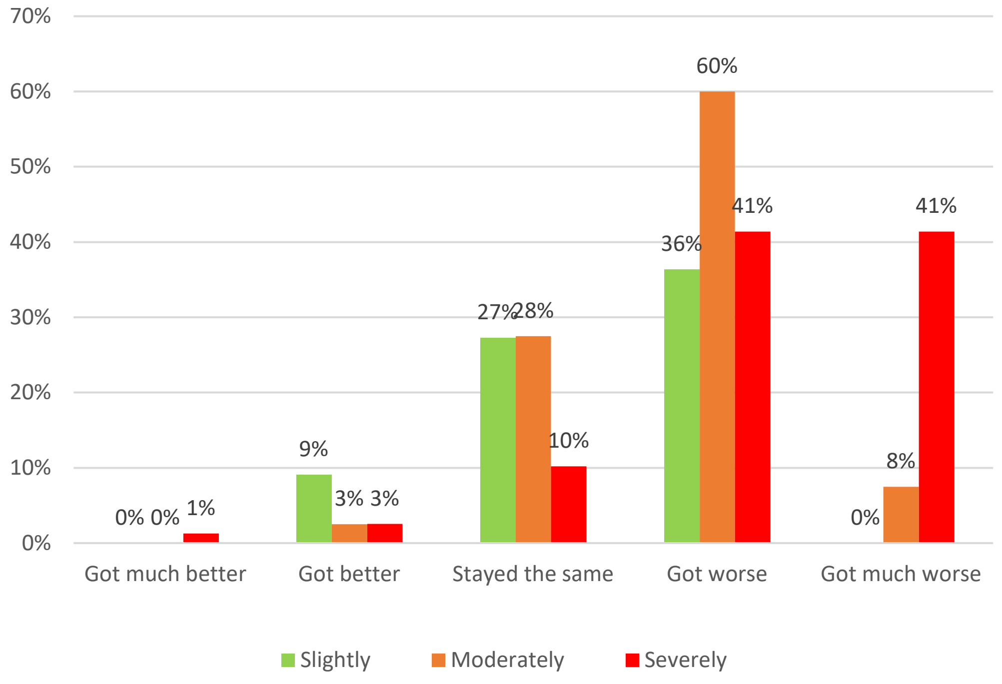

Fig 44. Changes in personal relationships with severity of MSA on quality of life

3.5.6 Impact on activities of living with MSA

The majority of the respondents stated that MSA has stopped them from being able to do things they most enjoy or from starting new activities. 82% (n=177) of the respondents reported mobility issues as one of the main problems.

From question Person living with MSA 28: Which of the following, if any, stop you from being able to do the things you enjoy, or from starting new activities?

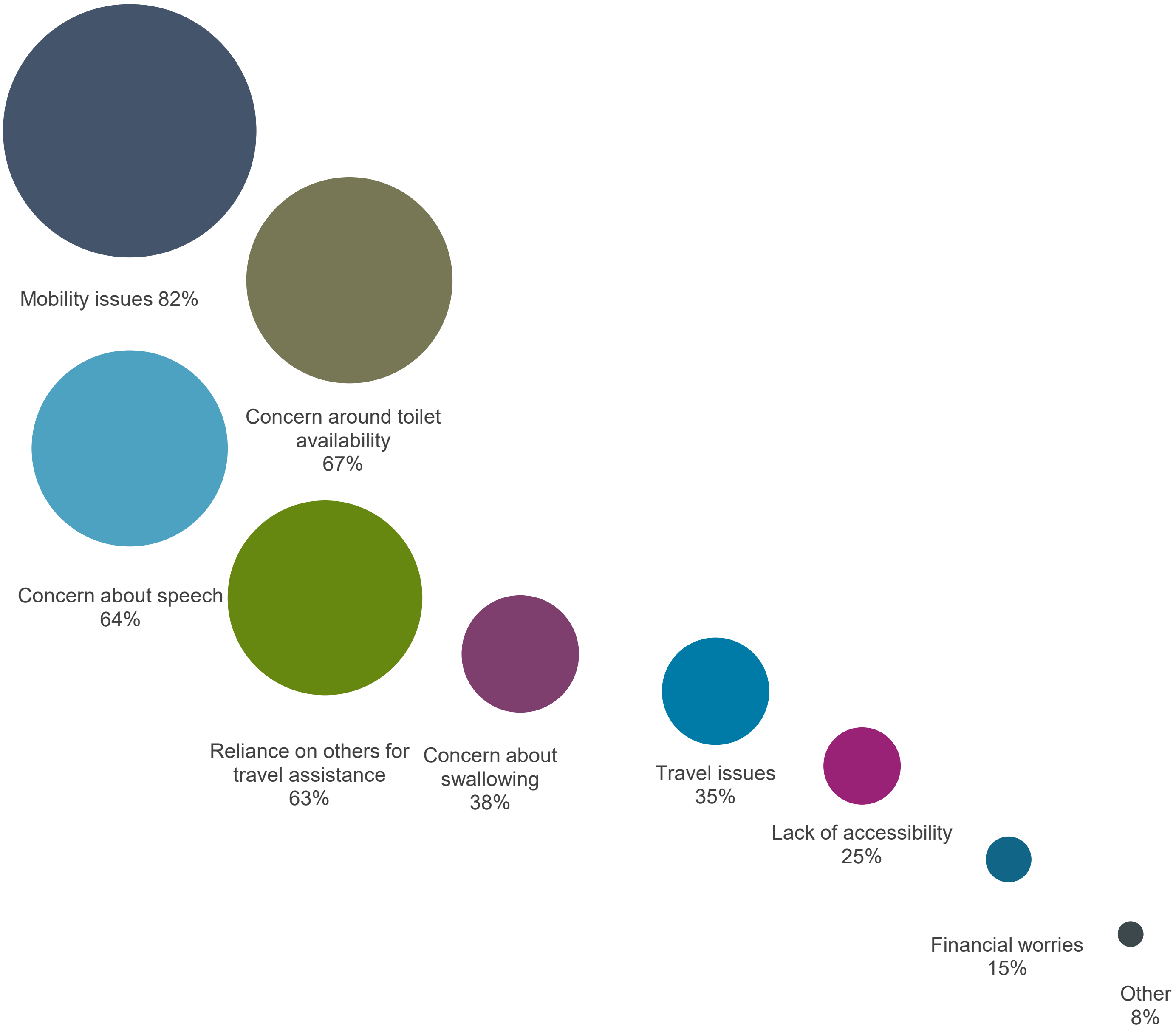

Fig 45. Impact of MSA on activities

3.5.7 Emotional support received by the person with MSA from healthcare professionals

When carers and Former Carers were asked if the person affected by MSA had received the emotional support they needed from healthcare professionals or psychological services, only 4% among the carers and 9% among the Former Carers thought this was the case. Nearly half of carers (45%) reported that no help was offered. This is a worrying picture that show clearly how the emotional impact of MSA is too often neglected by the healthcare system.

From question CC 28/FC 22: Do you think the person you care for gets the emotional support then need? This is referring to emotional support from a healthcare professional / psychological service and not the emotional support you may provide

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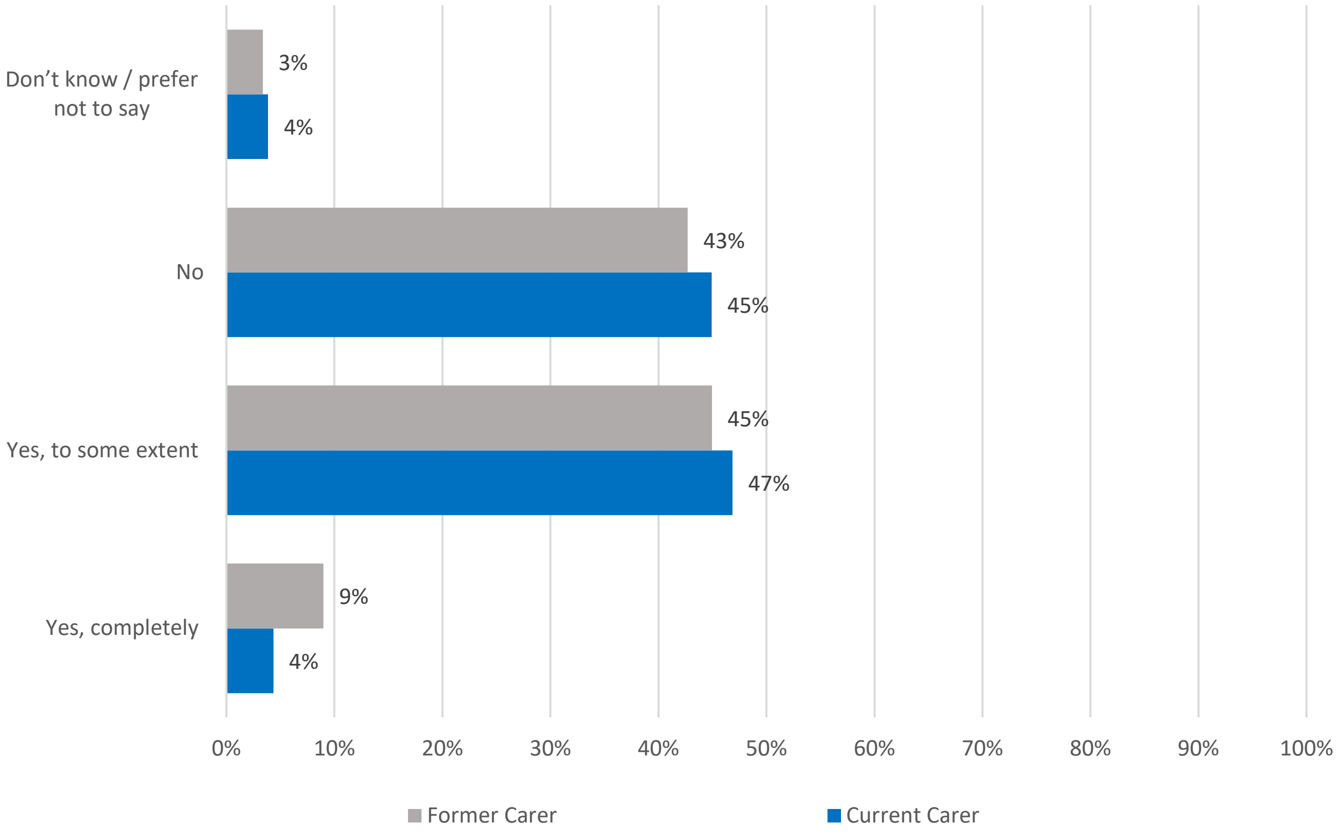


Fig 46. Emotional support received by the people living with MSA from healthcare professionals

3.5.8 Psychological issues experienced by carers and former carers of people with MSA

Caring and supporting someone with MSA has an emotional impact on carers and Former Carers who report being affected by anxiety, depression and social isolation. Below are some comments from the respondents.

"I became sometimes angry and frustrated at all the red tape and not being able to go to one place or person to find the help we needed."

"Loss of fulfilling career and friends. Some people abandoned us, others great at coming."

From question CC 25/FC 20: Does caring for the person living with MSA impact on your own emotional health in any of the following ways?

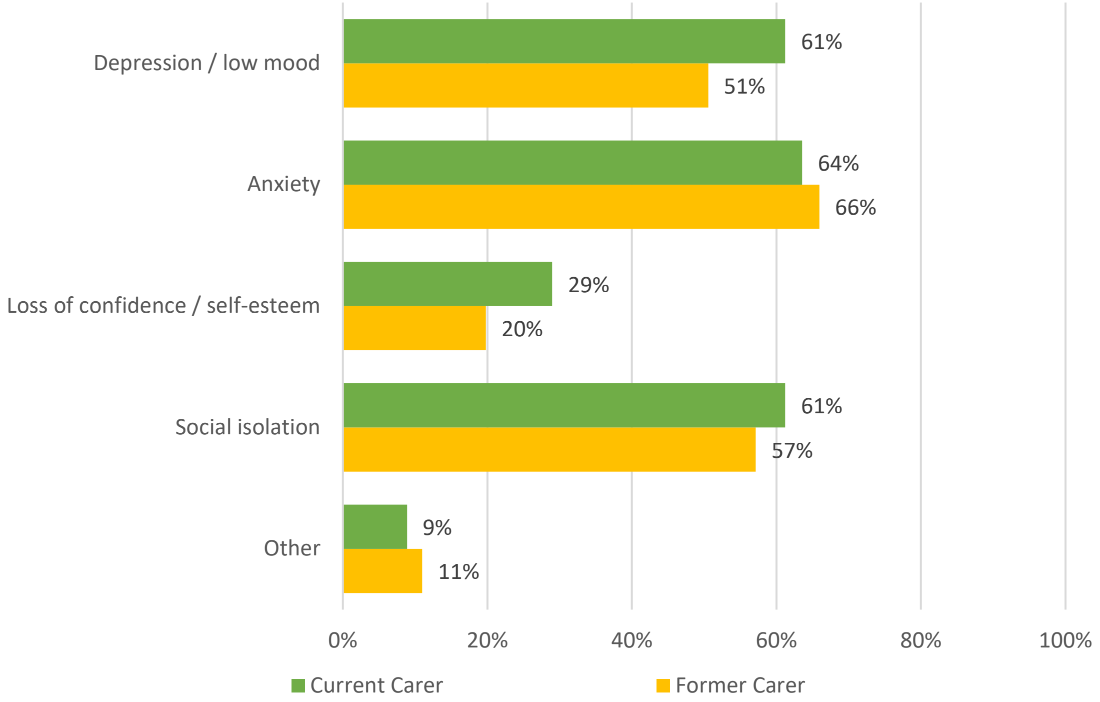


Fig 47. Impact of MSA on carer's emotional health

3.5.9 Impact on relationships caused by caring for someone with MSA

Understandably, MSA has an impact on different aspects of the carers' life as well as people living with the condition. Carers and Former Carers report that **relationships with friends** and their **social activities** are negatively impacted and there is an increasing **feeling of isolation**. Interestingly, and in line with the results of people with MSA, some respondents reported that their personal and family relations got better.

Again, here it is likely that carers are spending more time with close family as a result of the diagnosis and receiving a terminal diagnosis focuses them on family. The nature of MSA also means that inevitably carers will have less time for other relationships and social activities.

From question CC 35/FC 29: To what extent overall were the following affected as a result of caring for someone with MSA?

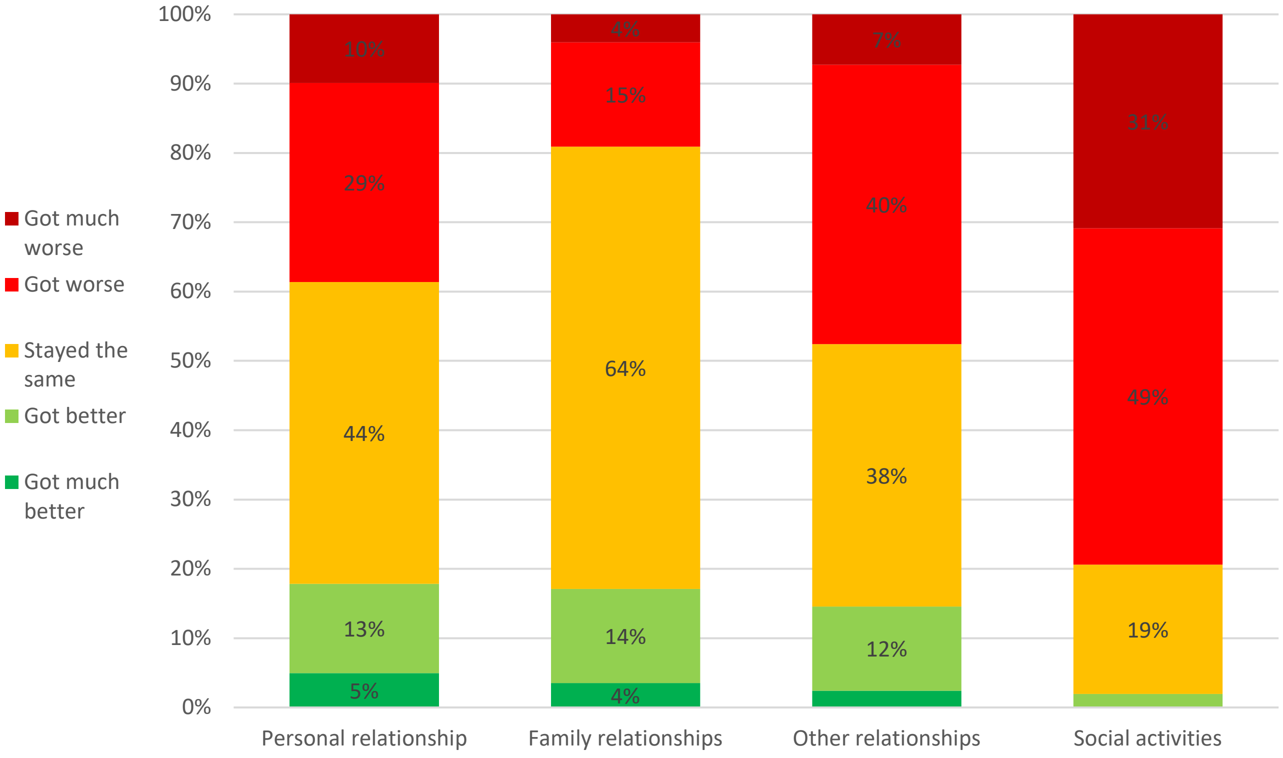
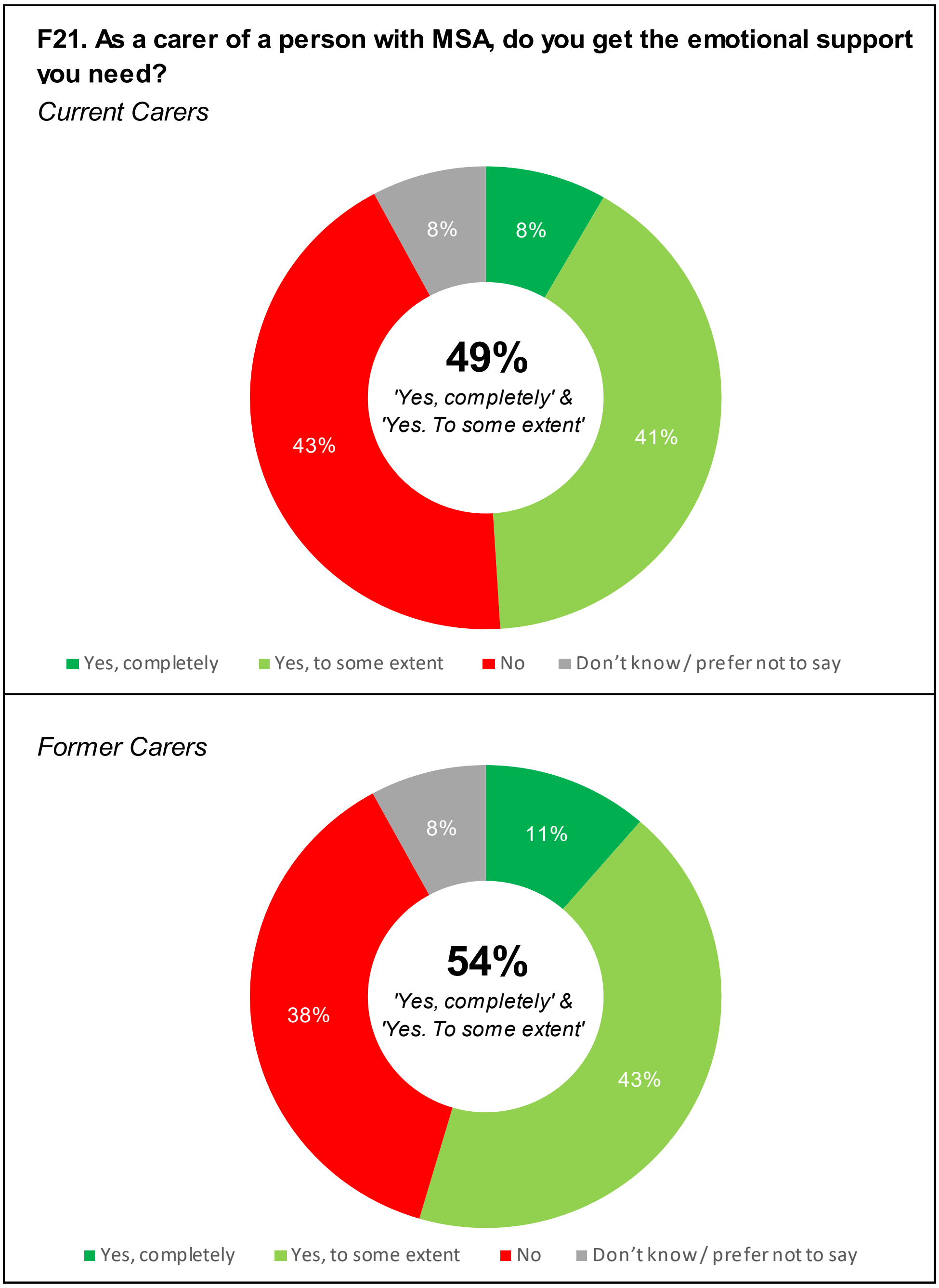


Fig 48. Impact of caring for a person with MSA on relationships and social activities

3.5.10 Emotional support for carers and Former Carers

Among carers 49% (n=100) received emotional support whereas 43% (n=88) stated that they did not get any support. A similar trend can be observed with the Former Carers where 54% (n=48) received emotional support. In line with the lack of emotional support offered to people affected by MSA, the responses here show that carers and Former Carers are often left to their own devices particularly if they don't have family living nearby. As we see below the emotional support offered was mainly through informal sources.

From question CC 26/ FC 21: As a carer of a person with MSA, do you get the emotional support you need?



F21. As a carer of a person with MSA, do you get the emotional support you need?

Current Carers

Former Carers

Fig 49. Carers and Former Carers' emotional support

3.5.11 Carers’ emotional support needs

When asked if they had anything else to say about their emotional support needs, some carers commented on the difficulties for them to come to terms with the inevitable changes in their life. Some comments can be seen below:

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

“Both myself and my husband have times when we feel we have an existence and not a life. We used to lead a full life with lots of travel before MSA”.

“They have no idea or if they do they do not want to face how hard our lives are. it's very hard. I wish they would try to understand what we go through but they don't mostly. MSA is very isolating - our world is very small.”

“The physical side of our relationship has ended, I miss sleeping next to my husband, he sleeps in a hospital bed downstairs. I don't want to be a burden on my children, so I don't discuss emotions with my children but I do have some close friends that I can talk to when I need to, that is helpful.”

“Whilst I am a strong personality due to the magnitude of what is going on, I do worry about the long term effects of managing what I am and if talking to a third party who understands MSA would be of benefit.”

3.5.12 Source of emotional support for Former Carers

In line with the carers results, the vast majority of Former Carers (84%, n=76) confirmed that they got their formal or informal emotional support from family and friends whilst 35% also got support from the MSA Trust. The lack of emotional support from external sources, aside the family, is evident and therefore reinforces the need to provide further help and support to those with MSA and their families. Even more evident is the lack of support for those that haven't got family or friends nearby.

The below figure will show in more details the different sources.

From question FC 23: Where did you get emotional support as a carer? This could be formal (from a professional) or informal (such as a friend or family member).

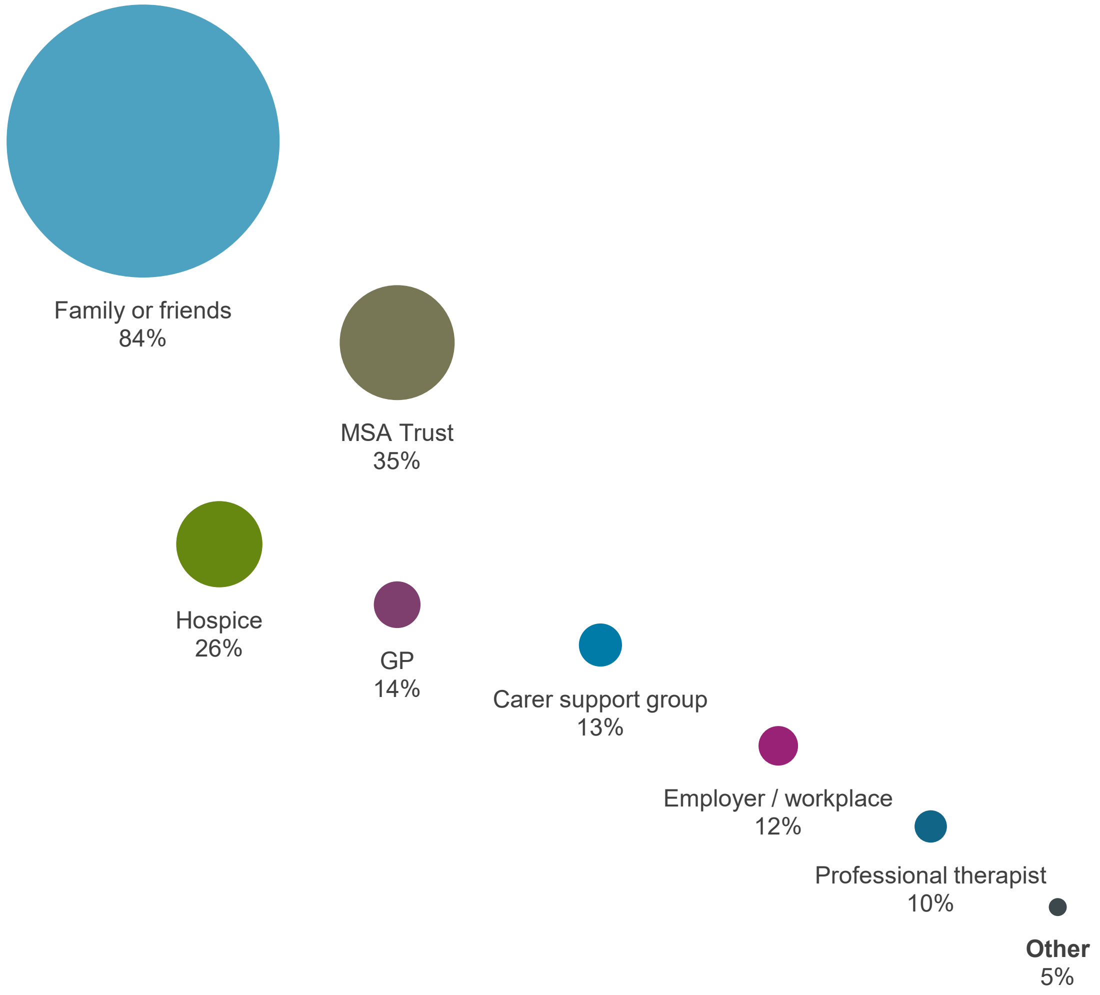


Fig 50. Former Carer's source of emotional support

3.5.13 Former Carers’ emotional support needs

51 Former Carers (56%) commented in their own words the emotional support needs that the person they cared for needed or they themselves needed. Below are some of the comments:

“My wife needed to know that I was physically at home to feel emotionally secure. I really didn't ask for emotional support, though I should have.”

“I think it should be a given that emotional support is provided for all carers. I had to give up my job to care for my wife full time and all my friends and family didn't visit near as much as they used to. It was such a big change in my life.”

“Everyone is different in their emotional needs and make up. Finding out how the person with MSA feels/ thinks early on before their communication difficulties are too affected is important so that you aren't missing things or overstepping their needs because they can't ask for more support, or tell you to leave them alone, later.”

“I doubt that I would have taken up any 'emotional support' for myself. My son was frequently asked at school and eventually went through one of their programmes. I'm not sure if my husband was offered 'emotional support' but I feel certain that he would have benefited from speaking to someone as he simply would not talk about his MSA and life limitations, he was not a happy man and frequently 'took things out' on his family - understandable, but nevertheless difficult and all rather sad really.”

“More emotion support was definitely needed for both myself and my partner, the hospice provided much support for myself, my and our family particularly our young grandson who benefitted from the support given.”

3.5.14 Sexual relationships/intimacy issues for people with MSA and carers

Nearly two thirds of respondents with MSA (62%, n=125) reported that their sex life had been directly affected because of MSA.

Interestingly, 21% (n=42) preferred not to say if they were affected, this may be due to the sensitive, nature of the topic here. The respondents with MSA might feel embarrassed and reluctant to talk as they may perceive the lack of a sex life as their fault.

Of those affected, just 6% (n=7) were receiving treatment to help. 46% (n=56) have not been offered any treatment and a further 41% (n=50) did not want treatment, again possibly pointing to the sensitive and stigmatised nature of this aspect of their symptoms. Compared to 2019 the data has remained stable.

From question Person living with MSA 31: Are you receiving treatment and / or support to improve your sex life?

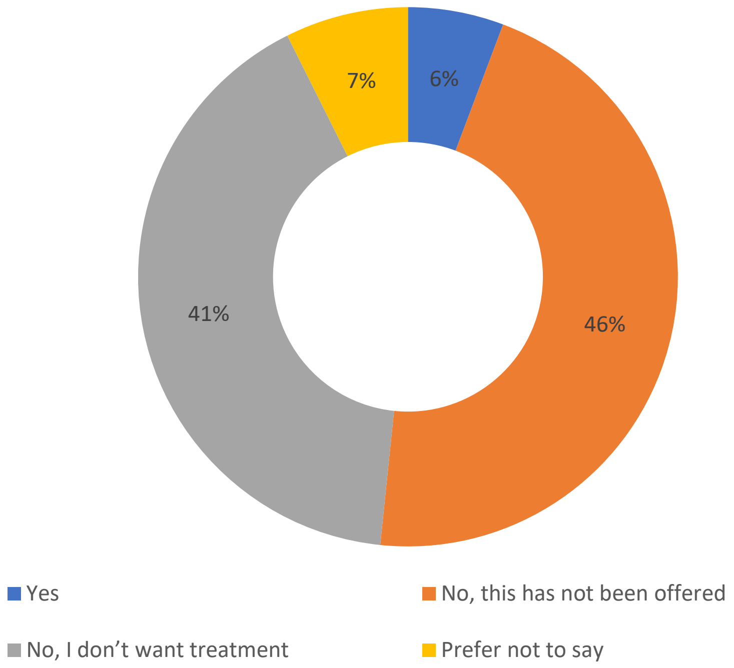


Fig 51. Sex life/intimacy issues and treatment support offered

This aspect of MSA has historically lacked attention and this is perhaps an area that would benefit from further awareness and support from healthcare professionals going forward.

3.5.15 Sexual relationships/intimacy issues for carers

Not surprisingly, 71% (n=147) of carers' sex life has been affected by caring and supporting a person with MSA, with a further 17% (n.35) that didn't want to say. Only 11% (n=22) reported no changes to their sex life and 2 individuals didn't know.

Healthcare professionals should gently instigate a conversation and direct the person with MSA and carers towards sources of emotional support in order for them to process and come to terms with a very big change in their relationship.

The below comments give a better insight into this issue:

"Sex life is non-existent due to heath issues (since 2019) however my wife needs love and support and intimate physical contact (hugs/cuddles etc.) to help reassure her that she is loved and needed and attractive to me."

"I have become like his mother rather than his wife".

"One of the initial symptoms of MSA was sexual impotency and since diagnosis my husband has shut off/avoided any intimacy or physical connection of any kind. Very quickly after diagnosis there was a definite change from being a partner to being a carer."

From question CC 29: Is your relationship and sex life / intimacy affected by caring and supporting a person with MSA?

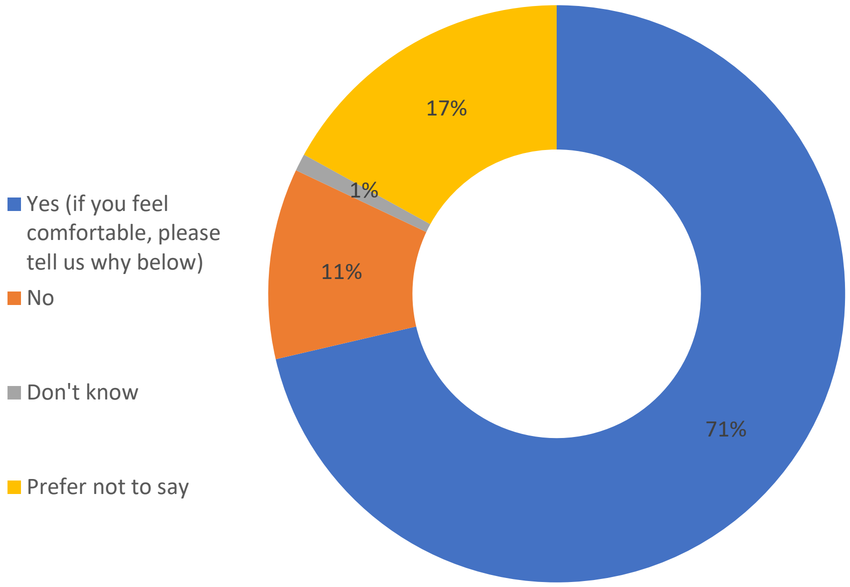


Fig 52. Impact of MSA on carers' sex life

3.5.16 Conclusions

People Living with MSA

Psychological impact

- It is difficult to say whether psychological issues are attributed to MSA or as a result of being given a terminal diagnosis. However, reports of low moods, depression, and anxiety are commonplace and support is perceived as poor in this area.
- Fatigue and tiredness are the most frequently experienced issues, followed by low mood/depression. These, coupled with the physical symptoms experienced, prevents many of the people with MSA from undertaking activities that they once enjoyed, or prevents them starting a new one.
- More than a quarter of respondents with MSA would value support for their mental wellbeing **throughout** the different stages of MSA.

Impact of MSA on relationships and activities

- Unsurprisingly, living with MSA often has significant effects on relationships. In particular, respondents reported that relationships with friends are severely impacted, increasing their feelings of isolation.
- Social activities were often curtailed the more MSA progressed, and their quality of life declined. Thus, the feelings of isolation and abandonment become amplified.
- Undoubtedly, MSA prevents people with the condition from doing many things they enjoy most or from starting new activities. Mobility issues, concerns regarding speech, and reliance on others for travel assistance, are the main problems reported.

Source of emotional support

- The majority of current carers and Former Carers reported that the person they cared for did not receive the emotional support they needed from the healthcare professionals or psychological services.
- The main form of emotional support usually comes from family. The external help for the mental wellbeing of people with MSA is poor. There is a clear need to improve professional support throughout the different stages of the condition, from diagnosis to the end.

Sex life

- Sex life is greatly impacted by the condition. This is a delicate topic that people with MSA might be reluctant to talk about and it’s often neglected or not raised by the Healthcare professionals.

Current carers

Psychological impact

- MSA does not only have an emotional impact on the person affected by the condition but also on carers who often experience anxiety, depression, and social isolation.

Impact of MSA on relationships

- Carers report that **relationships with friends** and their **social activities** are negatively impacted and there is an increased **feeling of isolation**.

Source of emotional support

- A high percentage of carers feel they don't receive enough emotional support. Some carers can rely on close family and friends for emotional support, others feel completely isolated.

Sex life

- The couple dynamics, in which one of the partners is affected by MSA, changes sex lives drastically. Some carers highlighted they no longer feel like spouses. The majority of the carers stated their sex life has been affected, with partners often being reticent to face the issue and not looking for help.

Former Carers

Psychological impact

- Former Carers confirmed similar experiences to the carers. The psychological impact of MSA, the feeling of isolation, changes in couple dynamics and friendships did affect them emotionally.

Impact of MSA on relationships

- Similarly to current carers, Former Carers report that **relationships with friends** and their **social activities** were negatively impacted and there was an increasing **feeling of isolation**.

Source of emotional support

- In common with carers, a high percentage of Former Carers felt they hadn't received the emotional support they needed, feeling completely isolated.
- Family and friends were an important source of emotional support for Former Carers during their journey when looking after a person with MSA. Additionally, more than one third of the respondents mentioned how instrumental the MSA Trust was in helping them emotionally.

3.6 Support Groups and Services for people living with MSA, carers and Former Carers

Support Groups are very important to everyone affected by MSA both as a source of information for a condition that appears to not be that well understood and as a source of emotional and physical support.

3.6.1 Access to Support Groups

The vast majority of people with MSA, carers and Former Carers, reported relying on MSA Trust, both online and in-person, for support.

Support Groups via the GP practice were reportedly very scarce (3%), whilst another 14% could not physically access them. The chart below shows in more detail the various Support Groups used by the respondents.

From question Person living with MSA 34/CC 31/ FC 25: Which support groups have you accessed for additional support?

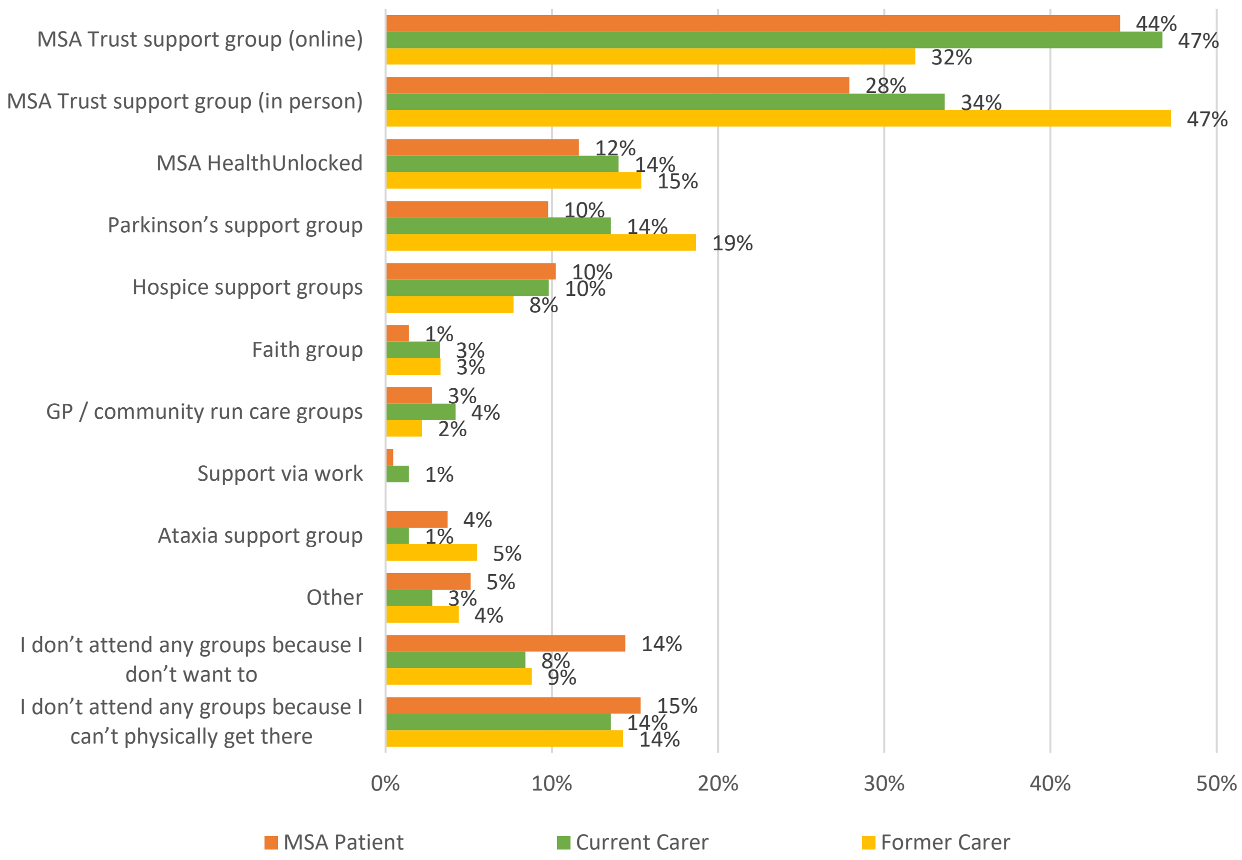


Fig 53. Access to support groups for additional support

3.6.2 Access to services

When looking at the gaps in support services it was evident that the majority of the respondents with MSA either did not access the services listed in the questionnaires because they were not available or because they didn't want to.
Of the services that the respondent wanted to access but couldn't, **complementary therapy** (40%, n=67), **exercise classes** (34%, n=60) and **group or individual counselling** (32%, n=60) scored the highest.
Interestingly, even a higher percentage of respondents reported that, even if available, they did not wish/need to access the services, like in the case of **psychological therapy** (59%, n=104) or **buddying/ peer support** (63%, n=115). Considering the impact MSA has on the mental health of patients and families it was a surprise to see these results.

Of those who are accessing additional support, the most reported were:

- Exercise classes (21%, n=37)

"*Made me more relaxed, helped with symptoms"*

"*I attended weekly exercise group, but it stopped due to lockdown and hasn't restarted."*

- Group or individual counselling (18%, n=33)

"*Counselling/psychotherapy helped to sort things out in my head and my husband and I initially had counselling together, which enabled us to talk about my diagnosis."*

"I had 6 counselling telephone sessions a couple of months after my diagnosis organised through work. It was useful to talk to somebody that didn't know me, it made me feel a bit calmer."

- Complementary therapies (15%, n=25)

"Complementary therapies - healing and acupuncture, relax me and seem to alleviate some symptoms for a while."

"The massage helped tremendously, felt a lot better after the treatment."

From question Person living with MSA 35: Have you accessed any of these services?

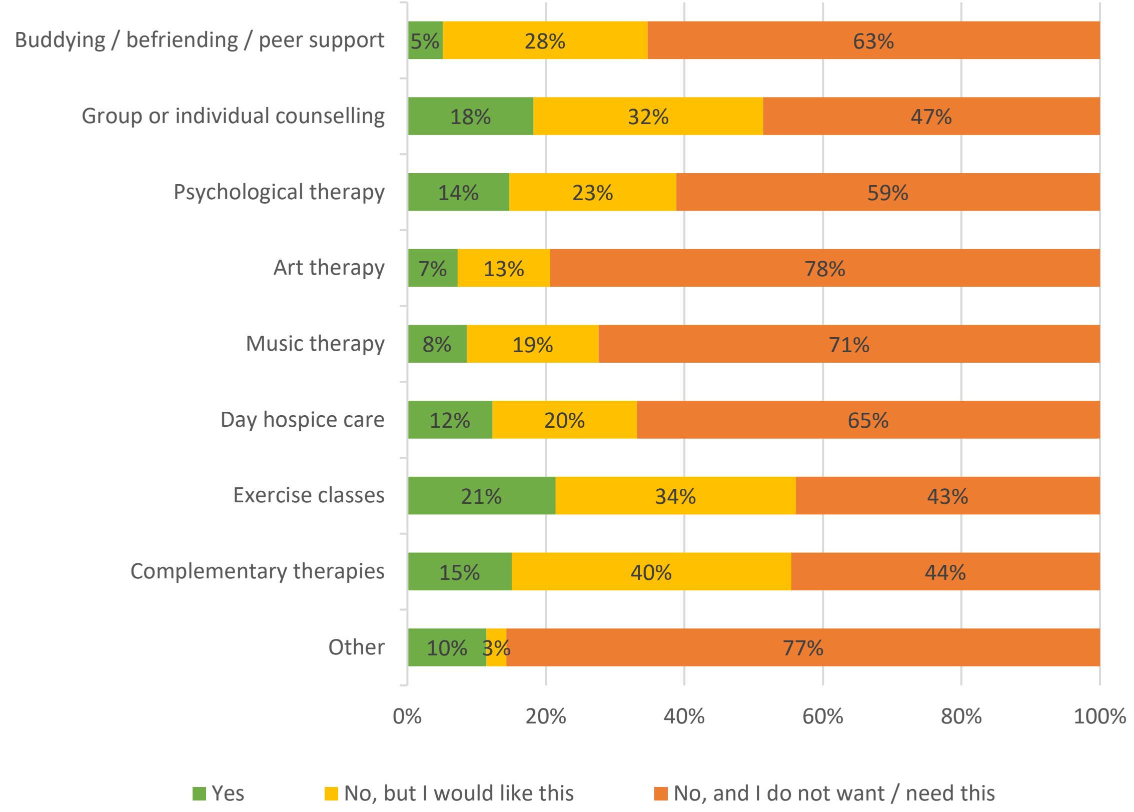


Fig 54. Access to services

3.6.3 Services available to help carers and Former Carers

When available, the source of help carers use the most is Hospice Support (32%).

It is not a surprise that an even higher percentage (49%) among Former Carers used this source of help. This is likely due to the later stage of MSA the person they cared for lived to. However, approximately one third of the respondents didn't have access to some of the remaining services even if they would have liked to.

From question CC 32/FC 26: Do you access any of the following sources of help?

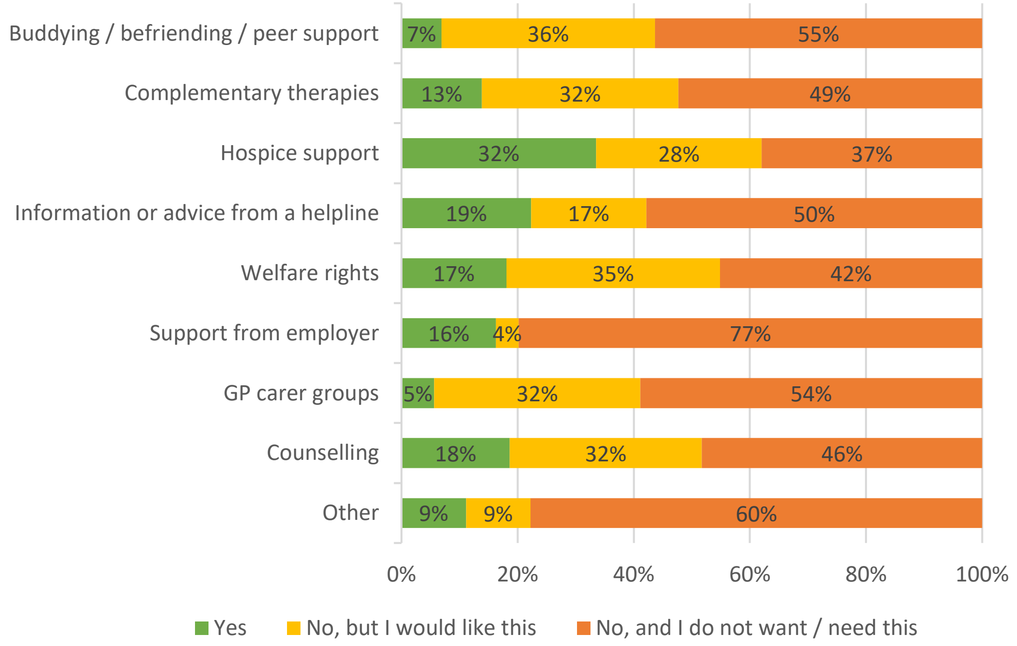


Fig 55. Services available for carers and Former Carers

3.6.4 Barriers experienced by Former Carers to access Support Groups

When Former Carers were asked what could have made it easier for people with MSA to access Support Groups, **proximity** was the most frequent answer. Below are some of the former carer's comments.

"Having them closer to where we live."

"There were none in the immediate area and so something more local would have helped."

"The only support group we went to was the local MSA Trust and only whilst my husband was relatively mobile and able to easily attend. When his health deteriorated, he simply did not want to travel."

"There is very little in Stoke on Trent. Our nearest was Blackpool."

"There weren't any support groups specifically for MSA local to us. I don't drive so was not able to access groups more than 5 miles away.

3.6.5 Carer’s support and gaps

Carers were asked which support they receive and the gaps they identified in their support, 85 carers (40%) commented with their own words.

Support from family, MSA Trust and funded care

The help from families/friends, funded care and the MSA Trust seems to be the most prevalent source of support among the carers.

“Only support from my family as husband's family do not live in this area. Difficult to attend carer's groups as no one to look after husband.”

“We are fortunate enough to have continuing health care funding”.

“The carers who get him up and put him to bed a night are very good.”

“I have found MSA nurse and welfare very helpful indeed I am not sure what I would have done without them.”

Gaps in respite care, information on support groups and training

Lack of access, or proximity, to respite care is one of the issues that increases the sense of isolation amongst carers. Lack of information about support groups available near the carer is often reported as well as lack of training, as commented in section 3.3.14.

Lack of access/proximity

“Respite nearer home needs to be more available.”

“Don't feel there is any support for the carer. We are the invisible person in this scenario”.

“I don't feel I am supported enough as a carer. I feel quite alone sometimes feel everything is on my shoulders.”

“Currently I have no support.”

“No support apart from MSA Trust. I would like some time off just to indulge myself in something other than MSA”.

“Other than the social worker organising a grant for respite there has been no support.”

“I feel very neglected as a carer, my needs are not met at all. I am physically disabled myself and 1 year ago asked for help to take my husband out, perhaps 2 hours a fortnight as I'm finding it harder to push his wheelchair and he can’t use a powered chair. I've heard nothing. The Carers hub send info about events for carers but I cannot leave my husband and there is no one to care for him while I attend. I recently dislocated my ankle and haven't even been able to go to A&E for treatment.”

More information on Support Groups

“Have support from family and friends and MSA trust and would like to know what other support is available to me as carer.”

“Very little to no support. Would be better if the GP was more proactive and more information on most appropriate support groups to access.”

“At present I only get informal support. If I want other support, whether this might be joining a group or arranging counselling, I would have to research what is available and then try to arrange it myself. Greater

proactive involvement/information from services involved with my husband would be helpful as, although I am an articulate professional, the effort involved in trying to set up a support system for myself feels too difficult, particularly when most of my time is spent trying to arrange services/input for my husband."

"I didn't know any of these groups existed no one has told us about them."

"Like I said I do not get any support didn't realise what was out there and was diagnosed then just nothing no advice no support groups nothing."

"I've only just been added to my carers centre email list to see what support groups they are running. I am usually at work when they take place. There is nothing for MSA carers locally and anything online is when I am working. I have a lady from the carers centre who rings me to see how I am, but that's about it."

Lack of training

"I would like a specific carers group and/or training. I would also like to know if there are any other local support groups apart from the MSA Trust for my husband to attend. We haven't had any local hospice input but it would be good to know what they can provide."

"Mental coaching, planning, practical advice, (financial, building etc) carer training (how to help)."

"I would like advice on safe methods of lifting/ transfers and possibly counselling on emotional responses for both myself and the MSA sufferer."

3.6.6 Conclusions

People Living with MSA

Access to Support Groups

- Support Groups are very important when trying to cope with a high-impact condition like MSA. The vast majority of people with MSA reported relying on the MSA Trust, both online and in-person, for support whilst Support Groups through GP Practices fared poorly.
- Some respondents reported being unable to physically attend any groups.

Access to services

- Most respondents are not accessing additional services to help with their MSA symptoms. There is an apparent gap in provision, very likely dependent on the area where the respondents are from. Interestingly, a high proportion of respondents did not want to access some services even when available. - like in the case of psychological therapy or peer support.

Current Carers

Access to Support Groups

- Similarly to people with MSA, Support Groups are important for carers to cope with this very challenging condition. The MSA Trust Support Groups, both online and in-person, are the most used among the carers.
- Support Groups provided through GP Practices rated poorly.

Source of support and gaps

- Most of the support for carers often comes from family, friends, and the MSA Trust. The willingness from the carers to look after their emotional and physical wellbeing is something that is often expressed but their ability to do so is often compromised.
- Among the gaps, lack of access or proximity to respite care and lack of training for the carers were identified as an issue. Additionally, it appears that even when available the sources of support are not well publicised by healthcare professionals.

Additional source of help

- When available, carers confirmed that Hospice Support was a valuable source of help that they use. Interestingly, despite around one third of carers wanting to access some services not available to them, a higher percentage did not wish to access some services such as counselling, peer support and welfare rights. During visits, healthcare professionals could interact more with carers and educate them on the benefits that these sources of help could bring to them.

Former Carers

Access to Support Groups

- Former Carers confirmed similar experiences to current carers. The MSA Trust, both online and in person, was the most used support at the time of looking after the person they cared for. In line with the other groups, the support provided through GP practices rated poorly.

Source of help

- Hospice support was used by nearly half of the Former Carers. The higher percentage compared to carers is very likely due to the later stage of MSA they had to deal with.

Barriers to access Support Groups.

- Based on their experience, Former Carers confirmed that barriers to accessing Support Groups were a lack of proximity coupled with the decreased mobility of the person affected by MSA.

Additional sources of help

A higher percentage of Former Carers compared to carers confirmed that Hospice Support and welfare rights were used by them when available. This should not come as a surprise given Former Carers look after people with a later stage of MSA, hence in more need of respite care and more aware of their welfare rights.

3.7 Impact on personal and home life for Carers and Former Carers

Understandably, the negative impact of MSA is felt not only by the person with the condition but also by their carers. It can be overwhelming for a carer to juggle daily family and financial responsibilities in addition to giving support both physically and emotionally.

3.7.1 Other significant caring responsibilities

Although the majority of carers and Former Carers are aged over 55+, some respondents still have other caring responsibilities such as children, siblings or older relatives. Among carers, 6% (n=13) had children under the age of 18, a further 9% had dependent children over 18 and 11% (n=24) were looking for after other relatives. This shows how challenging it must be for a carer and how important the support they need is.

"I look after my Mother-in-Law 97 years old."

"I cover for my daughter who has a SEN child I am her support she is a single parent"

From question CC 34/FC 28: Do you have other significant caring responsibilities whilst being a carer for someone living with MSA?

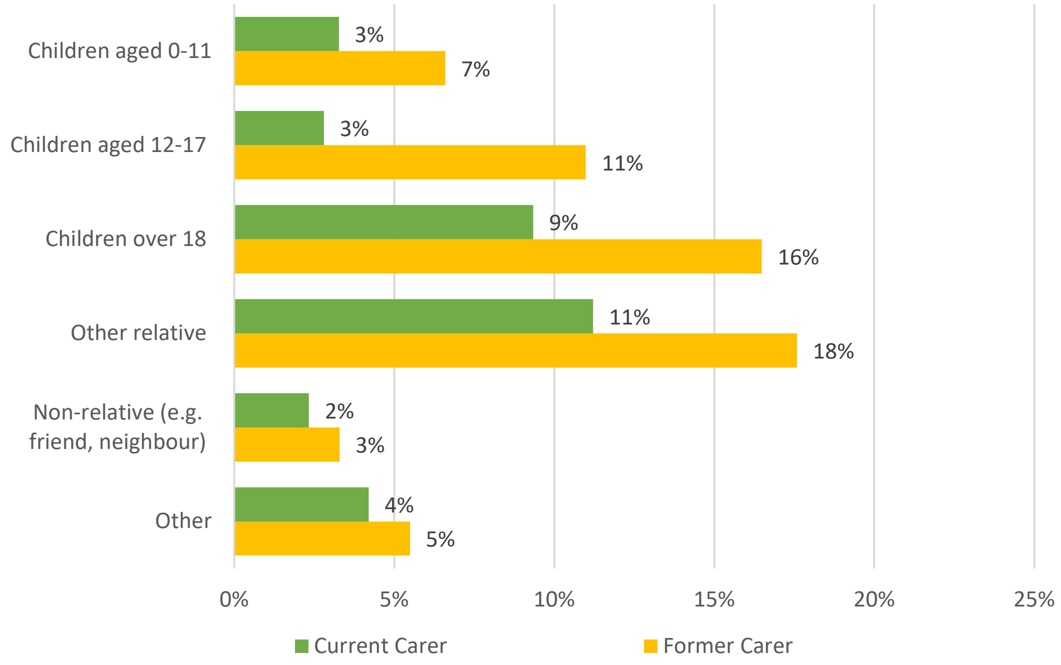


Fig 56. Carer's other caring responsibilities

3.7.2 Reasons preventing carers from doing enjoyable activities

When carers were asked what stops them from doing things that they enjoy or from starting new activities, the following causes were the most reported:

- Half of the respondents (n=106) are physically too exhausted.
- 45% (n=96) are unable to get appropriate care for the person living with MSA while they are out.
- For another 45% (n=96) the person with MSA doesn't want to be cared by other people.
- 21% (n=45) have financial worries.

It is not clear from this survey why almost half of people with MSA don't want to be cared by someone else. It can be assumed that at a later stage, when the physical care is more intrusive, it may be embarrassing for the person with MSA to have this care performed by someone else that is not their own spouse or partner.

This is a big issue for the carers to deal with, making it harder for them to have a much-needed break. This might also explain why some carers expressed a sense of guilt at leaving the person they care for at home.

"I feel guilty if I am out of the house for more than a couple of hours."

"I don't want to be out enjoying myself and leaving him behind."

3.7.3 Feeling of isolation

The feeling of isolation has been widely reported by respondents. When asked what could have helped, both carers and Former Carers confirmed that **In Person support Groups** and **Online Support groups** run by MSA Trust would be beneficial. The below chart shows in more details the different options.

From question CC 37/ FC 30: The Trust is looking at ways we can help people with feelings of social isolation. Which, if any, of these options would most help you?

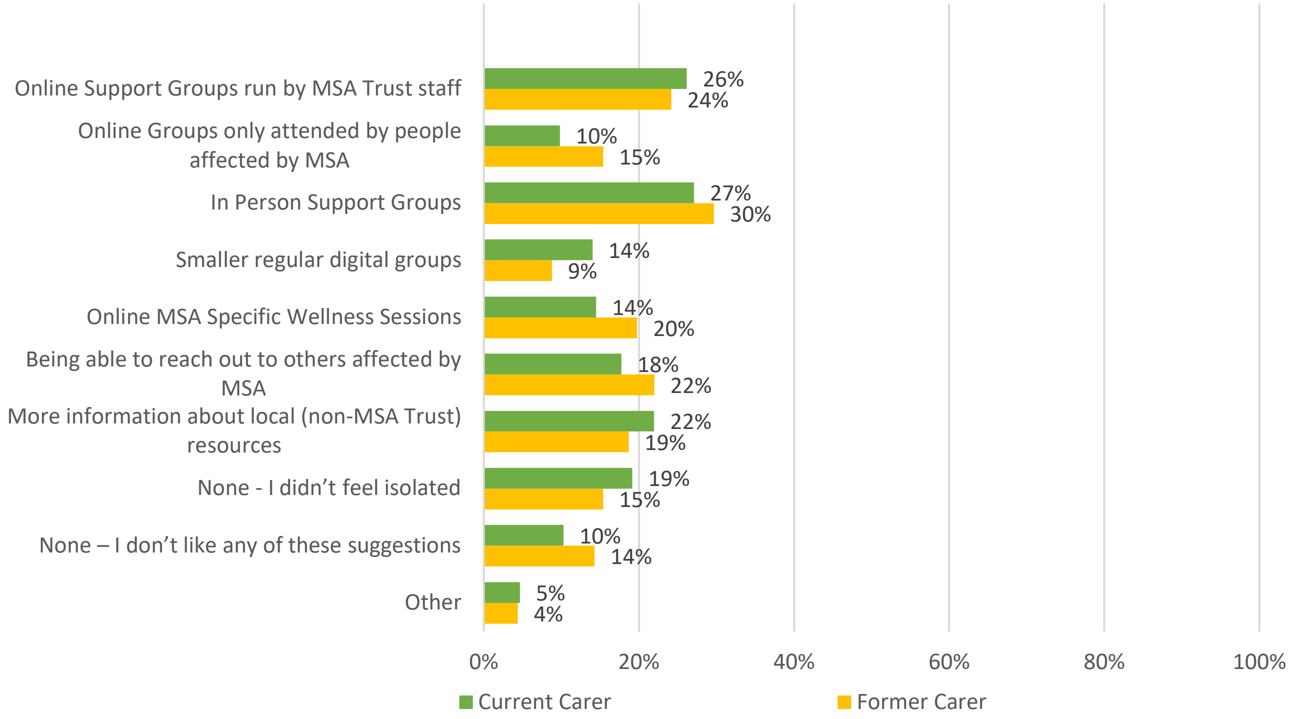


Fig 57. MSA Trust support with feeling of isolation

3.7.4 Respite breaks

Physical, mental and emotional exhaustion has a great impact on carer's wellbeing. The MSA Trust looked at what is accessible to carers for respite breaks. Over 60% of respondents reported a lack of **Respite Day care out of the home**, of **Overnight at care home** and having a **Break at a nursing home.** Some respondents reported with their own words that the only respite break they have access to is provided by close friends and family.

Former Carers reported that, when available, they were also able to access respite care through hospices. This is very likely linked to the later stage people with MSA were at. The recent crisis of lack of staff in nursing homes, particularly as a result of the COVID-19 pandemic, may have exacerbated the problem.

"Some close friends and family assist."

"Regularly visit my daughter and son-in-law, e.g., when I need to be away from home for work."

"Friend coming once a week for an hour so I can go to an exercise class."

“Son and daughter-in-law will take my husband to their house if I need a break.”

“Overnight stays at the hospice.”

From question CC 38: Which of the following respite breaks do you have access to?

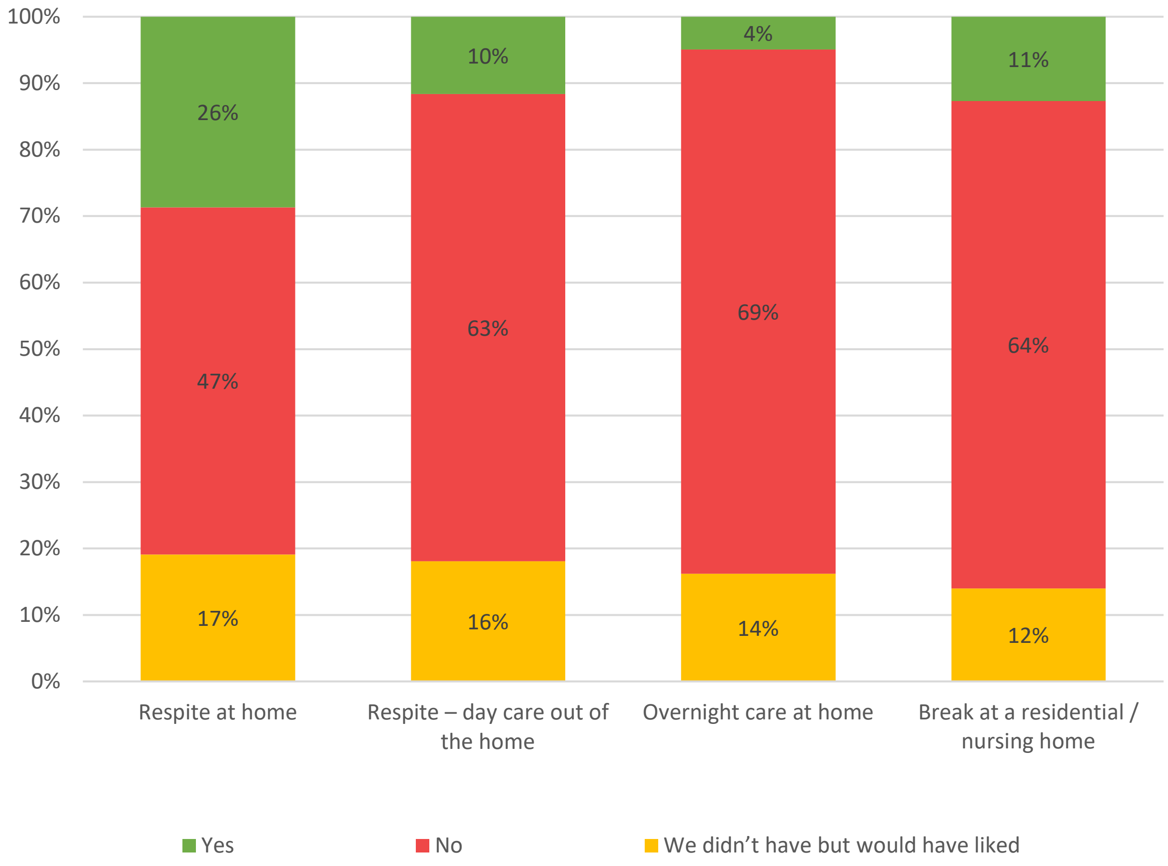


Fig 58. Carer’s access to respite care

3.7.5 Conclusions

Current Carers

Impact of MSA on carers

- The effect of MSA is not only devastating for the person with the condition but also for the carer who often has other caring responsibilities.
- Carers often stop doing the activities they once enjoyed, due to tiredness, or because they cannot find someone to help while they are out. Financial worries are also a factor in preventing carers from doing enjoyable activities.
- Nearly half of the respondents reported that people with MSA are reluctant to be looked after by someone else, which might explain why some carers express a sense of guilt when they go out. More work needs to be done to understand this as it is a significant barrier to respite for carers.

Social isolation

- Relationships with friends and social activities are greatly reduced because of lack of support and financial worries.
- Feeling isolated is widespread among carers, affecting them psychologically.

Support Groups

- In-person and online Support Groups run by the MSA Trust would be greatly appreciated by carers. The Trust should promote these services more widely and might split them into groups for just carers or people with MSA for separate discussions.
- This survey suggests that help from respite services is currently lacking. This could be partly due to the current issues around social care provision and lack of adequate care homes, leaving the carers often to their own devices. Carers often rely on close families and friends for a break if they live nearby.
- Additional physical and psychological support for carers should be provided so to prevent the strain and sense of isolation the carers report.

Former Carers

Impact of MSA on Former Carers

- The effect of MSA on Former Carers was even more evident due to the more advanced stage of the condition they had to deal with, coupled often with other caring responsibilities.

Social isolation

- Like the current carers, Former Carers’ relationships with friends and social activities were reduced greatly because of lack of support and financial worries.
- The feeling of isolation was widespread among Former Carers impacting them psychologically.

Support Groups

- In-person and online Support Groups run by the MSA Trust were beneficial for the Former Carers whilst going through the difficult stages of MSA, particularly in the final stage. The Trust should promote these services more widely, perhaps considering tailoring them according to the stage of MSA, as well as for carers only.

Respite services

- Nearly half of Former Carers used Hospice Support when available which is unsurprising considering the later stage of MSA they had to deal with. However, this survey suggests that help from other respite services was lacking. This could be due to the issues around social care provision and lack of adequate care homes, leaving the carers often to their own devices.

3.8 Social Care

3.8.1 Local council assessment for funded care

When the respondents living with MSA were asked if their local council carried out an assessment to evaluate their eligibility for funded care or support, only 24% (n. 51) reported that they had been assessed and were eligible for funded care. 45% (n. 94) stated that they had not been assessed. Considering the impact on activities of daily living MSA causes this was very surprising and should be explored further.

From question Person living with MSA 41: Has your local council / social services assessed your care and support needs to see if you are eligible to receive funded care or support?

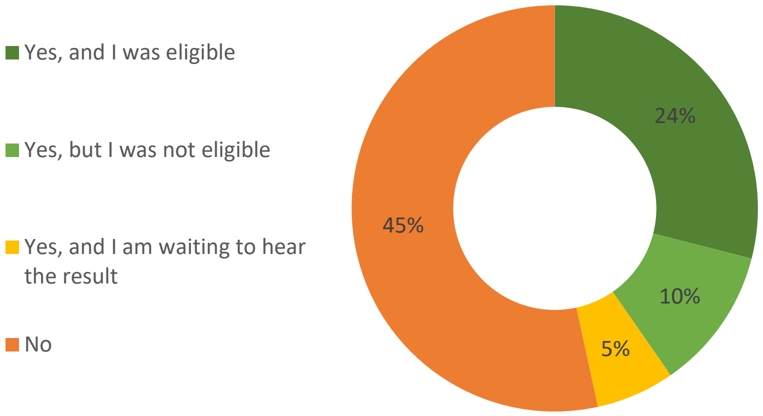


Fig 59. People living with MSA, local council assessment for funded care

From question CC 39: Has your local council / social services carried out an assessment to see if the person you care for is eligible for funded care or support?

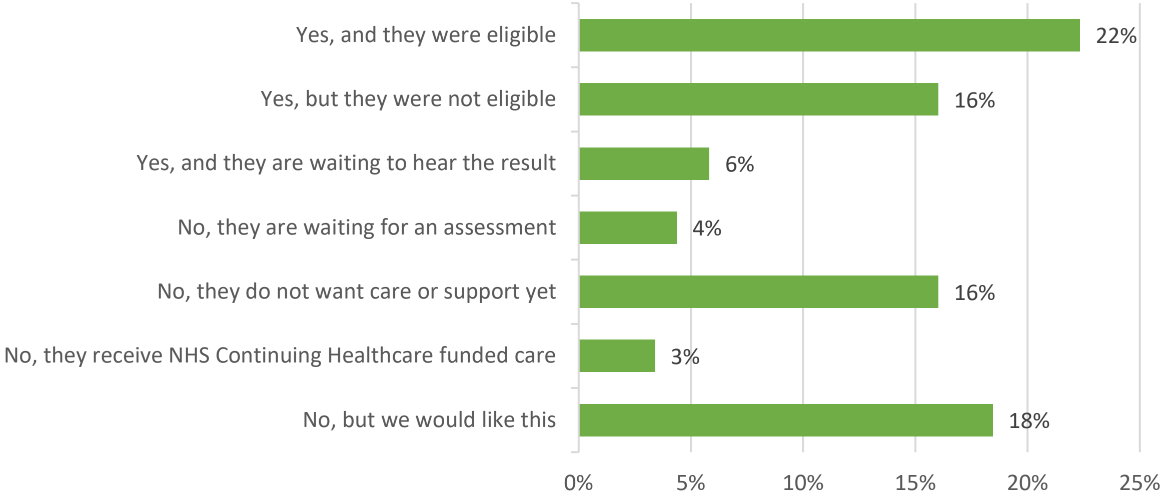


Fig 60. Carers, local council assessment for funded care

A further analysis was carried out to identify the level of independence experienced by the respondents. Additionally, respondents were asked if an assessment had been carried out by the local council. Worryingly, **even when totally dependent 21% had not been assessed for funded care by their local council**.

From question Person living with MSA 39/41: How would you describe your current level of independence? and Has your local council / social services assessed your care and support needs to see if you are eligible to receive funded care or support?

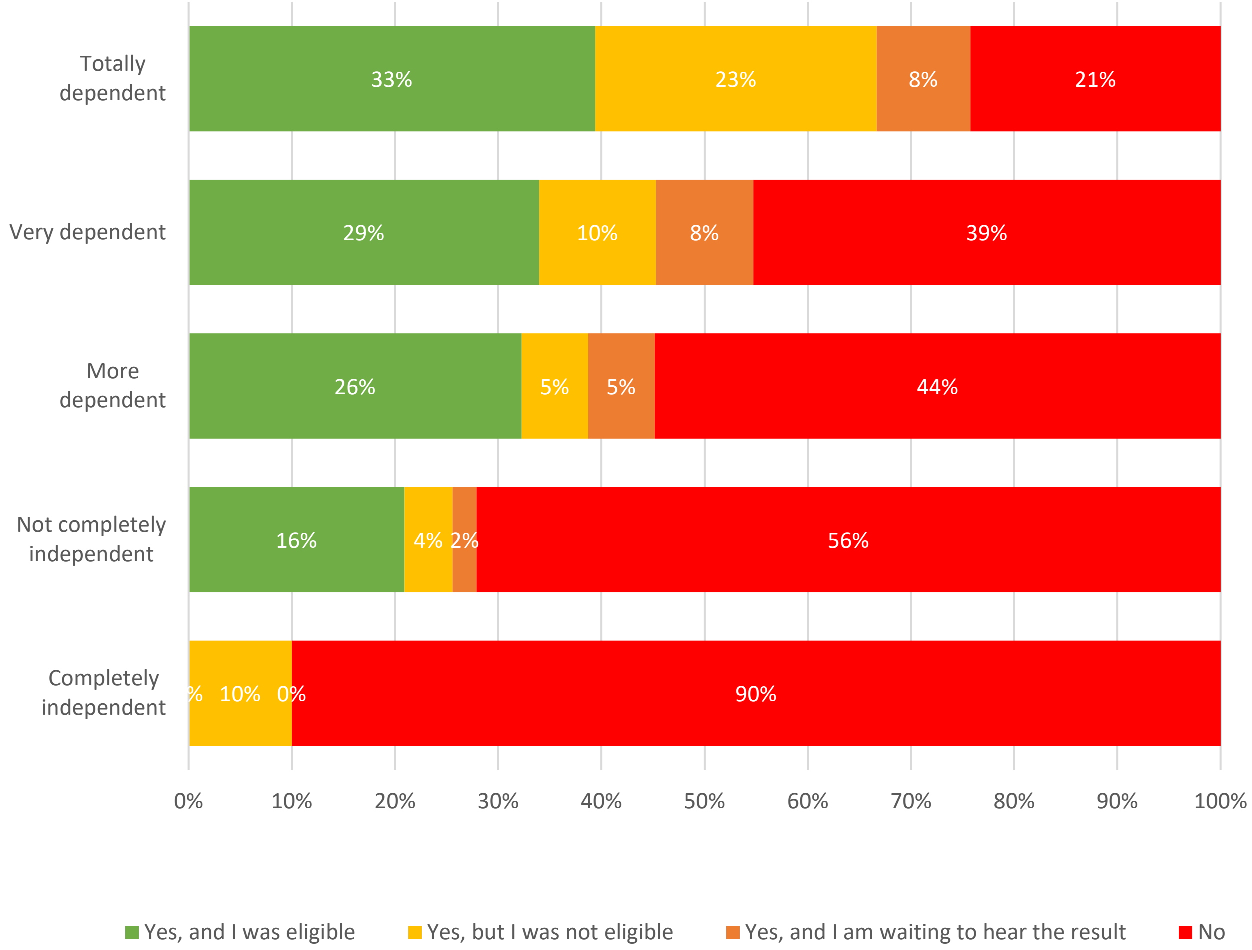


Fig 61. Level of independence versus local council assessment

3.8.2 Access to social care

Over half of the respondents with MSA reported that they don’t receive the sources of social care listed, followed by over a quarter of people reporting they don’t need social care yet. However, one third of the respondents confirmed that they received support for free for their home adaptations.

From question Person living with MSA 42: Are you receiving any of the following sources of social care?

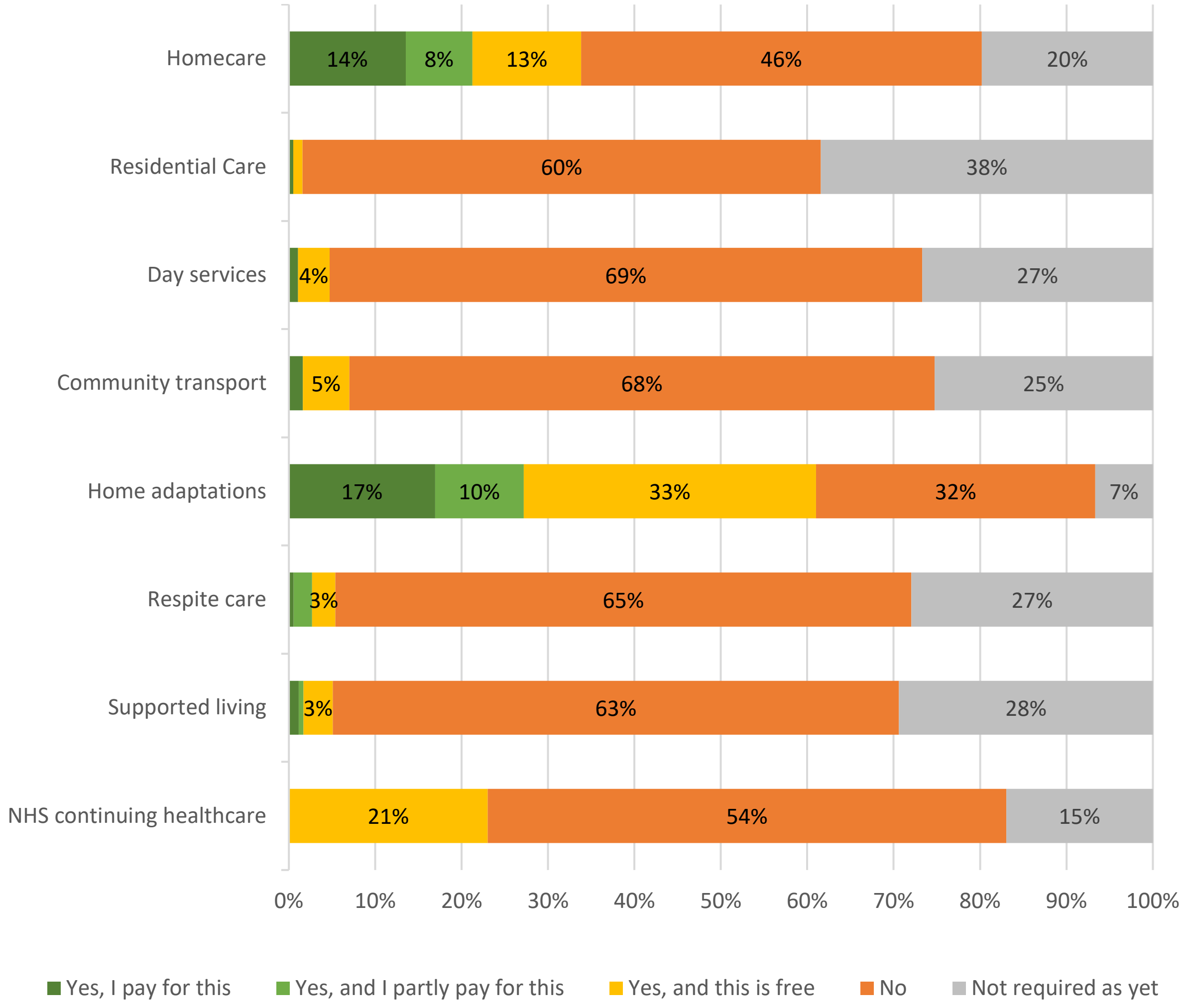


Fig 62. People living with MSA: Access to sources of social care

90% of carers reported that the person they are caring for has no access to **Residential Care**, **Day services**, **Community transport** or **Supporting living.** Although not every person will require these services, access to day services and transport for example could allow those with MSA to access support, improve their social situation and allow carers some respite. This might alleviate some of the emotional difficulties highlighted in the previous section.

From question CC 40: Is the person you care for receiving any of the following sources of social care?

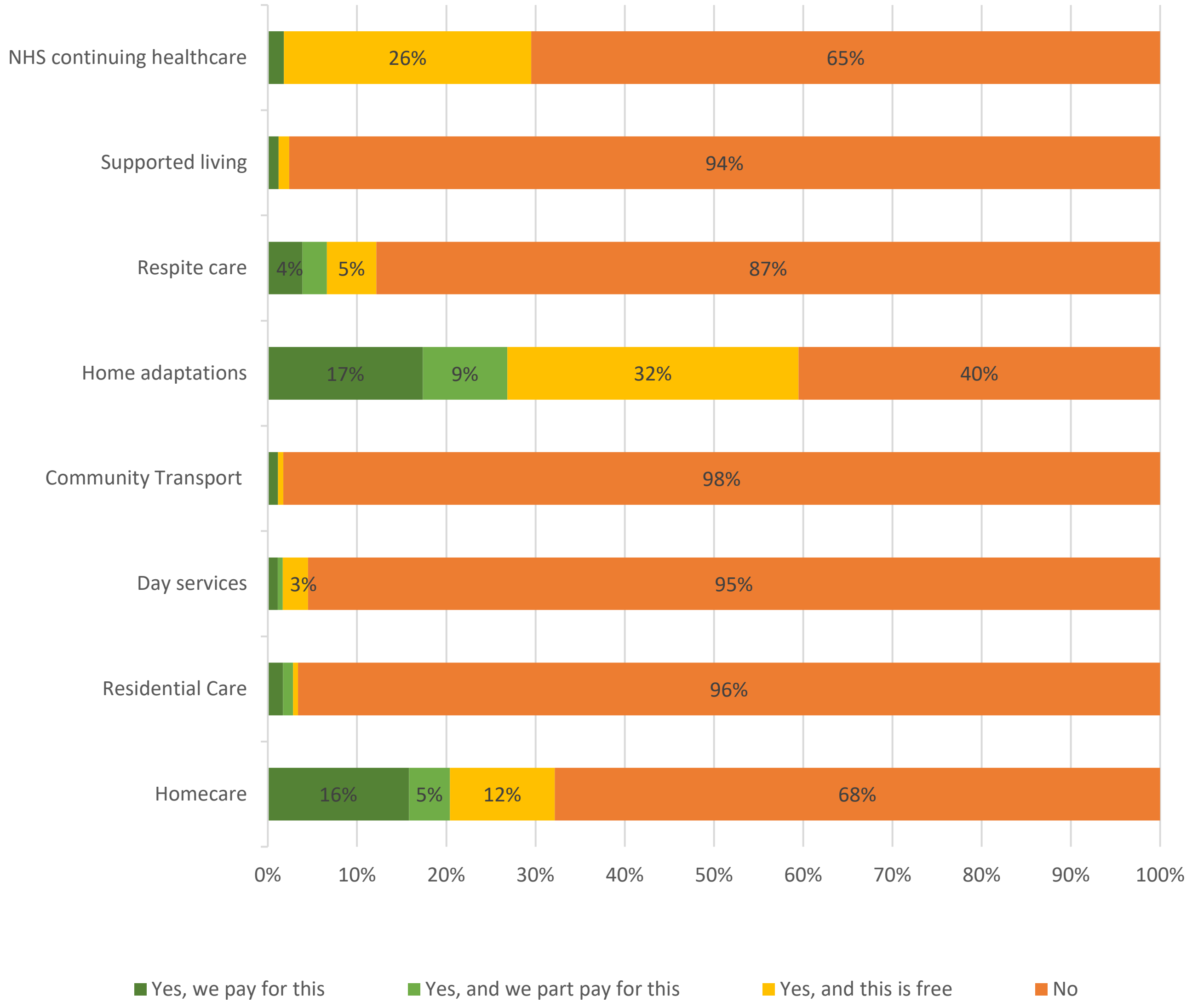


Fig 63. Carer - Access to sources of social care

3.8.3 Social care received versus the level of independence

To better understand if the lack of access to sources of social care was linked to the level of independence of the person with MSA, further analysis was carried out.

In line with what is mentioned above, the offering of **homecare** and **home adaptation** were strictly linked to the level of level of independence the person with MSA has. NHS continuing healthcare appeared to be offered to some extent regardless of the level of independence whilst the rest of the services were not offered or offered to a small percentage once very or totally dependent. Below are some examples.

From question Person living with MSA 39/42: How would you describe your current level of independence? and Are you receiving any of the following sources of social care?

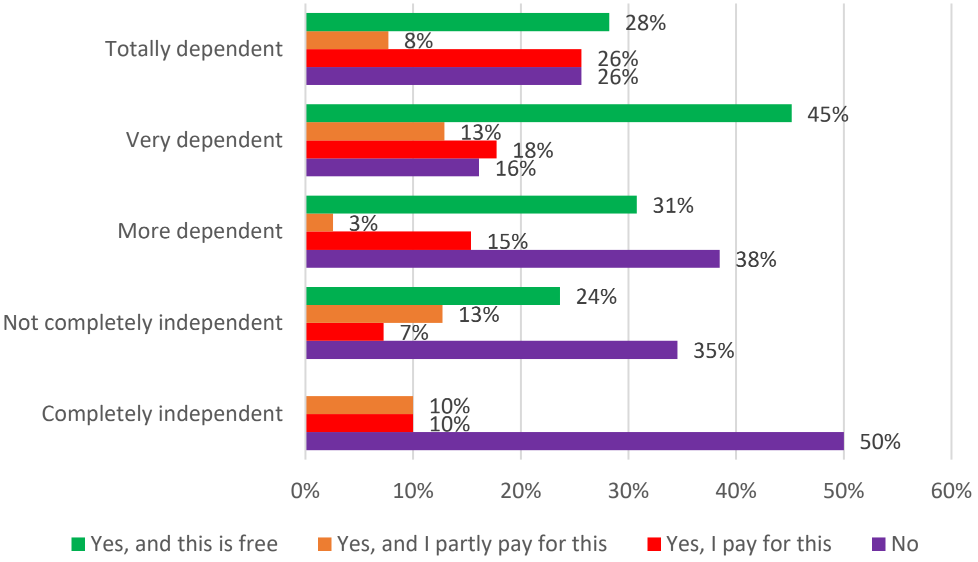


Fig 64. Cross analysis between level of independence and access to sources of social care- Home adaptations

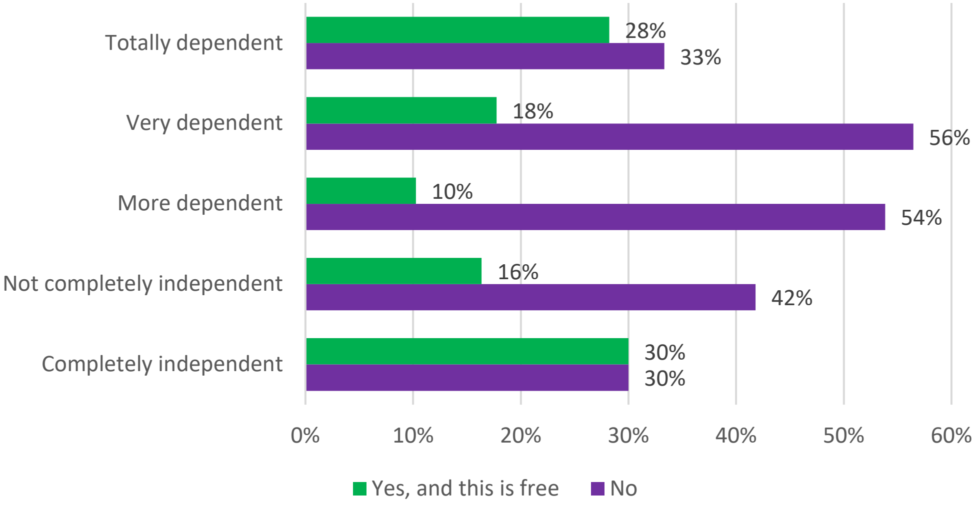


Fig 65. Cross analysis between level of independence and access to sources of social care- - NHS continuing healthcare

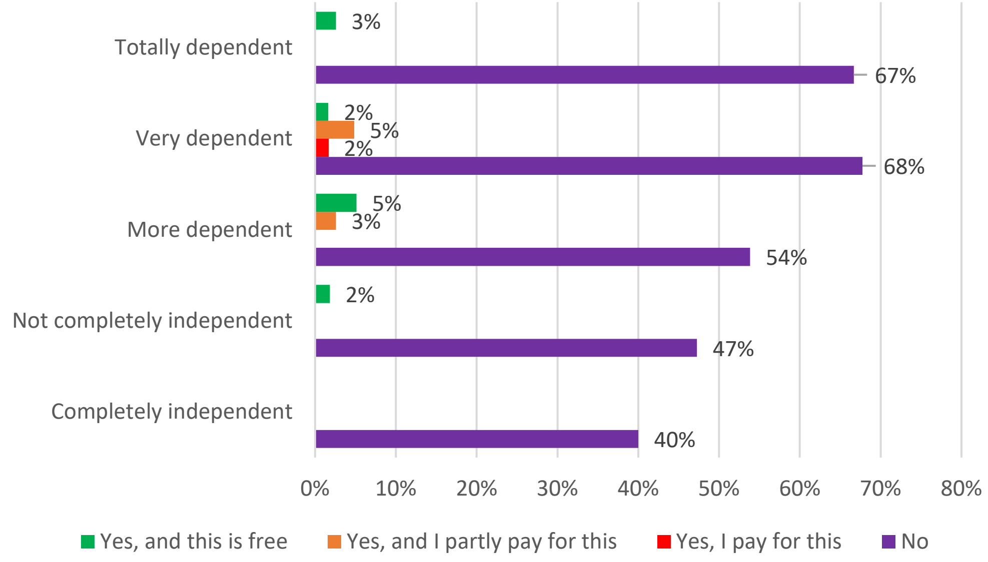


Fig 66. Cross analysis between level of independence and access to sources of social care - Respite care

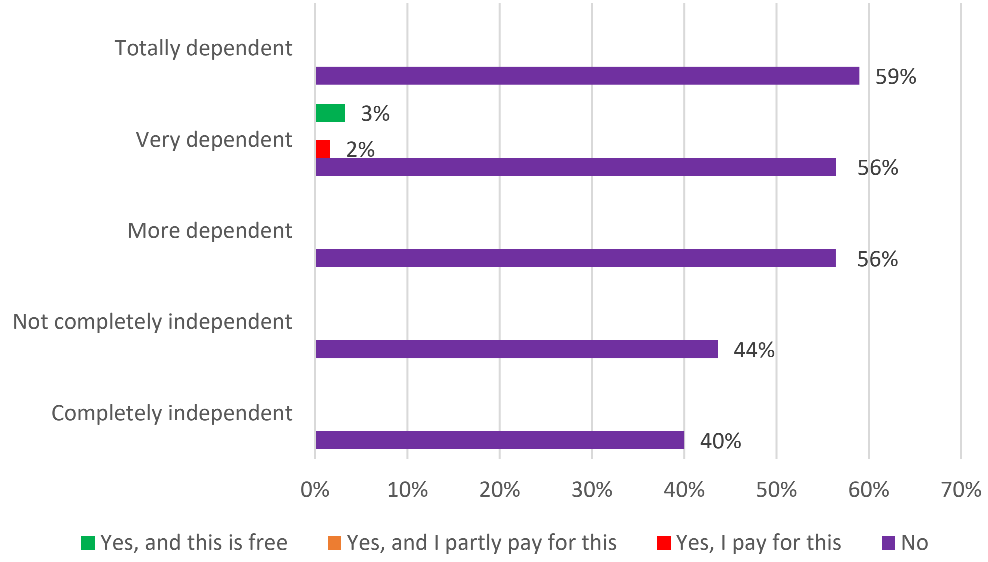


Fig 67. Cross analysis between level of independence and access to sources of social care - Residential care

3.8.4 Conclusions

People Living with MSA

Assessment for funded care

- Considering the severe nature of MSA, itis of concern that nearly half of the respondents were not assessed by their local council for funded care. Only one quarter were assessed and found eligible.
- The recent economic challenges experienced by local councils may help to explain the lack of assessment and access to services. However, the lack of access to funded care might also be exacerbated by a lack of knowledge and information around the condition.

Access to social care

- Over a quarter of respondents confirmed they didn’t require access to social services yet, in all likelihood due to being at an early stage of MSA. However, over half of the people with the condition don’t receive the help they need. This may be due to financial constraints, but also down to a lack of awareness and knowledge of MSA, and the needs of those with MSA and their carers.

Social care and level of independence

- Some of the provision of social care, such as **homecare** and **home adaptation,** appears to be linked to the level of independence of the individual with MSA. However, other sources of social care are not offered regardless of the decline of the independence of the person affected by the condition.

Current Carers and Former Carers

Assessment for funded care

- Carers echo the same concerns about the lack of assessment for funded care.

Access to social care

- The vast majority of carers confirmed the lack of access to Residential Care, Day services, Community transport and Supporting living. The application for services is often a lengthy and difficult process, and when combined with access issues, this becomes an additional burden for carers and people living with MSA.

3.9 Financial Impact

3.9.1 Employment

MSA is more prevalent in the older segment of the population, because of this 57% (n=118) of the respondents were already retired at the time of diagnosis.

Of those who were still in employment, only one individual was able to continue working as normal and 9% had their contract of employment terminated as a result of their MSA. For those that need their salaries to live and support family this is an added stress. The ability to work is not just a financial benefit, whilst still physically able to work this can have a positive impact on the emotional and mental wellbeing of those with MSA. Not being able to work may also necessitate the need to claim welfare benefits, which is often a difficult and complex process. The results are broadly in line with the ones from 2019.

From question Person living with MSA 43: Please select which option most accurately represents what happened to your employment status following your MSA diagnosis.

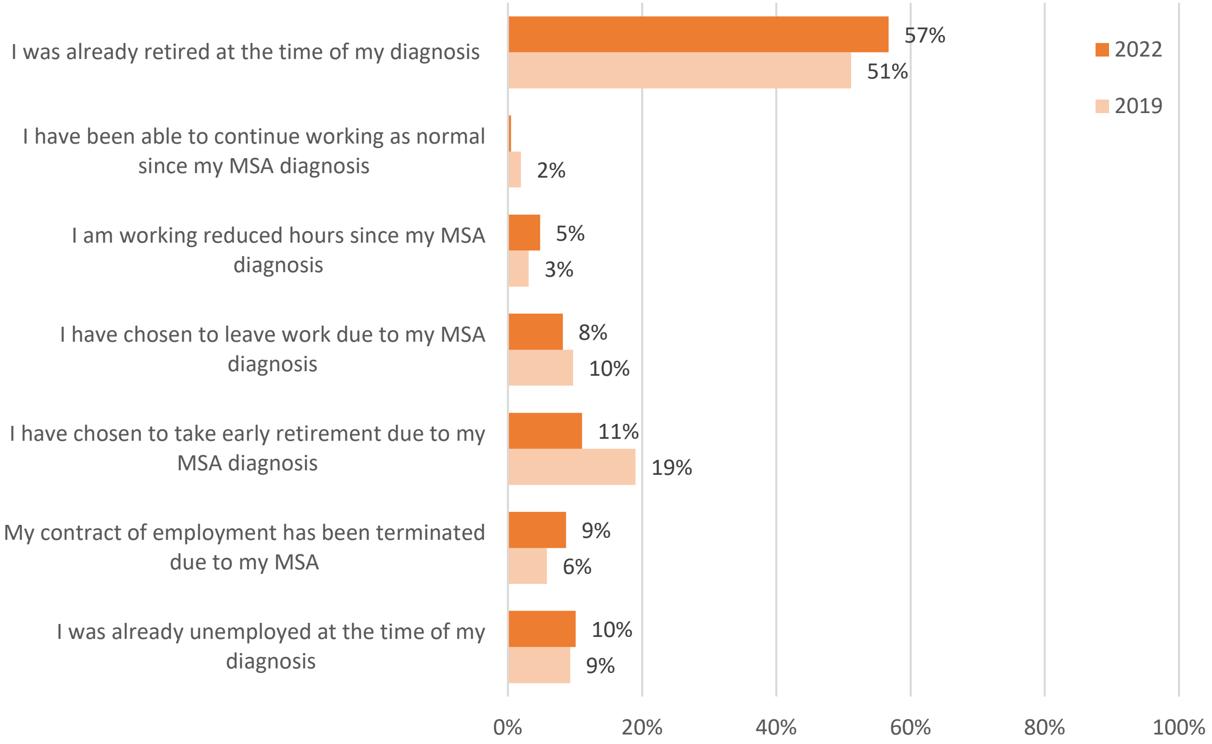


Fig 68. Impact of MSA on employment

“My employer told me to leave the premises when I was advised by my consultant to tell them I was being investigated for Parkinson's. To this day I am completely shocked. The stress that this has caused me is definitely hampering my abilities and my fatigue levels. If there had been any empathy or discussion to help me through this it would have made all the difference. My employers don't know yet that I have MSA, but it will not matter to them, I was completely discriminated against.”

3.9.2 Financial benefits claiming

When it comes to finances, only 17% (n=37) of respondents with MSA and 16% (n=33) of carers were **very confident** that they had claimed all benefits that they were entitled to.

Former Carers were more positive with just over a quarter (27%, n=24) reporting feeling very confident.

These figures are very low. Access to adequate financial support will be key to helping both people with MSA and their carers to be able to gain the appropriate support and services.

From question Person living with MSA 44/CC41/FC32 How confident are you that your household has claimed all the financial benefits to which you are entitled?

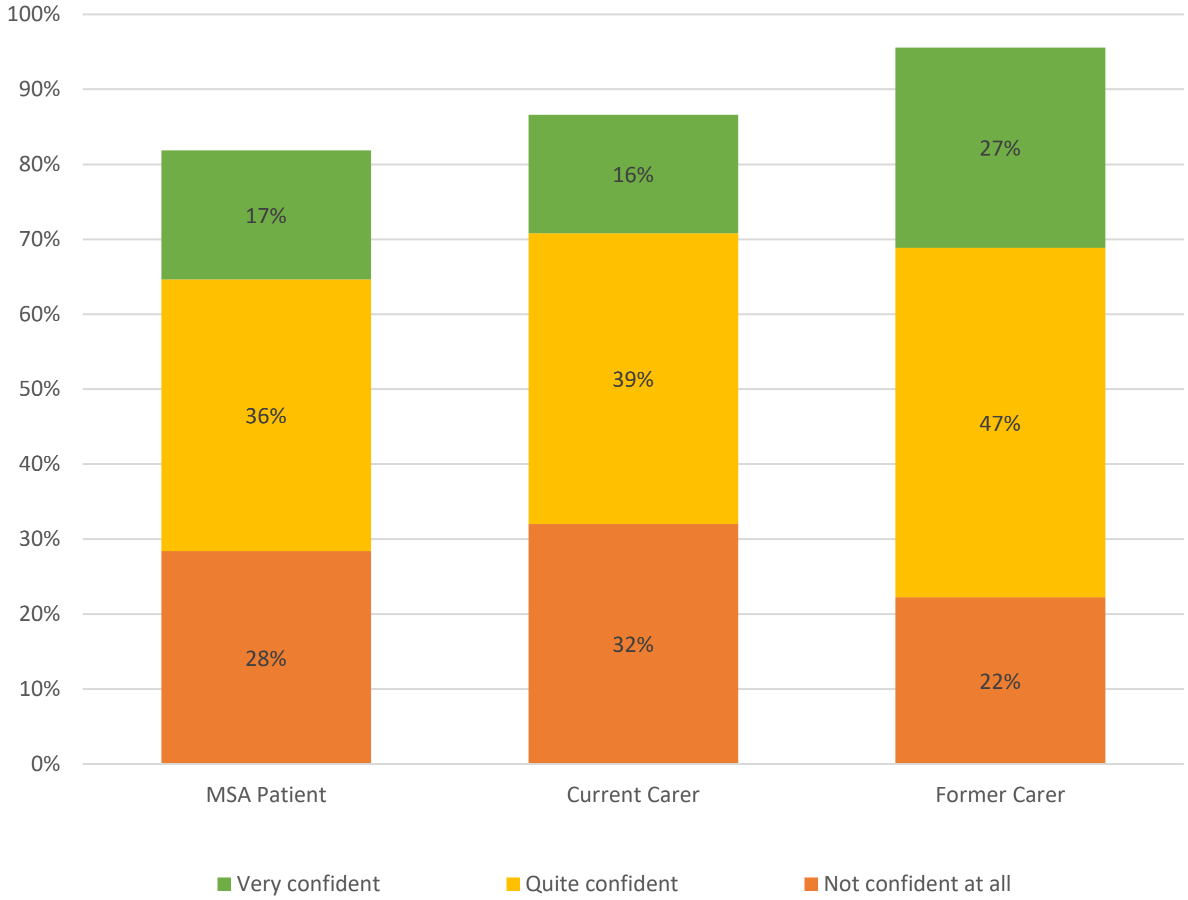


Fig 69. Households access to financial benefits

3.9.3 Specialist advice for welfare benefits

Among the three groups more than half of the respondents had not sought specialist advice for their welfare benefits. This might be due to a lack of knowledge and so information about finance and benefits should be something that all people living with MSA and their carers are signposted to.

From question Person living with MSA 45/CC 42/FC 33: Have you sought specialist advice for welfare benefits?

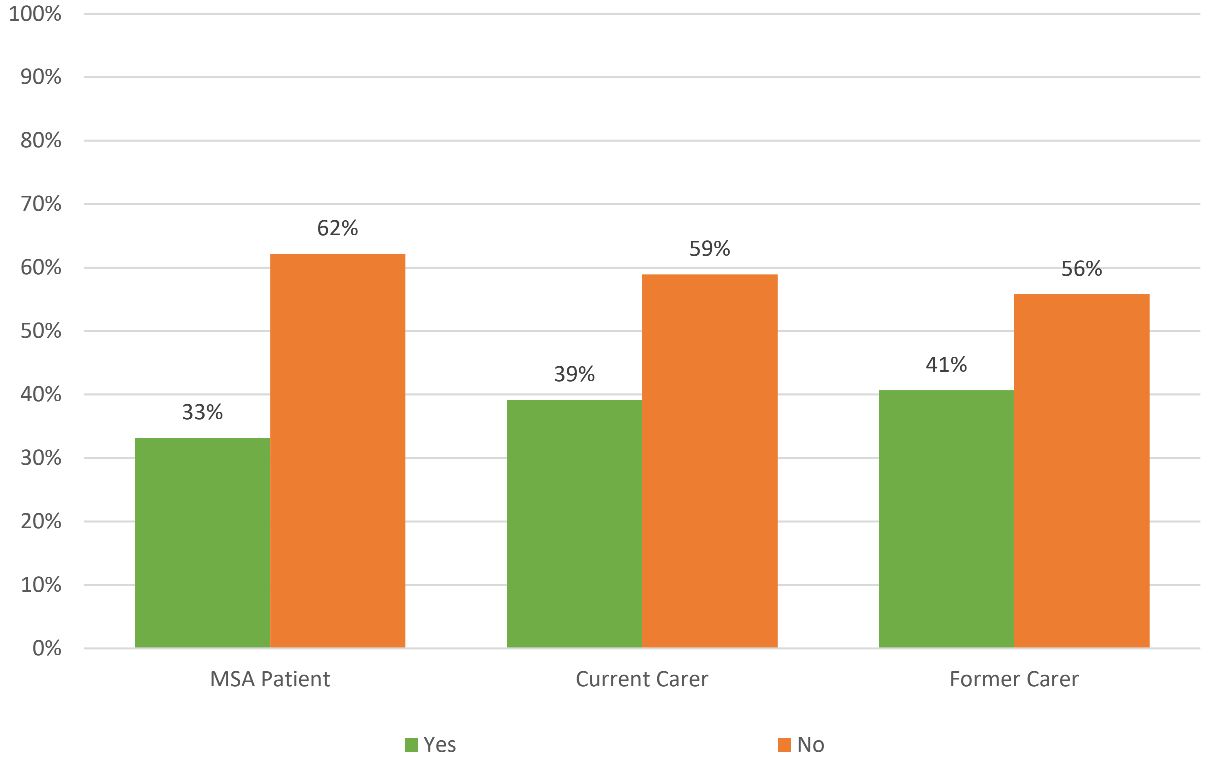


Fig 70. Respondents seeking specialist advice for welfare benefits

3.9.4 Financial impact on people living with MSA

There was less of a reported impact on finances than might be expected. Over half of respondents (54%, n=110) reported that their financial needs were covered although one third (34%, n=70) reported having some financial issues. Just 2% of respondents reported having severe financial issues whilst a further 10% (n=21) preferred not to say.

Although it may sound encouraging that more than half of respondents have not experienced financial issues, it must be noted that MSA is more prevalent in people aged 65 and over (66%, n= 139). Therefore, the majority of individuals could be retired and be able to claim a pension. As a result, we can infer that this group of individuals are less likely to have financial issues due to already being at retirement age and no longer needing to rely on a job for income. It appears the respondents have fewer financial issues compared to 2019.

From question Person living with MSA 46: To what extent do you feel your household's financial needs are being covered?

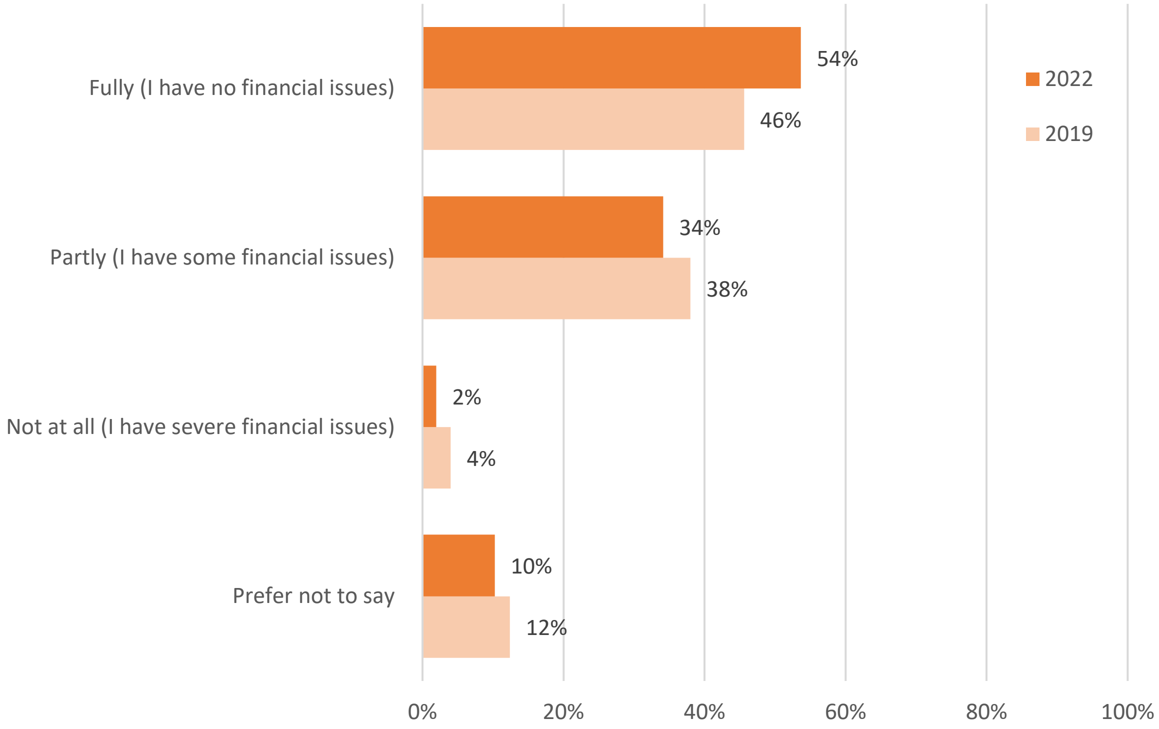


Fig 71. Extent to which financial needs are being covered

3.9.5 Financial impact on carers

Carers and Former Carers reported a higher impact on their financial situation as a result of living with someone with MSA with only 30% (n=59) of carers and 52%(n=46) of Former Carers not affected by financial issues.

From question CC 43: As a result of somebody in your household living with MSA, has your financial situation been affected?

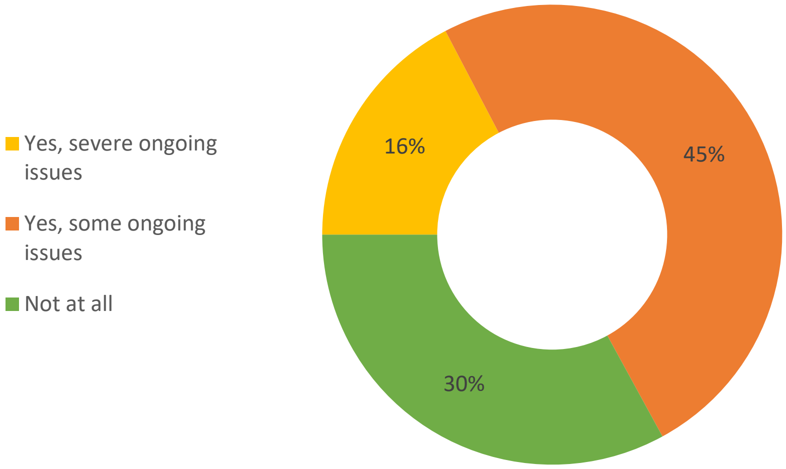


Fig 72. Financial impact on carers

From question FC 34: As a result of caring for someone with MSA, was your financial situation affected?

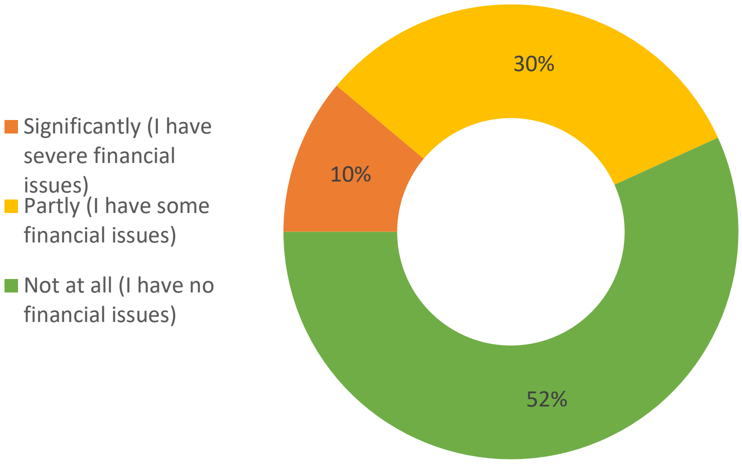


Fig 73. Financial impact on Former Carers

Current carers commented:

“Moved from regular paid work to carer and carers on pensions, had to fund creation of level access to home, pay for stairlift, build modified wet room, ensuite to bedroom with shower (seated) and special toilet.”

“I cannot claim carers allowance as I receive state pension. I cannot work because I am a full-time carer.

“Although we have sufficient funds to be able to provide for home care, etc. for the foreseeable future, the significant costs have an inevitable impact and, in time, may affect the resources that I have available for my future care should I need it.”

“I had to retire early with significant impact on pension.”

“We had to remortgage to pay for accessible facilities in an extension on the ground floor. Wet room and downstairs bedroom accessible to wet room as well as accessible access to the house which post his demise I will be paying for until 2025.”

3.9.6 Obtaining and claiming Travel and Critical Illness insurance

Of the respondents with MSA, 23% (n=47) had obtained Travel Insurance, however 68% of respondents stated this is not applicable to them, this is maybe because they cannot or find difficult to travel.

2% (n=5) reported obtaining Critical Illness Insurance. However, 81% stated this is not applicable. This could have financial implications at an already difficult and sensitive time.

Conversely, of those respondents with MSA that were able to obtain Travel and Critical Illness insurance, the majority received their claim pay-out (95% for Travel Insurance and 92% for Critical Illness).

3.9.7 Further financial impact of living with MSA

When the respondents with MSA were asked about the additional cost they had incurred or extra things they had to pay as a result of their MSA, 75 out of 215 (35%) commented with their own words.

An analysis was carried out and the comments were organised into four main themes. These are described below with examples:

1. **Physical home adaptations related to MSA**

Having MSA means that there are adaptations required to enable better mobility around the home, this was referred to regularly by those that commented.

“I know here in Ireland everything will be means tested. My wife is working, it's not huge wage, but it means we will not get any grants for housing adaptations and we will have to pay it all ourselves when the time comes. When my wife has to give up work, even the carer's allowance is means tested here and we will definitely be in financial turmoil then.”

“Had to have kitchen and bathroom adapted and will need to modify house soon. Bought sticks, wheelchair, assorted sleep pillows due to side effect of drugs meaning I shouldn't lay flat.”

“Stair lift, electric bed, support to get in and out scooter, domestic help. “

2. Mobility aids are important

Alongside adaptations to the house, people also commented on the need to access wheelchairs, mobility scooters and other essential mobility aids.

"I have had to buy a stroller to move about the bungalow, which we had to buy because I couldn't manage the stairs. A mobility pavement scooter, a rise and recline chair and bed. The bathroom refitted to suit my needs, the garden hard landscaped so I can access it on my mobility scooter."

"Own wheelchair - can't use wheelchair myself, not have one use myself for family take me out only. Adapt our scooter, all for some independence. Chairs and bed - brought ourselves. Other small bits for my safety."

"Purchase of a mobility scooter, careline package, bladder and bowel pads."

3. Increased household bills

Respondents noted the rise in household bills due to increased need for heating, washing and other daily activities.

"All the necessary equipment required daily increases our energy bills. There is no allowance for this. We both have work and state pensions, so assume we are not entitled to any other finance, but we now no longer pay for my care."

"Using more gas and electricity as I am always cold".

"More clothes washing and drying."

4. Additional costs

Outside of physical home adaptations, a diagnosis of MSA and the impact on the person with MSA's physical ability, necessitates the provision of many additional items.

"Extra laundering, especially bed linen. Treadmill to enable at-home exercise when not possible to go out and when support of treadmill arms required."

"Additional costs involve rollators, non slip mats and heating because I am susceptible to the cold."

"Incontinence wear, extra home help, extra hours for cleaner and transport."

3.9.8 Conclusions

People Living with MSA

Employment status after diagnosis

- As MSA is more prevalent amongst older demographics, nearly three fifths of the respondents were already retired by the time they received the diagnosis.
- Of those that were still working, ten percent of the respondents stated their employment was terminated by their employer. Other respondents commented their employment had been affected in some way.

Awareness of the benefits and support available

- Amongst the respondents only a small percentage were very confident that they had accessed all the benefits available to them. Nearly two thirds had not sought specialist advice, with a high chance that some available benefits had been missed out.

Financial impact on households

- Over half of respondents reported having no financial issues whatsoever. However, one third reported having some financial issues whilst 2% of respondents reported having severe financial issues. This finding could be surprising but it is important to highlight the age at which MSA manifests is generally towards the end of an individual's career.

Additional financial issues

- Whilst reducing working hours, or stopping working altogether, reduces the income the person with MSA used to have, new costs are also added. An example of the additional costs MSA patients face are home improvements, new equipment and increased utility bills. While some costs might be covered by the local council - like in the case of home improvements - the majority are not.

Current Carers

Awareness of the benefits and support available

- Similarly to those people with MSA, only a small percentage of carers were confident that they had accessed all available benefits and nearly three fifths had not sought specialist advice. This is in line with the results from people with MSA.

Financial issues

- Current carers have reported a more severe impact on their financial situation. This is probably due to them stopping working to care for a loved one.

Former Carers

Awareness of the benefits and support available

- Interestingly, amongst Former Carers, over one quarter of the respondents were very confident they had claimed the financial benefits they were entitled to, with nearly fifty percent reporting they were quite confident. This discrepancy in awareness among the three groups might be due to the advance stage of MSA the former carers were dealing with and the range of healthcare professionals that would be involved at that stage, which made them more aware of what they were entitled to.

Financial impact on household

- Two fifths of Former Carers highlighted they had ongoing severe, or some, financial issues whilst looking after the person with MSA. This is a lower proportion than current carers. The reason behind this discrepancy might be that dealing with a more advanced stage of MSA, and for longer time, Former Carers were more aware of all the benefits and support they were entitled to. It may be that significant extra costs are incurred whilst the person with MSA needs the range of items, equipment and support during their journey.

3.10 Palliative care/advance care planning

Because of the progressive nature of MSA, people and families affected by the condition find themselves facing difficult conversations and decisions on what will happen towards the end of their life.

3.10.1 Thinking of end-of-life options

Over three quarters of respondents with MSA (76% n=151) had thought about, or thought about to some extent, what they wanted to happen towards the end of their lives. Less than a quarter (22% n=44) had not thought about this at all, and a further 1% (n=2) preferred not to say. This could be because these respondents are at an early stage of the disease, but it could also suggest that some people find having these conversations difficult. Early conversations, and support, towards the end of their lives can make the planning process for their end-of-life care easier. People with MSA and their carers should be supported and assisted in this aspect of their care.

From question Person living with MSA 50: Have you thought about what you would like to happen towards the end of your life?

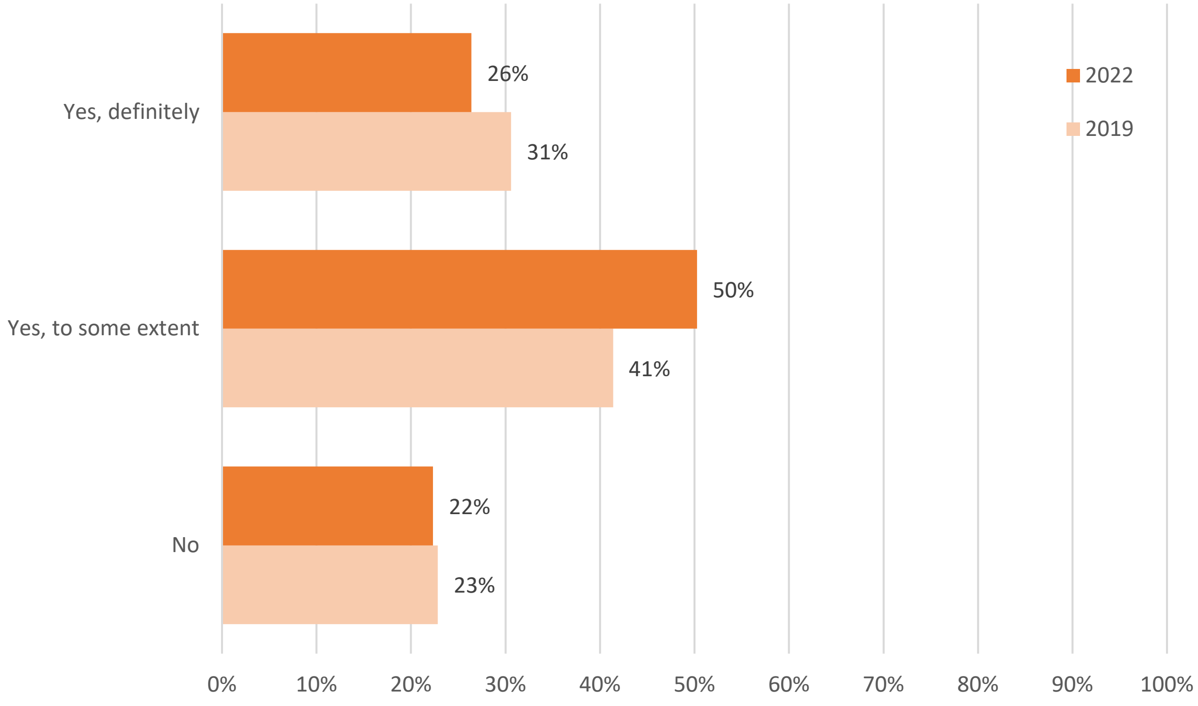


Fig 74. Respondents who had thought about end-of-life options

3.10.2 Discussion about end-of-life care with carer and Former Carer

When asked if treatment, care and support options were discussed with the person they cared for once MSA had advanced, over 66% confirmed that a discussion had taken place or had taken place to some extent. Almost one third didn't have this conversation and over 2% (n=4) preferred not to say. Again here, this suggests that there is to some extent a reluctance to discuss end-of-life care. Sensitive support at the later stages of their lives could help people with MSA, and their carers, to develop their plans and make the process as smooth as possible.

From question CC 44: Have you discussed with the person living with MSA what treatment, care and support they would want as their MSA advances?

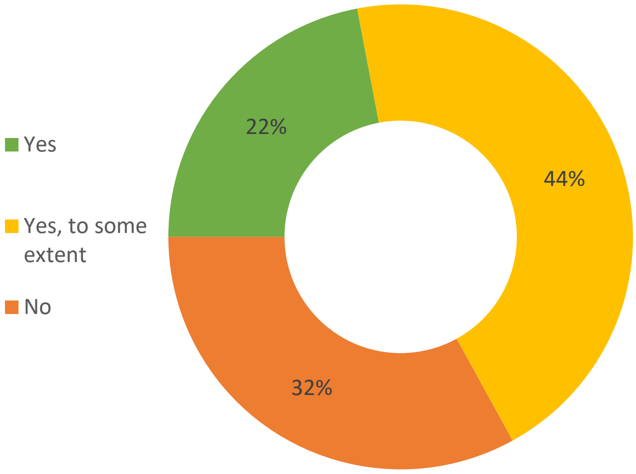


Fig 75. Discussion of end-of-life care between carers and person with MSA

From question FC 35a: Did you discuss with the person living with MSA what treatment, care and support they would want as their MSA advanced?

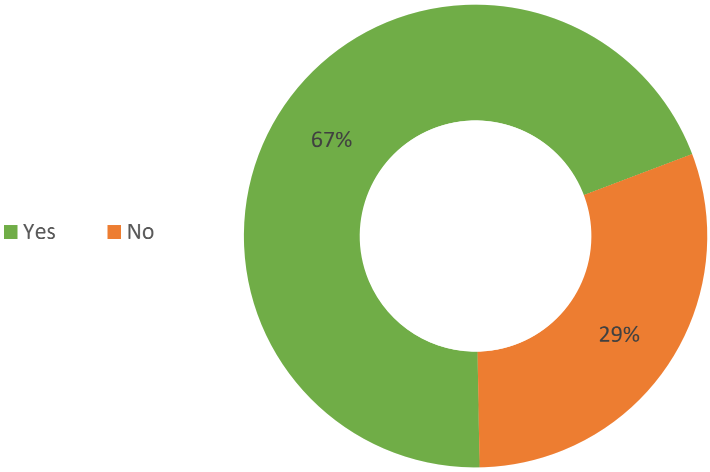


Fig 76. Discussion of end-of-life care between Former Carers and person with MSA

3.10.3 How the discussion about end-of-life care started with Former Carers

Being a sensitive topic, it was important to understand and further investigate the context that started the end-of-life discussion between the Former Carer and the person they were caring for.

Nearly half of the respondents (49%, n 45) commented with their own words. Often these discussions were facilitated by professionals and other support. The health deterioration of the person with MSA and fear to not be able to fulfil his/her wishes, was one of the reasons often brought up. Below are some examples:

“Someone we met died quite soon after being diagnosed. I wanted to be sure I was doing what he wanted and not what the professionals thought best.”

“Speech was fading.”

“An awareness that the illness was progressing and it was going to be inevitable that specialist care would be necessary.”

“The hospice "path" document which opened used up topics.”

“We had an 11-year-old son and my husband was concerned about the impact his MSA would have on his childhood. He didn't really want to go into specifics but he was adamant he did not want to die in the home and that he wanted the house to remain a home and not become a hospice.”

“She knew early on what MSA would involve and wanted her wishes known to me and the family.”

“End of life planning specialist clinician.”

“We had previously discussed end of life care and he was clear that he did not want to prolong his life unnecessarily so when diagnosed it was easier to broach the subject.”

“Conversation with our neurologist who suggested an end-of-life care plan.”

“I prompted it when I was getting to the point of no longer being able to cope.”

3.10.4 Discussion about end-of-life care options with medical professionals

More than half of the people affected by MSA and carers **did not** discuss the end of life care options with a healthcare professional. The percentage is much lower (32%, n=28) with Former Carers. This may be because many of the respondents that have MSA and are current carers are at an earlier point post diagnosis.

From question Person living with MSA 51/CC 45/FC 37: Have you ever discussed 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)?

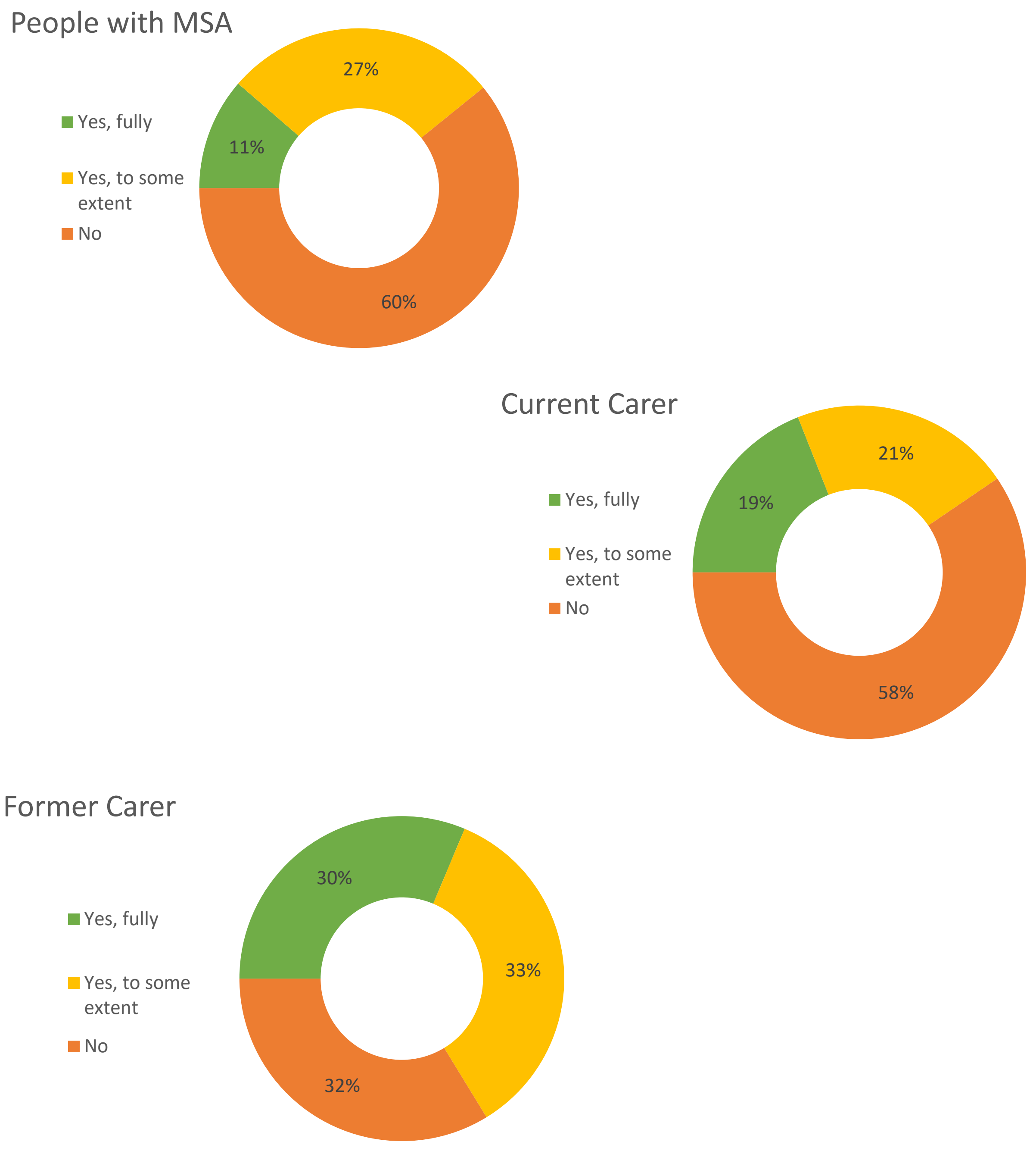


Fig 77. Discussion of end-of-life care options with healthcare professionals

3.10.5 Benefits of the discussion about end-of-life care

Of the people that had had these conversations, when asked where these conversations took place and with who, the responses centred around discussions with healthcare professionals and these were mostly at home, in clinic or in the Hospice. This shows that there is a wide range of potential support at this point in the process*.*

“Discussion with my wife and her consultant neurologist, his clinic and then further with her at home. She chose herself to have "not for resuscitation" placed on her medical records.”

“At home with neuro nurse specialist when a DNR was agreed.”

“At home with palliative team.”

“With hospice nurse visiting our home”

“With nurse at hospice and GP”.

Of those who had **had** this discussion, over 81% found it helpful, further illustrating how important a discussion with a healthcare professional can be for people with MSA and their carers. The results are broadly in line with those from 2019.

From question Person living with MSA 52/CC 47/FC 39: Was this a helpful conversation?

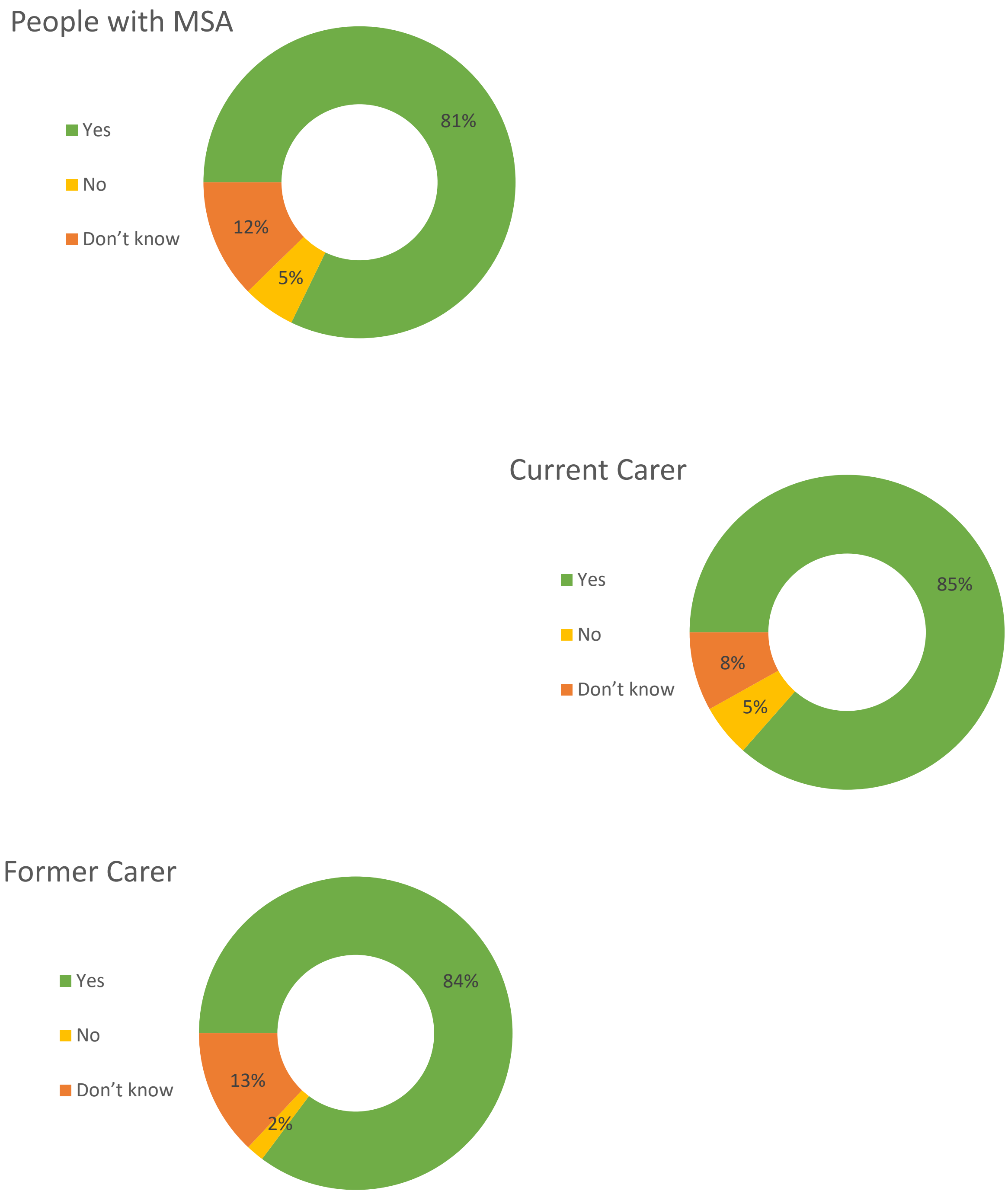


Fig 78. Benefits of discussion of end-of-life care

3.10.6 End of life care conversation

More than one third of respondents reported that they hadn’t had yet a discussion regarding palliative care/advance care planning, but that they would like to have this conversation. Interestingly, of the respondents with MSA who had **not** yet had this discussion, nearly one third (31%, n=36) didn’t want to have this conversation with a doctor. It is a very difficult, and sensitive topic to think about, let alone discuss. Older people may be less inclined to want to discuss this and may feel uncomfortable doing so. Healthcare professionals should introduce this conversation slowly and sensitively to every person affected by MSA during appointments and allow time for the person to open themselves up to these useful conversations. The results have slightly declined compared to 2019.

From question Person living with MSA 53: If you have not yet discussed palliative care / advance care planning is this a conversation you would like to have?

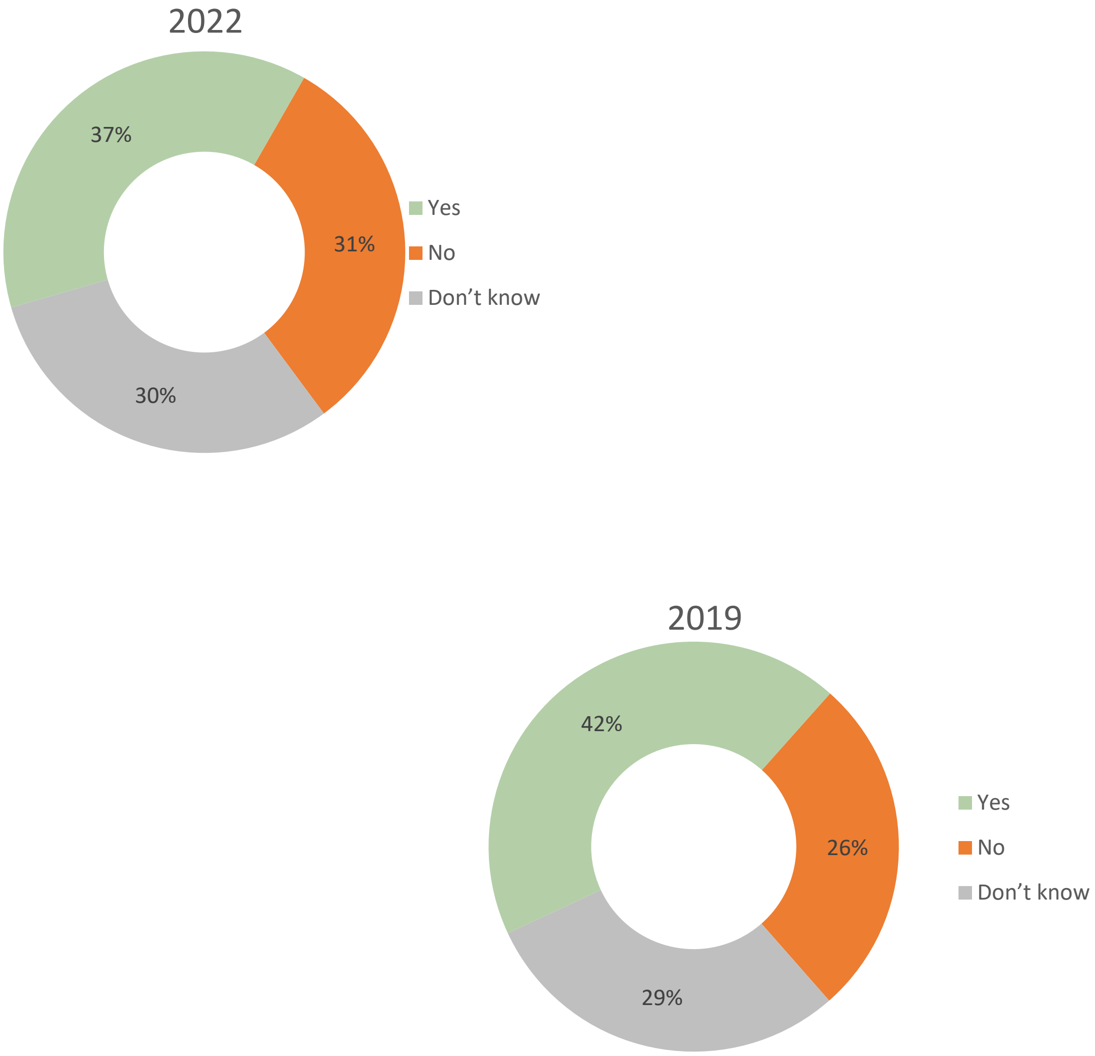


Fig 79. Conversation on end-of-life care

3.10.7 Referral to specialist palliative care

Of the respondents across all three groups, over one third (34%) reported that they were not referred for specialist palliative care or hospice care. The chart below breaks down the responses in more detail.

From question Person living with MSA 54/CC 49: Have you been referred to specialist palliative care / a hospice?

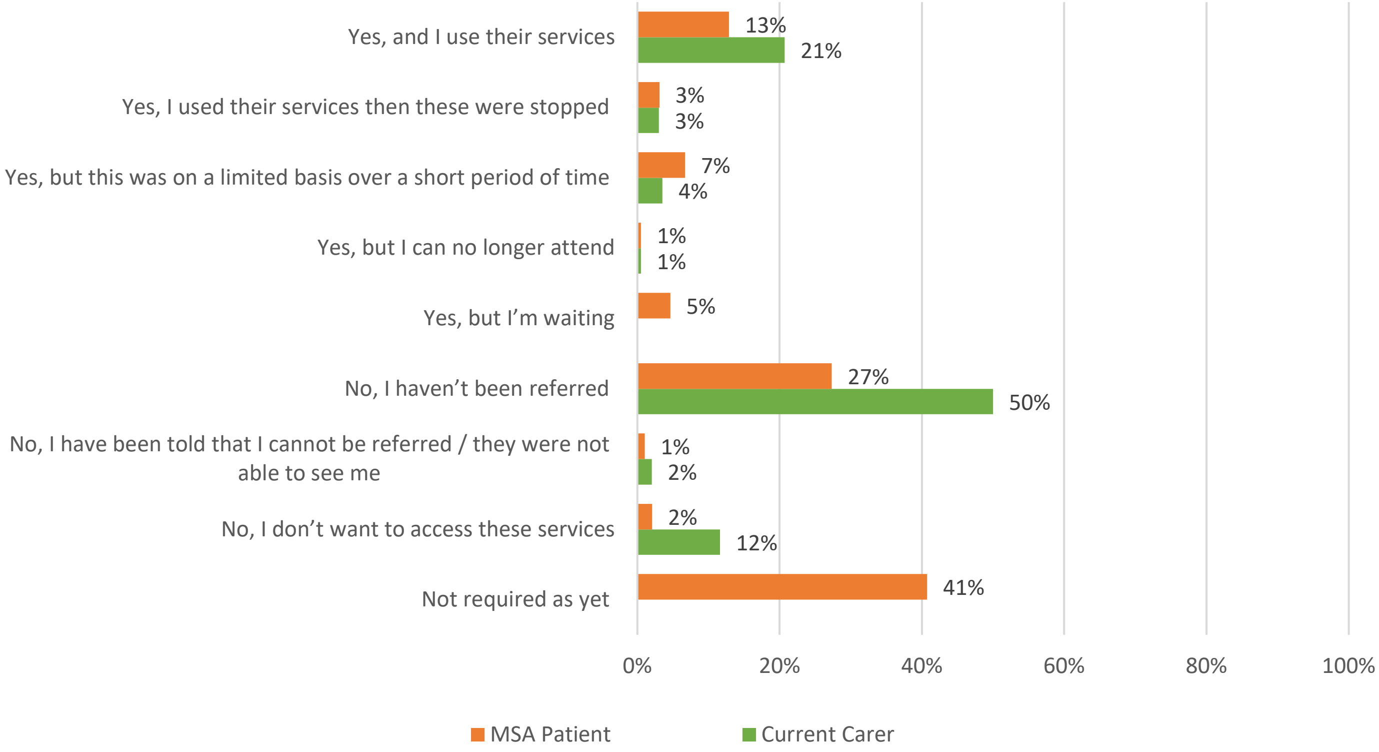


Fig 80. Referral to specialist palliative care

Of the respondents with MSA that were referred to specialist palliative care, the list below shows the services they had access to:

- More than half (51%, n= 23) were referred to a Day hospice.
- 38% (n=17) to a Community Palliative Care team.
- 16% (n=7) to an Outpatient Clinic with specialist palliative care doctor.
- 16% (n=7) as an Inpatient at the hospice ward.
- 9% (n=4) to Hospital Palliative Care Team, while at or in hospital.
- Only one individual (2%) had contact with the hospice service at clinic appointments.
- 13% (n=6) Other services.

This demonstrates the inconsistency in services that people with MSA access across the UK and Ireland.

3.10.8 Specialist palliative care and knowledge of MSA

Encouragingly, of the 29% of respondents that had access to specialist palliative care centres 82% (n=36) reported the centres had knowledge of MSA.

3.10.9 Formal advance care planning

In terms of formal advance care planning, among all the respondents here, the most reported were:

- A will (around three quarters, 73%, of respondents have one in place).
- Lasting Power of Attorney (POA) for property and finance (58%)
- Lasting Power of Attorney (POA) for health and welfare (54%).

From question Person living with MSA 57: Have you completed or considered any of the following as a direct result of your MSA diagnosis?

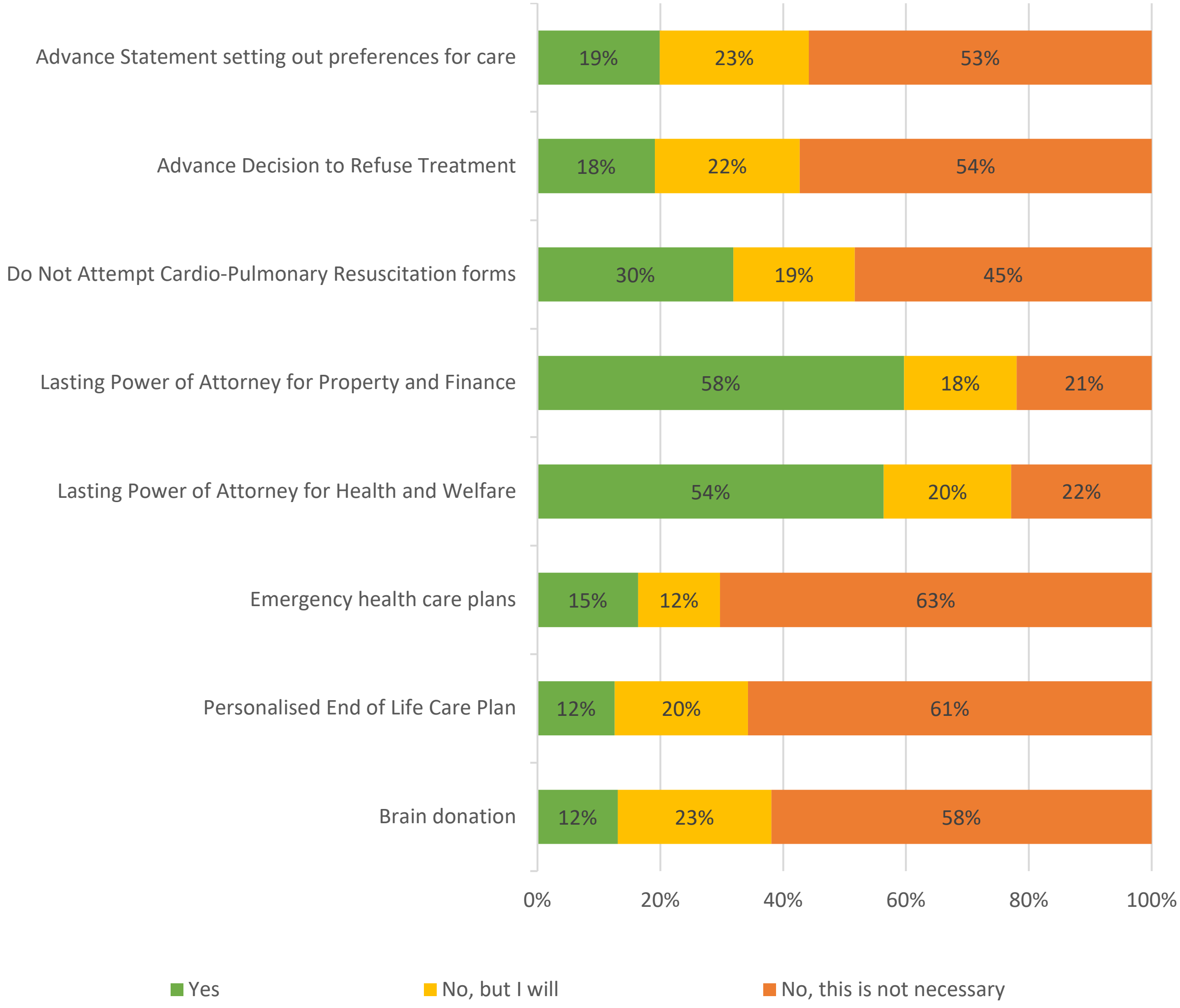


Fig 81. Formal advance care planning

3.10.10 Quality of end-of-life care

Nearly two thirds of Former Carers (65%, n=55) were satisfied or satisfied to some extent with the quality of the end-of-life care provided to the people with MSA that they had been caring for. 15% (n=13) were not happy and for 21% (n=18) end-of-life care was not required.

Less than one third of the respondents reported that the people they were caring for didn’t die where they had wanted to. From the comments provided by the respondents, this was often due to the person they cared for not being able to communicate or they were in hospital and too ill to be moved. See the comments below:

“She wasn't able to speak and too ill to move from hospital on the day she died.”

“Taken ill very suddenly.”

“I think my wife would have preferred to die at home but the hospital palliative care nurse said she was too weak to move and could well pass away in the ambulance on route to home. Also advised she could be made more comfortable at the hospital.”

3.10.11 What could change for palliative care and quality of end-of-life care

Former Carers were asked to consider how palliative and end-of-life care could be improved.

There is clearly a need for a timely discussion and involvement between healthcare professionals and families to prepare them for what is coming. It would also be invaluable to give guidance and access to resources at the right time. This needs to be done without adding unnecessary stress to families and people with MSA who are embarking on their final stage of their journey. Below are some of the comments:

“To be able to find out in good time about care and support available would be invaluable. We didn't meet a long term conditions nurse until a month or so before his death, his help earlier on would have been invaluable. Trying to negotiate the maze of healthcare, social care is your worst nightmare, trying to find out who can do or is responsible for the what, where and when is mind blowing all the time you are trying to do your best for your loved one so please will anybody be able put together a proper action plan or a plan just to point carers in the right direction, and not just pay lip service to the really important role we carers have done.”

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

“My wife spent 9 days in hospital before she died. This came as a shock as nobody had prepared me for such an outcome. I don't believe I was given enough information by the staff until the morning she was dying, she was just another case on the ward.”

“We are fortunate to live in a part of south London where medical services and facilities are good and seem to work very well. Lots of help was offered for all stages of the MSA journey and I can honestly say that we saw the NHS and other social services at their best. There were very few occasions that things didn't go right, or where we couldn't get the help or advice needed, but they were easily overcome.”

“There is not enough open communication. Difficult situations can be made so much worse by lack of clarity. Lack of staff means you do not get enough support as things near the end. It is very stressful having to fight for someone who needs help when you don't understand what is happening yourself.”

“Would have appreciated hospice involvement sooner, but my wife's last days were in the middle of the COVID lock-down”

“It took about 4 days of back and forth arguments trying to find carers to support him when he came home to die. But I couldn't see the difference from before when I, along with my local private carers were caring for him. He could have been home much earlier, however thankfully we did make the last night.”

3.10.12 Emergency care plan

The results for this question are very similar for carers and Former Carers. 76% (n=161) of current carers and 70% (n=63) of Former Carers did not have an emergency care plan in place in case they suddenly were unable to care for their loved one. Of those with an emergency plan in place, the majority were relying on family members, some were also supported by private carers or had already agreed arrangements with local care homes. The respondents made comments in their own words on this question and some of these comments can be seen below.

From question CC 7/FC 10: Do you have an emergency care plan in place (e.g. in case you suddenly can’t care for the person living with MSA)?

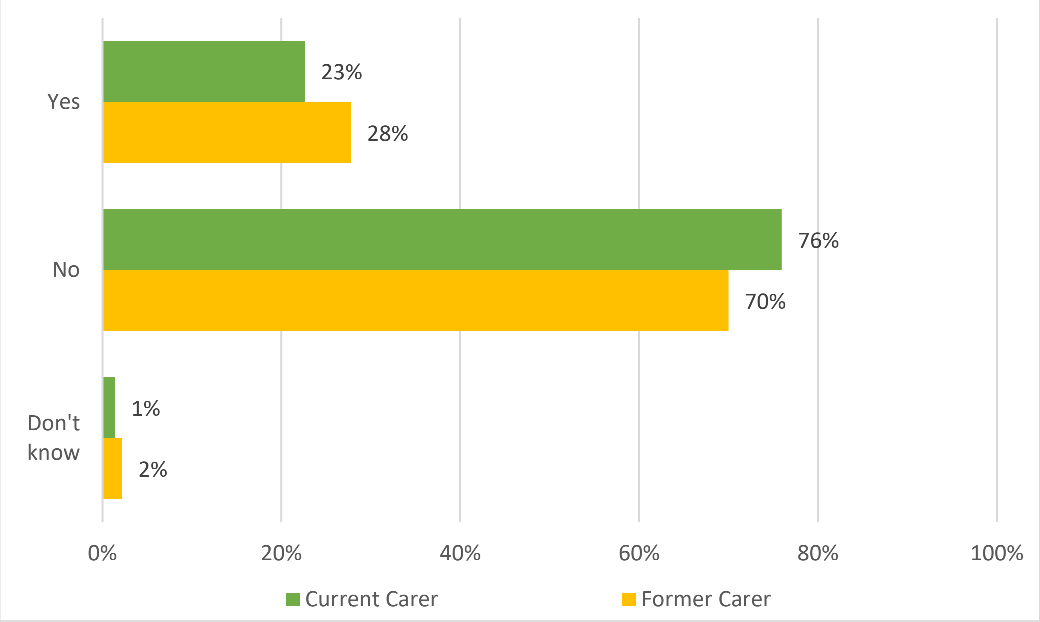


Fig 82. Carers and Former carers’ emergency planning

“Just me looking after him and our children when needed.”

“The plan has been agreed with…. via a Carers' emergency support back up system plus card to be kept with me at all time. The plan has details of all medication, routines, key contact numbers, and links to my husband's respect form completed with the guidance of our local hospice.”

“I was able to contact a local hospital neurology unit which provided free planned respite on a number of occasions and also when I was admitted to hospital in emergency. My adult children were able to cover for a weekend until the respite was organised. At other times my wife's sister would come and stay overnight if I was admitted to A&E at a local hospital.”

3.10.13 Carer Assessment and emergency planning

Interestingly, whilst nearly two thirds (63%, n=132) of carers stated that they have not received a care assessment, this was not the case for 67% of the Former Carers (n=61). There is a stark contrast between these two findings. This may be as a result of the change in care and support as a result of the recent pandemic or perhaps for example because the Former Carers received an assessment at a later stage of the disease.

3.10.14 Year and cause of death

99% of Former Carers reported that the person living with MSA died in the last five years with 57% listing MSA as the Primary Cause of death on the death certificate.

From question FC 4c: Year of death

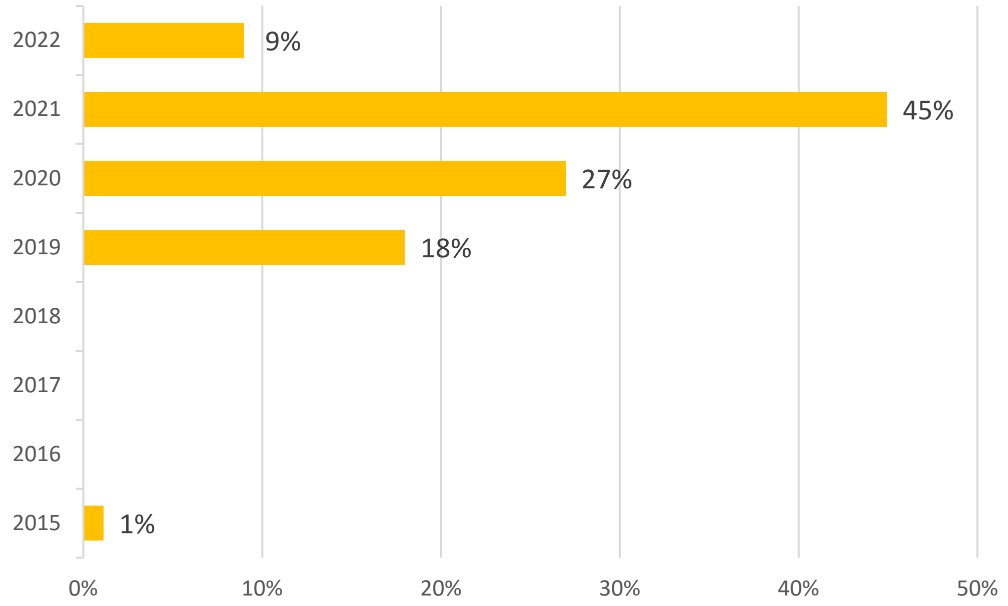


Fig 83. Year of death of the person with MSA

From question FC 6: It would be particularly helpful to know what was officially recorded on their death certificate?

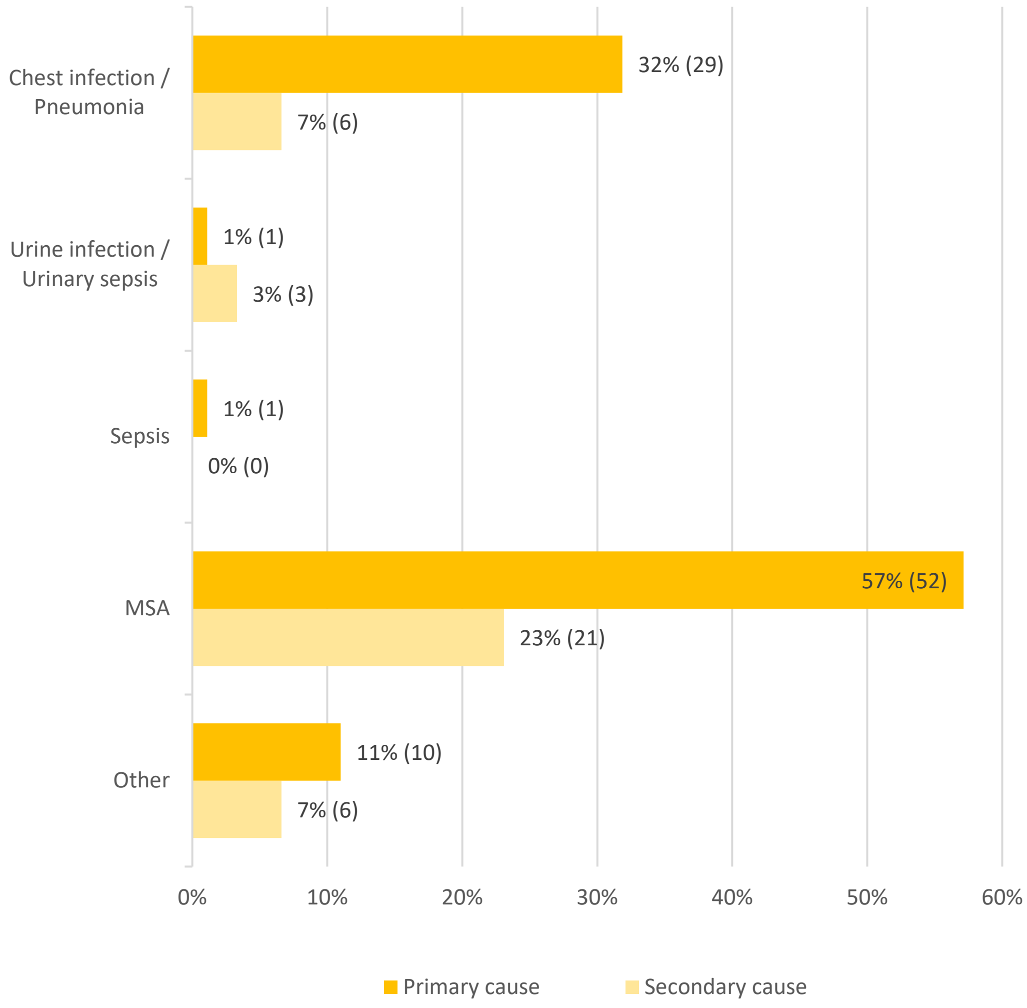


Fig 84. Cause of death

3.10.15 Passing of the person with MSA

When talking about the death of the person with MSA, only 22% of Former Carers were expecting the death at the time that occurred. A further 41% (n=37) were expecting the death of the person they were caring for, but they felt it happened sooner than they thought.

For a further 37% of the respondents the death of their loved one was unexpected.

From question FC 7: Did the person living with MSA die when it was expected to happen?

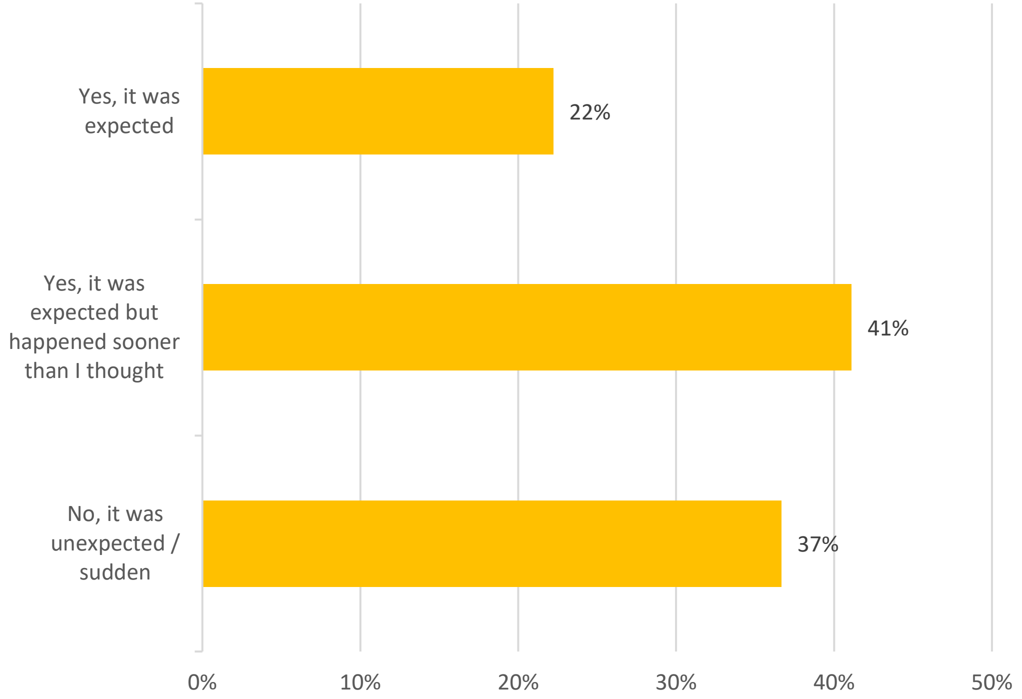


Fig 85. When it occurred, was the death of the individual expected or unexpected?

3.10.16 Conclusions

People Living with MSA

Discussion on end-of-life care options

- Even though the vast majority of people with MSA had considered what would happen towards the end of their life, more than half of respondents had not discussed end of life care options with a healthcare professional. Some individuals had no intention to have the conversation at all. However, the majority of the people that had the conversation found it useful.

Palliative care and Hospice care

- Over a quarter of the respondents reported that even if required it, they were not offered the option of specialist palliative, or Hospice, care. Budget cuts in local councils and the lack of Hospice spaces may help to explain why palliative or Hospice care was not offered.

Advance care planning

- 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 their preferences of care, and the option of brain donation. Both of these are reported less frequently.

Current Carers

Discussion on end-of-life care options

- One third of the current carers hadn’t had a conversation with their loved one about treatment, care, and support as the MSA advanced, probably because they find it difficult to face a topic that is extremely sensitive.
- In line with people affected by MSA, more than half of the carers have not discussed with a healthcare professional what will happen in the later stages of MSA.

Palliative care and Hospice care

- Half of the carers reported they were not offered specialist palliative care or Hospice care option.

Advance care planning

- In line with people living with MSA, the formal advance care planning measures most frequently reported were a Will and Lasting Power of Attorney for property and finance.

Former Carers

Discussion on end-of-life care options

- When Former Carers were asked if the end-of-life care options were discussed with their loved one, more than two thirds confirmed this was the case. This result should not be surprising, as this is probably due to the later stage of MSA former carers had to deal with.

Palliative care and Hospice care

- Over a quarter of former carers reported they were not offered a specialist palliative care or Hospice care option. This is very worrying as even at a later stage of the condition both patients and carers seem not to be properly supported.

Advance care planning

- Former Carers confirmed that for formal advance care planning the most frequently discussed options were a Will and Lasting Power of Attorney for property and finance.

Quality of end-of-life care provided

- Encouragingly, two thirds of the respondents were satisfied or satisfied to some extent with the quality of the end-of-life care that was provided to their loved one. Additionally, nearly three fifths of the respondents confirmed the person with MSA died where they had wished. When this was not the case, it was mainly due to a sudden death or for medical reasons.

3.11 Final questions and MSA Trust

3.11.1 Overall quality of life

The overall quality of life for people living with MSA can be considered poor. It is noticeably more severe compared to other neurological conditions. The vast majority of respondents (81%, n=171) rated their quality of life as average or very poor. 16% (n=34) rated their quality of life as good. Just 3% (n=7) rated it as very good.

3.11.2 MSA Trust services

The most accessed MSA Trust services are MSA Trust Information and Factsheets (88%, n=174), the MSA News Magazine (81%, n=162) and MSA Trust Healthcare Specialists (76%, n=137).

It is clear that people affected by MSA value and need the information the MSA Trust provide via information or through the access to MSA Healthcare Specialists. This shows, as previously commented, that the MSA Trust is filling a gap in the wider healthcare system which lacks the adequate provision of information or awareness of MSA among healthcare professionals. Promotion of specialist support offered through the MSA Trust could maximise the financial and welfare support that people living with MSA and their carers can access.

From question Person living with MSA 60: Have you used any of the following MSA Trust services?

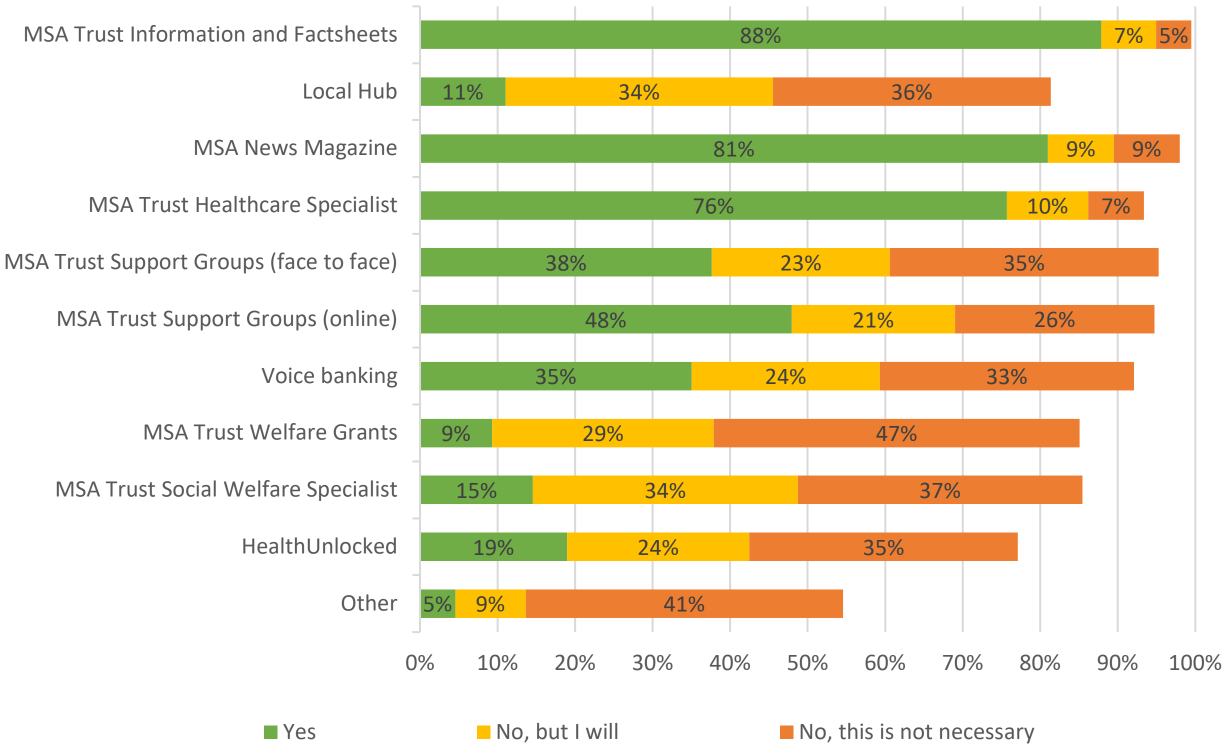


Fig 86. MSA Trust services used by the respondents

3.11.3 Support from the MSA Trust

Being well aware of the feeling of isolation people have, the MSA Trust is seeking different options to help. 33% of respondents (n=71) would find **Online Support Groups run by MSA Trust helpful**, together with another third (33%, n= 71) of respondents stating that **In person Support Groups** would be beneficial. These services are already offered by the MSA Trust, however, but there is a greater need to promote them more widely.

From question Person living with MSA 29/CC 37: The Trust is looking at ways we can help people with feelings of social isolation. Which, if any, of these options would most help you?

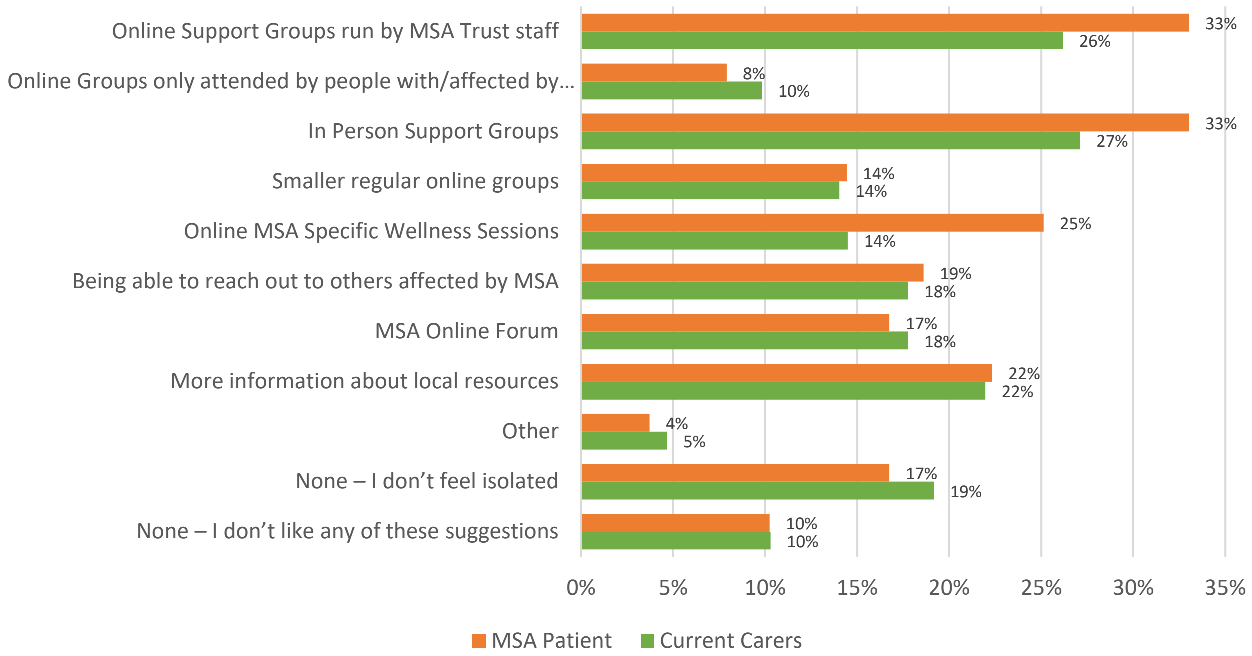


Fig 87. MSA Trust's impact on feeling of isolation

3.11.4 Positive and negatives of MSA Trust's services

When people were asked what is good, or bad, about the MSA Trust services they use, respondents with MSA, current carers, and Former Carers commented with their own words:

Positive comments

MSA Trust is clearly valued among the MSA community as being a beacon for positive support and helpful and honest information.

"The MSA Trust ID unique provides clear, factual, honest, un-biased information."

"They are all lovely and know what they are on about. I attend the Zoom meetings and also I had a lot of help filling in forms to claim PIP, which was brilliant because I had recently been diagnosed so was very low and still in shock. I probably wouldn't have done it without them. I have also had help getting my voice recorded on SpeakUnique which the MSA Trust funded."

In general, I'd have been lost without the MSA Trust.

“The MSA Trust has completely changed my outlook, I thought that was it - I was a goner, but meeting … and … at the support group and meeting all the other people living with this illness and their partners etc. made me really feel that I was not alone and I could actually live through this. You are all so much better than GPs and consultants, who do not always have time for you.”

“My wife attends the MSA Trust meetings on my behalf and finds it very supportive and informative. The MSA Trust nurses are very informative and accessible.”

“They have a positive impact, amenable without an apparent time limit. Factsheets very informative.”

“Very responsive, professional yet friendly, small team of familiar individuals, proven and pragmatic helpful first place to go for immediate knowledgeable supportive assistance.”

“They have been excellent. When my partner was admitted to hospital they stopped all his medication. They wouldn't listen to me. I phoned MSA Trust and they rang the ward to get it reinstated for him.”

“As my husband has a new MSA diagnosis from June 2022 the Factsheets and Q&A have been most useful. I would like there to be a doctor versed in MSA to ask questions of.”

“Knowing that someone who understood the condition could be contacted was of immense importance and gave a sense of security and support. MSA Nurse was brilliant. Support Group was really helpful. Being able to access fact sheets online before having to ask for advice was great.”

Negative comments

Respondents often found the support meetings either not tailored to their needs, not available in their area, or too upsetting.

“The online support group was harrowing and I can't face it now. I feel it was more for carers to discuss things. I am not ready to face the grimmer details.”

“Very little input from actual sufferers - presumably because of speech difficulty. Most contributors are carers”

“The support group was quite a long way to travel to. My husband and myself found the meetings quite distressing, seeing people in various stages of MSA, knowing what was to come. It was husband's decision not to continue going as he found it too upsetting.”

“Sadly support groups no longer available in our area.”

“Magazine sometimes has interesting info but I don't get much out of the online Zoom meetings.”

“We both find we cannot sleep well after meetings as there is so much going round in our minds - so they are very useful but we find them hard work and upsetting - these are our issues. I think they are very valuable but for us we need to feel in the right frame of mind”

“I don't think I've used them very much to be honest. I'm not very good at reaching out and working out what I need. The online info and leaflets are too overwhelming. I generally forget about them when I'm using my laptop with the assistive technology I need and my phone doesn't have it so I get a bit lost. An MSA friending service would be good where volunteers reach out (could even be via email) to see if members need help with anything.

“Initially very good, useful information pack, but I think more could be done advertisement-wise.”

3.11.5 Former Carers ongoing contact with MSA Trust

We wanted to look at the way that Former Carers continue to be supported. From the responses to this survey, 88% of the Former Carers confirmed they have sufficient ongoing contact with the MSA Trust with only 12% (n=10) reporting this is not the case. This is a positive testament to the hard work of the MSA Trust.

3.11.6 Taking part in research

More than half of the respondents hadn't been offered an opportunity to take part in any research. If offered, one third of the respondents would like to take part in research.

The reason behind the lack of offering of MSA medical trials is unfortunately due to the low investment into research for this rare condition that affects only a small portion of the population in the UK and Ireland (approximately 3,300 cases).

Raising awareness of this condition is therefore paramount for the MSA Trust to ensure more research is done to find treatments for this condition which is widely unheard of.

3.11.7 Conclusions

People living with MSA, current carers and Former Carers

MSA Trust

The MSA Trust has a great reputation among people and families affected by MSA as both a reliable sources of information and valuable support lead by empathic members of staff.

MSA Trust Services and Support Groups

- MSA Trust services are universally well received by respondents, this is a positive testament to the hard work of the MSA Trust.
- Support Groups organised by the Trust are highly rated even if not always physically accessible.
- MSA News Magazine and MSA Information and Factsheets are the services most frequently accessed and in one third of the cases the only source of information provided at the time of diagnosis.

MSA Trust Welfare Grants

- The MSA Trust Welfare Grants are the least accessed service, probably due to the fact that each Grant is assessed on an individual basis according to need and there is a finite budget commensurate with the size of the organisation.

People living with MSA

Quality of life for people with MSA

- The overall impact of living with MSA is severe and respondents are very dependent on the help from others.

Taking part in research

- Half of the respondents had not been asked to take part in research, this is very likely due to MSA being a rare condition and lack of funding available for new studies.

4. Conclusions and recommendations

4.1.1 Diagnosis: conclusions and recommendations

People Living with MSA

- Most respondents affected by MSA have been living with the condition for less than 10 years since first experiencing symptoms. As a rare condition, MSA can be difficult to diagnose as some symptoms can overlap with other conditions such as Parkinson’s Disease, (the condition which is most commonly diagnosed initially in MSA journeys). Only 5% of respondents received a diagnosis of MSA within one year of experiencing their first symptoms, for the majority of people it takes two years or more.

Recommendations

- Diagnosing the condition earlier would, amongst other benefits, allow better monitoring of progression and early intervention and support. Crucially, it would also allow research to take place at a much earlier stage of MSA. Further awareness and education campaigns targeting primary care practitioners could help to improve the current situation.

Information and diagnosis

- Two fifths of respondents were not given information on what to expect from living with MSA on the day they received their diagnosis. Of those that received information, one third received printed information from the MSA Trust.
- The MSA Trust rated highly as a source of information and support among the respondents, whilst GP Practices fared poorly.
- Being a rare condition, people with MSA would benefit from access to more information on treatments and research.

Recommendations

- Focus should be placed on ensuring the maximum number of people with MSA are given information at diagnosis to help them navigate their journey with the condition. Work with healthcare providers is needed to improve this.
- Providing additional, incremental, information where possible should be considered and could be provided at points as the condition progresses, for example, provide timely end-of life-information when the condition deteriorates.

Current carers and Former Carers

- The majority of carers confirmed that the person they care for has been living with MSA for 10 years or less since first experiencing symptoms. A higher percentage of Former Carers (14%) looked after and supported a loved one that had experienced symptoms of MSA for more than 11 years. This will be because those with MSA that Former Carers had looked after had passed away and therefore would have lived with the condition for a longer period of time.

Recommendations

- Carers and their families should receive enhanced support to cope with the difficulties ahead of them, this will require working collaboratively with healthcare providers to ensure access to information and support for carers.

Information at diagnosis

- More than one third of Former Carers confirmed that at the time of the diagnosis they did not receive enough information about MSA to prepare themselves for the months ahead.

Recommendations

- Reliable information needs to be provided to patients and carers on what MSA is and who to contact for further advice and support. This is particularly necessary due to it being a very traumatic time for both patients and families. There is a need to ensure that this is provided for patients and carers and that healthcare providers either supply this or are equipped to signpost.

4.1.2 Care by healthcare professionals: conclusion and recommendations

People living with MSA

Healthcare appointments

- MSA has a vast impact on the mobility of people affected by the condition. Only 7% of the respondents with MSA find it very easy to get to their various healthcare appointments. Lack or delayed appointments, issues with transport, mobility barriers and parking were the main problems reported.
- When asked what could be improved, the most common replies were better coordination, frequency of appointments, and improved access to clinics. Also, due to the mobility and speech problems experienced by people with MSA, there is a desire to not be rushed during appointments and to have time for questions and discussions.
- Following the Covid-19 Pandemic, remote appointments have become common practice. 43% of people with MSA reported that they prefer to have in-person appointments. This could be explained as people with MSA with subtle changes in their symptoms would struggle to show the progression of their condition in a remote appointment. However, 38% of participants would be open to consider a remote healthcare appointment depending on what the appointment was for.
- A high percentage did not respond to the question if their cultural and religious needs were met by the healthcare professionals. One reason reported was that respondents were not asked by the healthcare professional.

Recommendations

- More should be done to improve the access to clinics, remove mobility barriers, and create closer disability parking spaces. Highlight this with healthcare providers.

- When possible, healthcare professionals should provide longer appointments to people with MSA so they can have the time to express themselves and ask questions.
- Promote the need to provide flexibility in appointment options; this could be by allowing access to in person, online, and by telephone appointments.
- Consider how to encourage healthcare professionals to ask if their patients or carers' cultural or religious needs are met.

Specialist Support

- Except for Neurologists and MSA Trust Nurse Specialists, there appears to be a significant issue surrounding the lack of valuable support offered to people affected by MSA across the healthcare professions.
- GPs in particular appear to have a lack of knowledge and struggle to provide appropriate support for people living with MSA and their carers. This is not uncommon with rarer health conditions. Hospital staff are also rated poorly when managing patients affected by MSA. Training should be considered to make the patient's stay as comfortable as possible.

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. Work with healthcare providers to implement this.
- Raising awareness of this rare condition and supplying training among the healthcare professionals would help people affected by the condition to receive the right support when needed.

Current carers and Former Carers

Clinical support and GPs practices

- Broadly in line with the responses from people with MSA, carers confirmed they are mainly supported by Neurologists and MSA Trust Nurse Specialists but not so much by their GPs.
- Carers reported GPs having a lack of knowledge and an inability to provide support for both them and those individuals living with MSA. This is again typical with rarer health conditions.

Recommendations

- Care planning for the carers of people with MSA that would enable them to access primary, community, and specialised care services, needs improvement.
- Explore the barriers to information provision at the time of diagnosis in order to better support healthcare professionals. Consider working with professional bodies including the Association of British Neurologists and the Royal College of General Practitioners to explore further these barriers and how carers in particular might access this information.

Healthcare appointments

- Carers face a lot of challenges when helping the person they care for attend healthcare appointments, with only 8% finding it easy to access them. Relying on others, mobility issues, delayed appointments, and access to premises, were the main issues experienced by carers.
- Remote appointments have become common practice following the Covid-19 Pandemic. More carers compared to those living with MSA would be happy with a hybrid approach when the condition allows.
- More than half of the carers reported that their needs are not considered and discussed at the clinics.

Recommendations

- Where possible additional support should be provided to carers to help overcome the physical difficulties they experience when bringing the individual with MSA to appointments.
- In healthcare appointments itis vital that the needs of the carers are considered together with the needs of the person affected by MSA, and this should be promoted within the healthcare community.

Additional support received and unmet needs

- Carers reported how invaluable some of the support they receive from healthcare professionals is. Home visits, respite care, specialist support, suitable equipment, and the invaluable help from the MSA Trust make a difference in the day-to-day lives of carers.
- When asked what could be improved in the support received by the healthcare professionals, respondents commented on the inadequacy of information available on MSA. Additionally, they highlighted the lack of training, knowledge some health professionals have of the condition, lack of respite care available, and the lack of consideration for the carer’s physical and emotional needs.

Recommendations

- Promote the need for the same level of support and provisions to carers across the UK, as this is not always the case.
- Consider expansion of MSA Trust information service to fully meet the needs of all carers. Look at how to provide training to carers on how to undertake new assistance tasks.

4.1.3 Physical Impact: conclusion and recommendations

People living with MSA

Disease progression, level of mobility and level of independence

- Due to the nature of MSA, the level of mobility and autonomic functions of the body worsen as MSA advances. Multiple symptoms are experienced, with an increased need for physical support such as a walking aid, or wheelchairs, until the person with MSA is unable to leave their bed. The progression of symptoms prevents the person affected by the condition from pursuing the activities they once enjoyed and leads to a more insular lifestyle as it is difficult to both move and communicate.
- This survey provides a challenging picture around the length of time it takes from the first appearance of MSA symptoms to the impact on the mobility of the person affected. After seven years, half of the respondents are in a wheelchair and a further 8% are unable to leave their bed.

Recommendations

- Proper support should be put in place by the health and social care systems to help the individual with MSA cope with the growing mobility challenges and support them with aids, depending on what is most suitable. This requires timely intervention, often anticipating when intervention and support will be required. Working collaboratively with the healthcare community will be needed to improve the current situation.

Support

- With the progression of MSA the level of independence is greatly impacted with an increased need for support from both carers and a range of healthcare professionals resulting in a deterioration in quality of life. Sadly, two fifths of people with MSA reported the help they receive for their physical health needs is poor.

Recommendations

- Work collaboratively with providers to explore ways to improve the physical support that people with MSA receive.

Current carers and Former Carers

The demands of care and the future progression of the disease

- Carers experience significant difficulties when helping the person with MSA manage their symptoms. The difficulties reported were rated more severe amongst Former Carers due to the later stage of MSA they had to deal with.
- Mobility problems, falls, and problems breathing were reported as the most difficult to handle.
- Unsurprisingly, looking after a person with MSA, particularly at an advanced stage, has a detrimental physical impact on carers, with many of them reporting a number of physical effects on their health and wellbeing.

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 and training for helping carers to manage the physical symptoms of MSA without impacting their physical health.
    - Considering further expansion of advice and guidance offered by MSA Trust Health Care Specialists to carers, especially around physical symptom management.
    - Empowering those caring for someone living with MSA to seek the support of professionals. Healthcare professionals could help carers with assistive equipment – especially at an early stage of MSA following diagnosis.
- At the later stage of MSA, it is essential the carers feel physically supported. Proper palliative multidisciplinary support and potentially NHS Continuing Healthcare should be on hand to support.

Support received

- The support received by carers to help cater for the physical needs of the person they are caring for is poor. Over one third of respondents reported a lack of help in moving and managing the falls of those with MSA.
- The future demands of care is of great concern, with carers worrying about how they will cope physically and financially, especially with the increased needs of the person that they are caring for.

Recommendations

- Putting a plan in place with the help of healthcare professionals and local authorities would reassure carers, and those with MSA, and help them to cope with the challenging times that they have ahead of them. Supporting patients and carers to access care planning and especially care assessments would be beneficial.
- The MSA Trust to signpost to resources that provide explanations and support for the physical aspects of caring.

4.1.4 Emotional impact: conclusions and recommendations

People Living with MSA

Psychological impact

- Reports of low mood, depression, and anxiety are commonplace when living with MSA and support is perceived as poor in this area. More than a quarter of respondents with MSA would most value the support for their mental wellbeing **throughout** the different stages of MSA.
- Fatigue and tiredness are the most commonly experienced issues, followed by low mood/depression. This, coupled with the physical symptoms experienced, prevents many of the people with MSA doing the activities they once enjoyed or prevents them starting new ones.

Recommendations

- Every person living with MSA should have their mental, emotional, and cognitive wellbeing effectively and systematically screened wherever they live.
- Declining mental health has an impact in starting new activities, or from doing what they enjoyed before diagnosis. Access to counselling and psychotherapy for those living with MSA needs to be improved to counteract this.

Impact of MSA on relationships and activities

- Unsurprisingly, living with MSA can have serious effects on relationships, particularly relationships with friends. Additionally, social activities are greatly affected the more MSA progresses and quality-of-life declines. This increases the feeling of isolation and abandonment in people affected by the condition.
- Undoubtedly, MSA stops people with the condition doing the things they enjoy or from starting new activities. Mobility issues, concern about speech, and reliance on others for travel assistance, are the main problems reported.

Recommendations

- Support focused on MSA, and the negative effect on relationships, should be considered. This could be done through promoting information and support.
- Local support groups and other activities that are easy to access could provide people with MSA, and with mobility issues/speech difficulties with much needed breaks outside their homes where possible.

Source of emotional support

- The majority of carers and Former Carers reported that the person they cared for did not receive the emotional support they needed from healthcare professionals, or psychological services. This is a worrying picture that clearly displays how the emotional impact of MSA is often neglected.
- The main emotional support normally comes from family. The external help for the patients' mental wellbeing is poor. There is a clear need to improve professional support throughout the different stages of the condition, from diagnosis until the end.

Recommendations

- Work collaboratively to provide healthcare professionals with more training to help them to proactively identify patients' psychological needs and refer them to the right support avenue.
- More needs to be done to organise activities, therapy or connect patients with local groups.

Sex life

- Sex life is greatly impacted by the condition. This is a delicate topic that people with MSA might be reluctant to discuss. Currently it is neglected, or rarely treated, by healthcare professionals..

Recommendations

- Healthcare professionals need to tackle this delicate subject discreetly with patients and treat it, when possible. The MSA Trust can really make an impact in this area by changing the perception of this topic.

Current carers and Former Carers

Psychological impact

- MSA not only has an emotional impact on the person affected by the condition but also on the carer that often suffer from anxiety, depression and social isolation. The carers go through an emotional upheaval coming to terms with a life changing condition that directly affects their daily life.

Recommendations

- Every person caring for someone with MSA should have their mental, emotional and cognitive wellbeing effectively and systematically screened wherever they live.
- Access to counselling and psychotherapy for carers needs to be improved.

Source of emotional support and the impact of MSA on relationships

- Only a small percentage of the carers feel they receive the emotional support they need, some can rely on close family and friends for emotional support, others feel completely alone.
- Carers report that **relationships with friends** and their **social activities** are negatively impacted by MSA and there is an increasing **feeling of isolation**.

Recommendations

- Support Groups focused on MSA and the negative effect on relationships should be considered for carers to prevent feelings of isolation.

Sex life

- The dynamic of couples changes drastically when one of the partners is affected by MSA. Carers confirmed they no longer feel like spouses. The majority of the carers stated their sex life is affected, with partners often being reticent to face the issue and not looking for help.

Recommendations

- Healthcare professionals need to ask carers questions on this delicate topic and offer targeted support, perhaps without the presence of the person with MSA to help open up the conversation. The MSA Trust could look to offer information and support on this specific issue.

4.1.5 Support Groups and services for people living with MSA, carers and Former Carers

People Living with MSA

Access to Support Groups

- Support Groups are very important in coping with a high-impact condition like MSA. The vast majority of people with MSA reported that they rely on the MSA Trust, both online and in person, for support whilst Support Groups through GP Practices fare poorly. This is not uncommon with rarer health conditions and it should be noted that GP Practices have been under pressure as a result of the pandemic in recent years.
- Some respondents reported being unable to physically attend any groups.

Recommendations

- MSA Trust to consider extending the offer of Support Groups.
- MSA care and support should be provided regardless of the patients' location or mobility issues, explore where the current gaps are and work to address these.

Access to services

- Most respondents are not accessing additional services to help with their MSA symptoms. There is an apparent gap in provision, very likely dependent on the area where the respondents are from. Interestingly, a high proportion of respondents did not want to access some services even when available such as in the case of psychological therapy or peer support.

Recommendations

- Raise awareness amongst people with MSA on the benefits that different services might have in order to cope with their condition.

Current carers and Former Carers

Access to Support Groups

- In line with results from those with MSA, Support Groups are important for carers to cope with a very gruelling condition. MSA Trust Support Groups, both online and in-person, are the most used amongst carers. Again, GP Practice support groups rated poorly. As for people with MSA this is likely due to MSA being an uncommon, rarer health condition coupled with the pressure GP Practices have been under as a result of the pandemic in recent years.

Recommendations

Seek to expand the offer of Support Groups to carers, especially those who are most isolated and marginalised.

Source of support and gaps

- Most of the support for carers comes often from their family, friends and MSA Trust. It is frequently expressed by the carers the willingness to look after their own emotional and physical wellbeing, however they often cannot follow through due to the commitments of caring for the loved one.
- Regarding gaps, lack of access or proximity to respite care, and lack of training for carers, were identified as issues. Additionally, it appears that even when available the sources of support are not well publicised by healthcare professionals.

Recommendations

- To meet in person or online with other carers that share the same experience would be beneficial and would help the carers with their sense of isolation.
- More should be done to increase the support for carers who have heavy caring duties, and carers should be made aware of the help and support when available.
- Ad hoc training needs to be supplied to carers on how to handle the physical aspects of caring for a person with MSA.

Additional source of help

- When available, carers confirmed that Hospice support was a valuable source of help that they use. Nearly half of Former Carers confirmed that they used Hospice support and welfare rights. This higher percentage compared to carers is very likely due to the later stage of MSA they had to deal with. Interestingly, despite around one third of carers wanting to access some services not available to them, a higher percentage did not wish to access some services such as counselling, peer support and welfare rights.

Recommendations

- During appointments, healthcare professionals should interact with the carers more and educate them on the benefits that some of the unused sources of help could bring to them. Promote this through raising awareness and education with the healthcare community.

Barriers to access Support Groups.

- Based on their experience, Former Carers confirmed that barriers in accessing Support Groups included a lack of proximity to them coupled with the decreased mobility of the person affected by MSA.

Recommendations

- More work should be undertaken to find out what activities and/or Support Groups would be useful to people and to try to find out more about how barriers to accessing these can be mitigated.

4.1.6 Impact on Personal and home life for carers and Former Carers: conclusions and recommendations

Current Carers

Impact of MSA on carers

- The effect of MSA is not only devastating for the person with the condition but also for the carer who often has other caring responsibilities. Carers often stop doing the activities they once enjoyed due to tiredness, or because they cannot find someone to help whilst they are out.
- Nearly half of the respondents reported that people with MSA are reluctant to be looked after by someone else. The reason is unclear, but it explains why some carers express a sense of guilt when they go out.

Recommendations

- 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, explore ways to achieve this.
- Explore ways to ensure the person with MSA does not rely only on one carer to be looked after, this could be through care/emergency planning and work in support to increase confidence or supporting enhanced respite care options.

Social isolation and respite services

- Relationships with friends and social activities are greatly reduced because of lack of support and financial worries. This survey suggests that help from respite services is currently lacking. This could be partly due to the current issues around social care and Hospice provision and the lack of adequate care homes leaving carers to their own devices. Carers often rely on close family and friends for a break if they live nearby.
- The feeling of isolation is widespread amongst carers, affecting them psychologically.

Recommendations

- More should be done to increase the accessibility of respite services and Hospice services.
- Social isolation is widespread and damaging. Consider services to better support carers around feelings of isolation.
- In-person Support Groups and Online Support Groups run by MSA Trust were beneficial for Former Carers whilst going through the difficult stages of MSA. The MSA Trust should promote these services more widely perhaps tailoring them according to the stage of MSA and for carers only.

- MSA Trust could consider resources for friends and family members that live further aware, providing advice on what might be helpful.

Former Carers

Impact of MSA on Former Carers

- The effect of MSA on Former Carers was even more impactful and overwhelming due to the advanced stage of the condition they had to deal with, often coupled with other caring responsibilities.

Recommendations

- Promote early access to palliative care and Hospice support for people with MSA.

4.1.7 Social Care: conclusions and recommendations

People Living with MSA

Assessment for funded care

- Considering the severe nature of the condition, it's concerning that nearly half of the respondents were not assessed by their local council for funded care. Only one quarter were assessed and found eligible.
- The recent economic challenges experienced by local councils may help to explain the lack of assessment and access to services. However, the lack of access to funded care might also be exacerbated by a lack of knowledge and information around the condition.

Recommendations

- Steps need to be taken by local councils for people with MSA to be periodically assessed and ensure their growing needs are supported throughout their journey.
- Expand MSA Trust information service on how funded care can be more easily accessed.

Access to social care and level of independence

- Although over a quarter of respondents confirmed they don't require social services yet, this may be due to being at an early stage of MSA' However, it seems over half of people with the condition don't receive adequate help. Some social care services, such as **homecare** and **home adaptation,** appear to be linked to the level of independence of the person with MSA. However, other sources of social care are not offered regardless of the decline in the individuals independence. This may be due to financial constraints as well as a lack of awareness, and knowledge, of MSA and the needs of those with MSA and their carers.

Recommendations

- The MSA Trust should continue to raise awareness of the condition with providers so the needs of those affected by MSA are met.

Current carers and Former Carers

Access to social care

- The vast majority of carers highlighted a lack of access to services such as Residential Care, Day services and Community transport. The application process for these services is often lengthy, and access is difficult, therefore producing an additional burden for carers and people with MSA.

Recommendations

- Promote more effective and better funded social care through working with other similar organisations and through individual advocacy support.

4.1.8 Financial impact: conclusions and recommendations

People Living with MSA

Employment status after diagnosis

- As MSA is more prevalent amongst older demographics, nearly three fifths of the respondents were already retired by the time they received their diagnosis.
- Of those that were still working, ten percent of the respondents stated their employment was terminated by their employer. Others commented their employment was affected in some way.

Recommendations

- Ensure MSA Trust information resources give relevant information about employment rights.

Awareness of the benefits and support available

- Among the respondents only a small percentage were very confident that they had accessed all the benefits available to them and nearly two thirds had not sought specialist advice. It is very likely with these respondents that they had missed out on some available benefits.

Recommendations

- Healthcare professionals should be trained and give people with MSA, and their families, as much information as possible on the benefits and financial support available to them. Work collaboratively to promote the benefits with healthcare professionals.

Financial impact on households and additional financial costs

- More than one third of respondents reported having some/severe financial issues. Cutting working hours or stopping working altogether reduces the income the person with MSA used to have whilst new costs are added. The additional costs faced by people affected by MSA include home improvements, new equipment, and increased utility bills. Whilst some costs may be covered by the local council - like in the case of some home improvements - the majority are not.

Recommendations

- The benefits system needs to be more flexible to better serve its purpose in enabling people to get on with their lives despite their condition. The MSA Trust should address issues around accessing benefits through an MSA Trust Social Welfare Specialist and supporting those with MSA to access and maximise their benefits.

Current carers and Former Carers

Awareness of the benefits and support available

- Only a small percentage of carers were confident that they had accessed all available benefits. Nearly three fifths had not sought specialist advice. This is in line with those with MSA. Interestingly, amongst the Former Carers, over one quarter of the respondents were very confident they had claimed the financial benefits they were entitled to, with nearly fifty percent reporting they were quite confident. This discrepancy in awareness among the three groups might be due to the advanced stage of MSA the Former Carers were dealing with that made them more knowledgeable of what they were entitled to.

Recommendations

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

Financial issues

- Carers have reported more severe impacts on their financial situation. This is probably due to them having to stop work to care for a loved one. Two fifths of Former Carers reported they had severe, or some, financial issues. This is less than stated by carers.

4.1.9 Palliative care/advance care planning: conclusions and recommendations

People Living with MSA

Discussion on end-of-life care options

- Even if the vast majority of people with MSA had thought about what would happen towards the end of their life, more than half of respondents had not discussed end of life care options with a healthcare professional- with some not having any intention to face the conversation.

  Recommendations

- 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.

Palliative care, Hospice care and advance care planning

- Over a quarter of the respondents reported that even if required they were not offered a specialist palliative care or Hospice care option. The budget cuts in local councils and lack of resources for Hospices may help to explain this situation.
- For formal advance care planning, the most commonly reported items were a Will and Lasting Power of Attorney for property and finance.

Recommendations

- People living with MSA need to be better supported to access palliative care support and there is a need to promote equitable access for all those with MSA to these services.
- 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.
- 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 and could be supported through information and discussion through the MSA Trust.

Current carers and Former Carers

Discussion on end-of-life care options

- One third of carers hasn’t had a conversation with their loved one about treatment, care and support as MSA advanced, probably because they find it difficult to face a topic that is extremely sensitive.
- In line with people affected by MSA, more than half of carers have not discussed with a healthcare professional what they want to have in place at a late stage of MSA.
- When Former Carers were asked if end-of-life care options were discussed with their loved one, more than two thirds confirmed this was the case. This result should not surprise, this is due probably to the later stage of MSA Former Carers had to deal with.

Recommendations

- MSA Trust could 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.

Palliative care and Hospice care

- Half of carers reported they were not offered a specialist palliative care or Hospice care options.
- Over a quarter of Former Carers reported they were not offered a specialist palliative care or Hospice care options. This is very worrying as even at a later stage of the condition both patients and carers were not properly supported.

Recommendations

Carers to be better supported to access palliative care support. This provides a touch point for offering a discussion with the person living with MSA to explore end of life options.

Advance care planning

- In line with people with MSA, in the formal advance care planning, the most commonly reported items that were completed were a Will and Lasting Power of Attorney for property and finance. Carers should encourage people with MSA to complete other Advance Statements setting out preferences of care, for example.
- Former Carers confirmed that for formal advance care planning, the most commonly reported items were a Will and Lasting Power of Attorney for property and finance.

Recommendations

- More could be done to educate carers on Advance Statements setting out preferences of care, and the option of brain donation. Both of these are reported less frequently and could be promoted and discussed through the MSA Trust.

Quality of end-of-life care provided

- Encouragingly, two thirds of former carers were satisfied or satisfied to some extent with the quality of the end-of-life care that was provided to their loved one and nearly three fifths of the respondents confirmed the person with MSA died where they had wished. When this was not the case, it was due to a sudden death or for medical reasons.

Recommendations

- Ensure that carers and those with MSA are aware of and can discuss how and where they wish to receive care, this could be done through information and discussion through the MSA Trust.

4.1.10 Final questions and MSA Trust: conclusions and recommendations

People living with MSA

Quality of life for people with MSA

- The overall impact of living with MSA is severe and respondents are very dependent on the help from others.

Recommendations

- It is particularly important that people with MSA are provided with written as well as verbal information at the point of diagnosis and the MSA Trust should work collaboratively with healthcare professionals to promote the benefits of this and signposting to support services.

Taking part in research

- Half of the respondents have not been offered an opportunity to take part in research. This is probably due to MSA being a rare condition and lack of funding available for new studies.

Recommendations

- When possible MSA Trust should make their members aware of new research or studies and facilitate the contact, this could be done through publishing online, newsletters and through collaboration with healthcare professionals for example.

- **People living with MSA, Carers and Former Carers**

MSA Trust

MSA Trust has a great reputation among people and families affected by MSA as both a reliable source of information and valuable support led by empathetic members of the staff.

MSA Trust Services and Support groups

- MSA Trust services are universally well received by respondents, this is a positive testament to the hard work of the MSA Trust.
- Support Groups are highly rated, even if not always physically accessible.
- MSA News Magazine and MSA Information and Factsheets are the services most frequently accessed and in one third of the cases the only source of information provided at the time of diagnosis.

Recommendations

- Consider running Support Groups according to the stage the person with MSA is at. It can be distressing for an unprepared person with early MSA to be in the same Support Group as a person with a later stage of MSA.
- Consider further promotion of MSA Trust forums and helpline service.

Quality Health (an IQVIA business) 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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