Improving MND Care

MOTOR NEURONE DISEASE (MND) ASSOCIATION'S TRACKING SURVEY:

THE EXPERIENCES AND VIEWS OF PEOPLE LIVING WITH MND

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PICKER INSTITUTE EUROPE

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Picker Institute Europe

Picker Institute Europe is a not-for-profit organisation that makes people's views count in healthcare. We:

- build and use evidence to champion the best possible person-centred care
- work with people who use health and social care services, professionals and policy makers to strive continuously for the highest standards of patient experience.

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CONTENTS

Message from the MND Association 4

Executive summary 6

Background 13

Methodology 14

Demographics 19

Findings 20

Diagnosis 20

Getting a diagnosis 20

Day of confirmed diagnosis 25

After confirmed diagnosis 30

MND Association services 37

Your choices as the disease progresses 46

Conclusion 53

Problem Scores 59

Comparison with previous wave (2009) 66

Message from the MND Association

A diagnosis of MND turns your world upside down.

Coping after such a devastating diagnosis is always a challenge – but help is available. With the right care and support, many people have told us they can maintain their quality of life and find ways to still manage day-to-day tasks. Even the later stages of what is ultimately a fatal disease can be met with dignity and a sense of control, when the right support is there.

Sadly not everyone receives the best care and support, and it's our role to address this. We do this by influencing and educating those working in health and social care, and through our own services and direct support. The *Improving MND Care* survey is vital as it helps us understand where we should focus our efforts and resources, because it involves listening to those best placed to know what it's like now – people living with MND themselves.

More than 950 people took the time to share their experiences, views and opinions. Our thanks go to all of you. We are also grateful to the people with MND who helped us develop and test the survey, making sure we asked the questions that go to the heart of what matters to people living with this disease.

By carrying out surveys every 4-5 years, we can see where care is improving, thanks to the efforts of our volunteers, staff, partners and supporters.

The 2013 *Improving MND Care* survey shows a significant improvement from 2009 in the following areas:

- **People's ability to access and receive support with their breathing, in particular take-up of non-invasive ventilation (NIV).** This follows our successful campaign for NICE guidance on NIV and a programme of educating and influencing health professionals.
- **The actual experience of being diagnosed, for example, people having tests explained to them, opportunities to ask questions and being given the news in a private place.** However, the time it takes to give people their diagnosis is still too long. We need to continue educating GPs to ensure early referrals, and to investing in research to find a definitive test for MND.
- **The number of people who have heard of MND by the time they receive their diagnosis.** While we have had success with campaigns to raise awareness, we know there is still more to do.
- **The number of people who have a named person co-ordinating their care.** We know this makes a positive difference to people with MND, and have influenced and funded co-ordinator posts nationwide.

The survey has also helped us identify where we best focus our efforts now:

- **Working to shorten further the time to diagnosis, and influencing more neurologists to refer people who have just been diagnosed to the MND Association.** Referring people to us matters: four out of five say being in touch with the Association means they have greater awareness of the support available to them.

- **Seeking improvements to social care** – these are the services that help with day-to-day living, usually provided by local authorities. They includes home carers, certain equipment and adaptations, and support from social workers.
- **Providing more information and support for people about the later stages of MND** including end-of-life decision-making.
- **Challenging NHS and social care providers to better co-ordinate all the different services that a person with MND needs**, and raising awareness still further with those working in the health professions.
- **Improving the support available to family members and friends** who care for people with MND.
- **Recognising the growing number of ways people with MND wish to receive support and communicate with us**, and doing more to meet their expectations. This includes improving how we engage with people online, while also continuing to meet the needs of the 28% of people with MND not online.
- While satisfaction with our services is high, we want to **increase the proportion of people who give them a top rating.**

The 2013 *Improving MND Care* survey is the UK's largest ever survey of people with MND. So many people took the time to share what matters to them. It is only right that we use it as the basis for action – to help improve things for all those living with MND.

Sally Light
Chief Executive

Executive summary

In November 2012, the MND Association commissioned Picker Institute Europe to run their feedback tracker; a quantitative study of people with MND. The study had been run previously on two occasions: in 2005 and again in 2009. In commissioning the Picker Institute to run the survey in 2013, the MND Association wanted to build on the previous research conducted by The Picker Institute Europe to understand choices and decisions around end-of-life decision making faced by people living with MND.

A study advisory group was convened by the MND Association's Board of Trustees. The Picker Institute's research team comprised quantitative and qualitative researchers, all of whom had experience of interviewing vulnerable people and dealing with sensitive subjects.

The ethical implications of the section on choices at the end of life were carefully considered and it was decided that a pre-approach letter would be sent to all participants. This gave all respondents the chance to opt out of the survey altogether, or to request a version of the questionnaire without the end of life section. Both the online and paper versions of the survey 'screened' the section, ensuring only respondents who actively wished to view the questions, were able to do so.

A mixed methodology approach was decided upon for the research. An email invitation was sent to all contacts with email addresses, which contained a link to the online survey. Just like a paper survey, the online link could be left for later and returned to numerous times for completion. The remaining sample who did not have a registered email address were sent a paper copy of the survey in the post. The questionnaires were mailed out to members' home addresses. We also included a link to the web version of the survey for them to complete online if preferred.

A total of 2,933 people with MND were sent the pre-approach letter. Following the response from the letter (67 deceased notification and 28 opt outs), 2,838 were invited to complete the survey. We received a further 131 notifications (102 deceased and 29 opt outs) and achieved a response from 951 people giving an overall response rate of 34%.

This is the largest survey of people with MND (in the UK) to date, and although not completed by the entire membership of the MND Association, is a robust sample that is representative of people living with MND and provides a strong clear voice of the service, support, issues and what is important to those living with the disease. Throughout the analysis we found few significant differences amongst sub-groups, which in itself is a strong message, giving a clear unified voice from people living with MND.

Diagnosis

A third of those responding had received their confirmed diagnosis within the last year, with a further third stating that is was between one year and 3 years and the remaining third receiving the diagnosis between 3 years and more than 10 years ago. Of those, significantly more females than males had been diagnosed within the last year.

Getting a diagnosis

The majority of respondents were referred to a Neurologist within six months from first consulting their GP. However, a fifth of respondents waited a year or more, with respondents aged 71 years and above significantly more likely to wait more than a year for referral compared with younger respondents. Nearly two-thirds of respondents were happy (definitely/ to some extent) that the referral was as soon as they would have liked, while a third would have liked it sooner.

More than half of all respondents were referred to other healthcare practitioners before referral to a Neurologist; but once referred, three-quarters of respondents were seen by the Neurologist within three months. Respondents who had received their confirmed diagnosis within the last year were significantly more likely to feel that they should have been seen earlier.

Following their appointment with the Neurologist, half of all respondents received a confirmed diagnosis within three months. A third of respondents waited between three months and one year for the diagnosis, whilst nearly a fifth waited over a year. Those who were diagnosed more than five years ago where significantly more likely to have waited a year or more for their diagnosis compared with those diagnosed within the last three years. Nearly two-thirds of respondents felt they received the diagnosis as soon as they would have liked (definitely/ to some extent), and a third would have liked it sooner. Females were significantly more likely to say that they would have liked their diagnosis earlier compared with males.

Tests and investigations were explained in a way that just over half of all respondents could understand, however two-fifths felt they could have been explained better.

Day of confirmed diagnosis

Four-fifths of respondents had heard of Motor Neurone Disease before their diagnosis, although only half of them understood what it was.

Almost all respondents received their confirmed diagnosis in person, during an appointment with a Neurologist. Over half of the respondents had not been advised to bring a friend or relative with them. Over half were told about the support offered by the MND Association but just under half were not asked if they wanted someone from the MND Association to contact them.

When being given their diagnosis, the majority of respondents were given theirs in a private place behind closed doors. Respondents were generally happy with the way their diagnosis was given and felt they were given the opportunity to ask questions, and many agreed that the person giving the diagnosis had a good understanding of MND. Over half of all respondents felt the people giving the diagnosis understood how they might be feeling.

Over half of all respondents felt supported throughout the consultation, however, a third of respondents felt they could have been better supported throughout their consultation.

After confirmed diagnosis

Three quarters of respondents currently have a named person in either health or social care who is responsible for co-ordinating their care and support; a tenth of respondents don't have one, but would like one. For the majority of those with a named person co-ordinating their care, the relationship works well. Respondents aged 81 years and over are significantly more likely to say the relationship works very well compared with younger respondents.

The most affected area of the body for respondents were their legs, while many mentioned their arms (& hands). Fatigue was also something three-quarters of respondents said affected them.

Just over half of all respondents had not needed surgery to insert a feeding tube to help with breathing, while nearly a third have had surgery to insert a feeding tube. Just over a tenth of respondents had been offered surgery but decided against it. Females were significantly more likely to choose surgery compared with males.

Only a tenth of respondents had their breathing monitored annually, nearly half of all respondents had breathing assessments and monitoring at least every few months. Just over half of all respondents do not receive any special help with their breathing; the top three areas of help are; non-invasive ventilation, specialist exercises/ posture advice and cough assist. Three-quarters of respondents rarely or never experienced difficulty obtaining help with their breathing, however a tenth of respondents have had difficulty getting help with their breathing.

The most used items of equipment are the manual wheelchair, walking aids, riser/ recliner chairs and grab rails. The least used are communication pointer board, environment controls and suction units.

- The manual wheelchair is mainly funded by another source
- The hoist is the item mainly funded by others
- Buggies/ scooters are mostly self-funded (either in whole or part)
- Nearly two-thirds of Light Writers are provided by the MNDA
- Of those provided with riser/ recliner chairs, the MNDA fund almost half of them
- When home adaptations are required, over half of respondents self-fund (either in whole or part)

When looking how well each piece of equipment meets their needs;

- The Light Writer is the item that least meets respondent needs, followed by buggy/ scooter and communication pointer board
- Unsurprisingly, the items that most meet respondents needs are those which are mainly self-funded – door widening, lift and wet rooms
- Powered wheelchairs better meet the needs of respondents than manual wheelchairs

When asked to consider a series of statements about their care and treatment since diagnosis, two-thirds to three-quarters of respondents either '*agreed strongly/*'*agreed*' with all statements. The statements with the highest level of agreement (agree strongly/ agree), were 'I am treated with dignity and respect' and 'when receiving health care services, I feel my independence/ autonomy is respected'. However, disagreement is high for:

- All the different services are co-ordinated well
- I think that family members and carers are well supported
- I get the social care services I need when I need them

The benefits received by most respondents were Blue Badge, Disability Living Allowance, Attendance Allowance, Council Tax Benefit and Carer's Allowance. Two-thirds of respondents had not experienced any difficulty in obtaining their benefits. Respondents aged 70 yrs and younger where more likely to experience difficulties obtaining benefits than those aged 71-80 yrs and over.

The most important area that respondents feel needs addressing/ improving is 'knowledge and support from GP', closely followed by 'support for family members or friends who act as carers'. The third most important area is 'support with planning for the future, including later stages of MND'.

Four-fifths of respondents rated the overall care they received from the NHS for their disease as either excellent or good. The overall rating for care received from social services wasn't quite as favourable, although still mainly positive.

MND Association services

At the time of their diagnosis is where just over half of respondents first heard about the MND Association, while via the '*internet*' and via '*other health professionals*' were the joint second most common mentions.

Association visitors were most often the first contact that respondents had with the association, followed closely by MND Connect Helpline Service and Branch contact. Respondents aged 60 years and younger are more likely to contact the Association via the MND Connect Helpline Service. For respondents aged 61years and over, first contact with the Association is more likely to be via the Association visitor.

Information leaflets were the most used resource, second most used resource was the MND website. The least used resources are the Association online forum, financial support and support from Regional Care Development Advisors. Females are significantly more likely to receive support from an Association visitor. Respondents aged 60 years and younger are more likely to make use of the MND Connect and the Association online forum.

- Equipment loan is the service users are most satisfied with
- Nearly three-quarters of those accessing 'financial support' are '*very satisfied'*
- The resource with the lowest level of satisfaction amongst users is the 'Association online forum'

Nearly all respondents were aware that they are entitled to free membership of the MND Association, with benefits including the regular magazine and the right to vote at the national AGM.

As a result of being supported by the MND Association, four-fifths of respondents agree (strongly/somewhat) that they have greater awareness of the support available to them. Over half of respondents feel their quality of life is better than it would be otherwise and three-quarters feel they have more confidence in managing life with MND as a result of being supported.

The three most important functions of the MNDA are:

- Funding and promoting research into causes and treatments of MND
- Providing support to people with MND in terms of information, advice and financial assistance
- Increasing levels of knowledge about MND amongst health and social care professionals

Respondents aged 61 years and over are significantly more likely to select ‘funding and promoting research into causes and treatments of MND’. Those diagnosed within the last year are more likely to select ‘providing support to people with MND in terms of information, advice and financial assistance’.

Overall satisfaction with the Association is high with three-quarters of respondents rating them as either excellent or very good. However, a tenth of respondent felt the support was either fair or poor.

Your choices as the disease progresses

To build on the qualitative work conducted in 2012 by the MND Association around choices people with MND face at the end of their lives, questions were developed to capture the voice of a larger number of members.

Great care was taken to ensure that those who would find these questions distressing had the opportunity to avoid this section without having to read any of the questions. Three-fifths of respondents overall opted to complete some or all of these questions and thus provide a unified voice on the choices they face.

Of those who completed the End of Life questions, a third of respondents were not given information about the choices and options available at the end of life but would have liked this, although two-fifths had been given this information.

A third of respondents have been given the opportunity to, and actually discussed end of life issues with a care professional, however just over a tenth were not given the opportunity but **would** have liked to. A third of respondents felt it was too early for them to have these discussions. Females are significantly more likely to choose to have these discussions. Respondents diagnosed more than 10 years ago are more likely than those diagnosed less than 10 years ago to say they did not want to discuss these issues.

Hospice or palliative care team members were overwhelmingly the most popular choice for most respondents to discuss end of life issues with, followed by a member of hospital staff and GPs. Only a small number had these discussions with a member of staff from the MND Association. Two-fifths of respondents instigated the conversation, while almost half said it had been raised by a care professional. Four-fifths of respondents felt the care professional put them at ease/ shown sensitivity about discussing these issues. Two-fifths of respondents who discussed end of life issues felt it had been helpful, a quarter agreed that it had been helpful ‘*to some extent*’. Only a small number commented that it had not been useful for them.

Two-thirds said that having control at the end of life meant ‘deciding when the time is right to die’. The second most popular response was ‘ensuring that others (family/ carers) know what my wishes are’. ‘Deciding when the time is right to withdraw treatment that may be helping to sustain life’ was the third most selected.

Two-fifths of respondents have already taken steps to ensure they have control/ choice at the end of their life whilst nearly half of respondents said they had not yet but they will. Females are significantly more likely to say they have taken steps to ensure they have control at the end of their life.

A third of respondents have made an Advance Care Plan or Advance Directive/ Decision, whilst a third felt it was too early to do this, and a tenth plan to make one. Worryingly, a quarter of respondents do not know what an Advance Care Plan or Advance Directive/ Decision is. Females are significantly more likely to have made an Advance Care Plan or Advance Directive/ Decision and significantly more males do not know what an Advance Care Plan or Advance Directive/ Decision is.

Almost all respondents who have an Advanced Care Plan or Advance Directive/ Decision say theirs reflects their current views. Of those respondents who are aware of Advance Care Plans or Advance Directive/ Decision, half were offered support/ help making one. A quarter of respondents were not offered help or support to make one but **would** have liked it. Respondents diagnosed more than 10 years ago are more likely to say 'no, but they do not need this'.

When asked for their views on assisted suicide, almost half of respondents said they would consider assisted suicide in some form:

- A third would consider it if the law was changed to make it legal for somebody to assist them
- A tenth would consider it as the law stands at present
- 6% would consider travelling outside of the UK for it

A fifth of respondents felt it was too early to say and a quarter of respondents would not consider this for themselves.

Just over half of respondents feel they have somebody to talk to if they wanted to have further discussions or access support around end of life choices. However, a tenth of respondents said they didn't have anybody but would like somebody and a small number, 6%, said they do not have anybody as they are concerned about others' reactions.

The top five areas for the MNDA to provide information and support in are:

- 'Information on all of my options for end of life care'
- 'Information about treatments to help the final stages be as peaceful and dignified as possible'
- 'Opportunity to discuss options for taking control at the end of life'
- 'Options around organ donation or donation to research'
- 'Information on how to talk about these issues with family members and friends'

It’s clear, that although in many areas half of all respondents report positively, the findings highlight many areas for where improvement can made:

- Timely referral directly to a Neurologist
- Improved waiting times for confirmed diagnosis
- Co-ordination of multiple services
- Improved quality of care from social care services
- Provision of social care
- Better support for family members and carers
- Consistency of quality care within the NHS
- Support and information leading up to and during the diagnosis consultation
- Improved levels of respect for independence/autonomy in social care services
- Better understanding of respondents’ needs from clinicians and social care staff
- Provision of regular reviews

Background

Motor Neurone Disease (MND) is a rapidly progressive degenerative neurological condition, affecting the nerves that control movement. Degeneration of the motor neurones leads to weakness and wasting of the muscles, causing an increasing loss of mobility in the limbs and difficulties with speech, swallowing and breathing. MND can affect adults at any age, but most are diagnosed between 50-70 years. There is no cure and average life expectancy is between two to five years from the onset of symptoms. In the UK, during 2008, 1,600 people died from MND, equivalent to more than four people each day. MND is a complex disease that places considerable demands on all those involved and presents challenges for statutory services across health and social care.

The *Motor Neurone Disease Association* (MNDA) is a national charity that both funds research into MND, and also offers support for people living with the condition and their families and carers. It also campaigns and lobbies decision makers at local and national level.

The MND Association recognises the importance of gaining feedback from its members, to both evaluate their own service provision, and to gain regular data about the experiences of people with MND and the issues they face, particularly around care provision. Their current tracking survey has been conducted at roughly 3-4 yearly intervals. However, the MNDA have now partnered with Picker Institute Europe to review the survey itself as well as its implementation. This is to ensure that it is as robust, person-centred and focussed as possible and provides actionable feedback which will ultimately help improve services.

In November 2012, the MND Association commissioned Picker Institute Europe to run their feedback tracker, a quantitative study of people with MND. The study had been run previously on two occasions: in 2005 and again in 2009. In commissioning the Picker Institute to run the survey in 2013, the MND Association also wanted to build on the previous research conducted by The Picker Institute Europe to understand choices and decisions around end-of-life decision making faced by people living with MND.

A study advisory group was convened by the MND Association's Board of Trustees. The Picker Institute's research team comprised quantitative and qualitative researchers, all of whom had experience of interviewing vulnerable people and dealing with sensitive subjects.

Ethical approval was investigated for the section on choices at the end of life, but was not required. Great care was taken to ensure respondents had the opportunity to opt out of this section – a pre-approach letter was sent to all respondents giving them the chance to opt out completely, or request a version of the questionnaire without the end of life section. Both the online and paper versions of the survey 'screened' the section, ensuring only respondents who actively wished to view the questions, did so.

Methodology

Planning

Data review and questionnaire design

The existing questionnaire covered a mixture of respondent pathway experience questions, lifestyle questions and feedback on the Association itself. Initial impressions of the questionnaire were that it was quite long, which may have had a direct impact on response rates. In addition, whilst some of the questions provided important background information on their members, we recommended focusing on questions that could provide the Association with **actionable** feedback as well.

We performed a full evaluation of the questionnaire, in order to ascertain which questions and question areas were of most value in terms of providing actionable feedback.

Survey Development

Existing data analysis

Full data analysis took place on the previous datasets providing suggestions on ways to improve the survey.

We performed a **statistical analysis** on some of the data from the existing questionnaire in order to test questions for relevancy and redundancy. It was appreciated that a large number of the questions were factual/ information questions, but proposed to screen the questions for low response and lack of variability in responses.

In addition to the analysis of the quantitative data, we also looked at the qualitative responses to the 'freetext' questions to identify issues that may not have already been covered and also help to verify the response codes used in the closed questions.

Questionnaire design

When the analysis had highlighted which questions were most relevant from a statistical point of view, we met with the MNDA and, with input from the steering group, we looked to re-design the questionnaire. We kept in mind that it is a tracking survey, so it was important that **priority tracking questions** were identified and that those largely remained as they were, to monitor change over time.

However, we also considered that there were between three and four years in between waves, and a lot could have changed in terms of care pathways, policy and perceptions at that time. Therefore, it was likely that the questions needed to change to reflect this. In addition, there were enhancements to the way in which some of the questions were asked, which made it easier for respondents to complete.

Together with the MND Association we designed a questionnaire that:

- Takes into account priority areas for tracking information
- Keeps in mind that one of the aims of the survey is to drive improvement for people with MND so asks questions in such a way that they will be able to have practical application and provide actionable feedback for the Association.
- Is motivating to encourage completion

In addition, we worked to include some of the issues that have emerged from the **recent qualitative work** carried out with the Association into end of life care. These covered issues such as; ease of talking about death and dying; choice at the end of life; and whether they would welcome a public debate on end of life issues. We were careful to test these questions with the target audience before the survey. These questions were included in a separate part of the questionnaire, with a caveat warning respondents about the sensitive nature of the questions, with the option for them to skip if preferred.

Cognitive testing of surveys

With any survey design, the most important part of the process is to **cognitively test** the surveys with the target population. Cognitive testing involves running through the questionnaire with members of the target group, encouraging them to 'think aloud' as they go through it. It aims to look at question-answering from the respondent's perspective and understand how questions are interpreted and understood.

The purpose of cognitive testing is threefold:

1) Firstly it helps to **reduce misinterpretation** of questions included on the survey instrument, leading to more accurate survey data;
2) Secondly, it can test **recall levels;**
3) Finally, it can serve as an additional mechanism to **reveal any gaps** in the question set or response options that may not already have been addressed.

Cognitive interviews were undertaken with eight respondents. The questionnaire evolved during this process to produce a set of questions that are validated, robust, and fit-for-purpose.

Fieldwork

Sampling

A mixed methodology approach was decided upon for the research. An email invitation was sent to all contacts with email addresses, which contained a link to the online survey. Just like a paper survey, the online link could be left for later and returned to numerous times for completion. The remaining sample who did not have a registered email address were sent a paper copy of the survey in the post. The questionnaires were mailed out to members' home addresses. We also included a link to the web version of the survey for them to complete online if preferred.

Mailing out/ launching the survey

The Picker Institute oversaw the survey mailings and online survey. Response rates were successfully boosted by sending out reminders to non-responders.

The postal mailings consisted of the following:

> **Mailing 1:** Sending out a questionnaire, cover letter from the MNDA, and FREEPOST envelope for returning the survey in, to all members without a registered email address;
> **Mailing 2**: Sending a reminder letter to non-responders, 2-3 weeks after the first mailing.

The online mailings consisted of the following:

> **Mailing 1:** Sending out an email invitation letter from the MNDA, with a link to the online survey and a link to 'opt-out';
> **Mailing 2**: Sending a reminder email invitation to non-responders with a link to the online survey and a further link to 'opt-out'.

Every member was given a unique reference number (URN) that was either printed onto the questionnaire or attached to their email address, so that each respondent was represented by a unique code. This was used to track who had completed a survey and who needed to be sent a reminder. Those who wished to opt out could return a blank questionnaire, call our Freephone service or use the 'opt-out' function in the email. The URN was used to identify those who had returned a completed questionnaire or opted out, to ensure that they did not receive any further correspondence.

Due to the sensitive nature of the survey, the Picker Institute ensured that all ***survey materials*** sent to members outlined:

- The **purpose** of the research
- How we **obtained their details**
- **How the information** will be used
- **What was involved** for those who decide to take part
- It also highlighted that **participation was voluntary** (and highlighted the process for **'opting-out'** of further mailings regarding the survey) and explained that all information was confidential and used only in an anonymous format, so as not to link feedback directly to a particular individual
- A **Freephone helpline** was implemented during the survey for survey related issues and also followed an approved protocol to offer a link to other support and counselling services, including a named member(s) of MNDA's MND Connect team for those who were in need of this additional support.

Logging survey responses

The Picker Institute logged survey responses on a daily basis and provided the MNDA with regular updates on response rates for both the online and postal elements. Daily logging of respondents was required to ensure that those who did respond were removed from further reminder mailings and to avoid causing any distress to those recently bereaved.

Freephone helpline

Picker Institute Europe ran a confidential Freephone helpline staffed by specially trained advisors, for respondents who had queries or concerns about the questionnaire they had received. The phone number appeared on the front of the questionnaire and/or in the covering letter sent out with the survey and in the email invitation. It also enabled respondents to opt out of the survey if they wished, or they could ask to complete the survey over the phone with an advisor.

Confidence Intervals

The survey undertaken was with a ‘sample’ of members. As the survey was not of all members, the results may not be totally accurate. However, we can estimate the level of confidence we should have in the results. The table below shows the level of confidence we would have for various numbers of respondents.

Number of respondents	Confidence Interval (+/-)
50	12.0%
100	8.5%
200	6.0%
300	4.9%
400	4.2%
500	3.8%
600	3.5%

Example: For a particular question, 300 patients responded, of which 25% answered ‘yes’. From the table above, we can see that for 300 respondents the confidence interval would be +/- 4.9%. We would therefore estimate that the true results could be between 20.1% and 29.9%. However, if only 50 patients responded, and 25% answered ‘yes’, the confidence intervals would be +/- 12% so the true result could be between 13% and 37%.

Significant differences

In the report we have identified questions where there are significant differences between subgroups. By 'significant' difference, we mean that the finding is statistically reliable and that the difference is likely to be 'real'. The calculation used to test the statistical significance of scores was the two-sample t-test.

Rounding of percentages

Note that throughout the report, partial percentages have been rounded to the nearest full number. For example 12.8% is rounded up to 13%, while 5.3% would be rounded down to 5%. Therefore not all figures shown will add to 100%.

Word clouds

Included in the report you will see some word clouds, they provide a quick way of visualising large amounts of verbatim text and give a feel for what is being said. Word clouds take all of the individual words and counts the number of times they are mentioned. The more mentions a word gets, the bigger the size of the word in the cloud. All of the words are adjusted proportionately and randomly placed within the cloud. Common English words are ignored when the cloud is produced. Word clouds are case sensitive, so text has been set to lower case to ensure all words (where possible) count together.

Demographics

A total of 2,933 people with MND were sent the pre-approach letter. Following the response from the letter (67 deceased notification and 28 opt outs), 2838 were invited to complete the survey. We received a further 131 notifications (102 deceased and 29 opt outs) and achieved a response from 951 people giving an overall response rate of 34%. Key demographics for the 951 respondents are as follows:

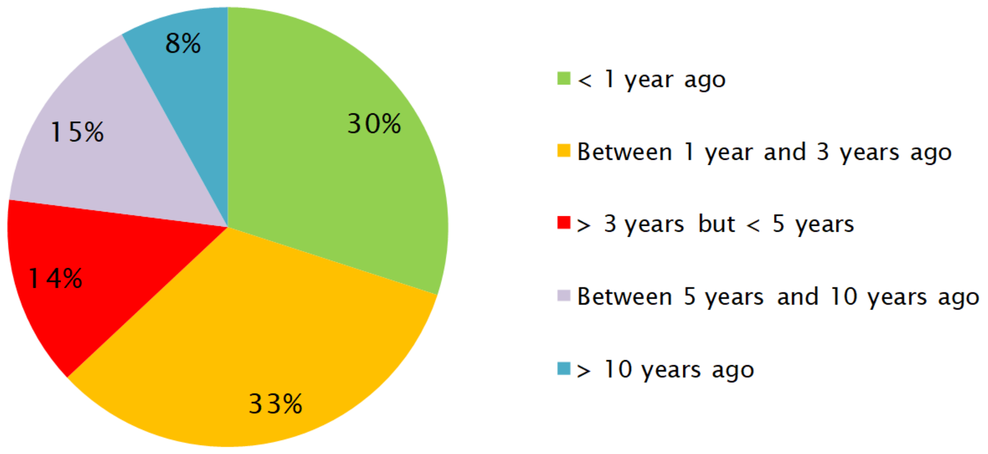
	Number in Sample	Percentage in Sample
Interview method		
Online – with EoL	332	35%
Online – No EoL	9	1%
Postal – with EoL	589	62%
Postal – No EoL	21	2%
Gender		
Male	614	65%
Female	337	35%
Age groups		
50 years and under	73	8%
51 – 60 years	156	17%
61-70 years	366	39%
71 – 80 years	250	27%
81 years and over	95	10%
Household Status		
Married / in a civil partnership / living with partner	718	79%
Single / divorced / widowed and living alone	147	16%
Single / divorced / widowed and living with my parents	4	0.2%
Single / divorced / widowed and living with other adults	35	4%
Time since diagnosis		
Less than 1 year ago	278	30%
Between 1 year and 3 years ago	311	33%
More than 3 years ago but less than 5 years ago	128	14%
Between 5 and 10 years ago	139	15%
More than 10 years ago	78	8%

Findings

Diagnosis

A third of the people living with MND who completed the survey had received their confirmed diagnosis within the last year (30%, n=278) with a further third stating that is was between one year and 3 years ago (33%, n=311) with the remaining third receiving the diagnosis more than three years ago (37%, n=345):

Q1. When did you receive your confirmed diagnosis of MND?
(answered by 934 respondents)



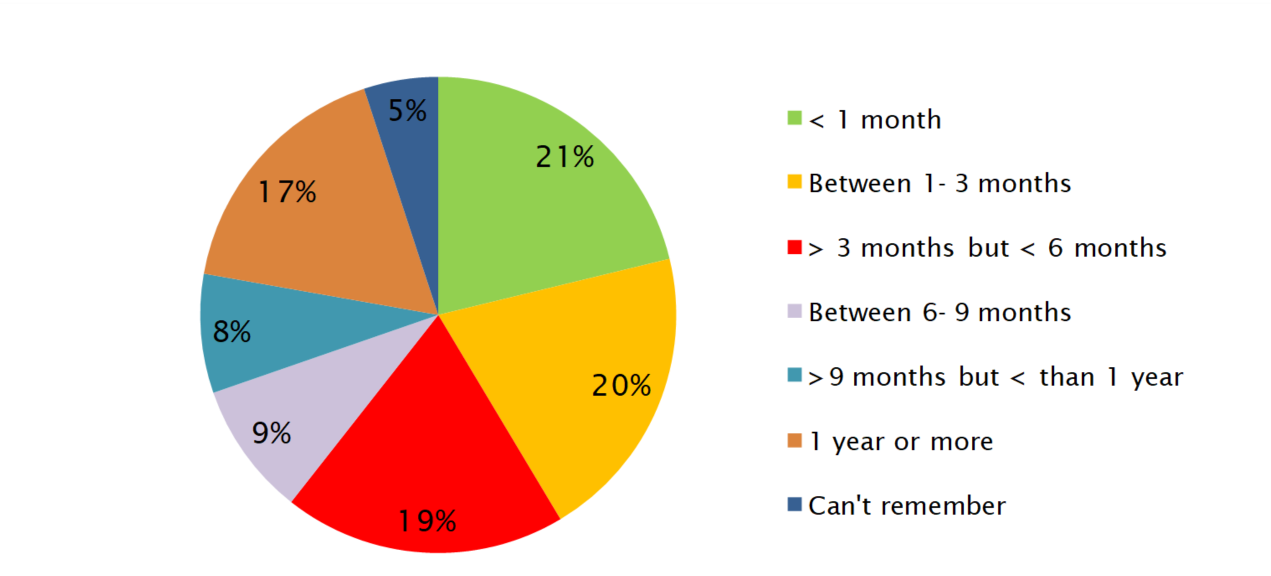
There were significantly more females (34%, n=112) than males (27%, n=166) that had been diagnosed within the last year completed the survey.

Getting a diagnosis

When asked how long it had taken from the first consultation with the GP to being referred to a Neurologist, the majority of respondents reported this was within six months – '*less than one month*' (21%, n=197), '*between 1-3 months*' (20%, n=190) and '*more than 3 months but less than 6 months*' (19%, n=176). We can see from the chart below that a fifth of respondents waited one year or more (17%, n=162).

Q2. How long was it from when you first consulted your GP until you were referred to a Neurologist?

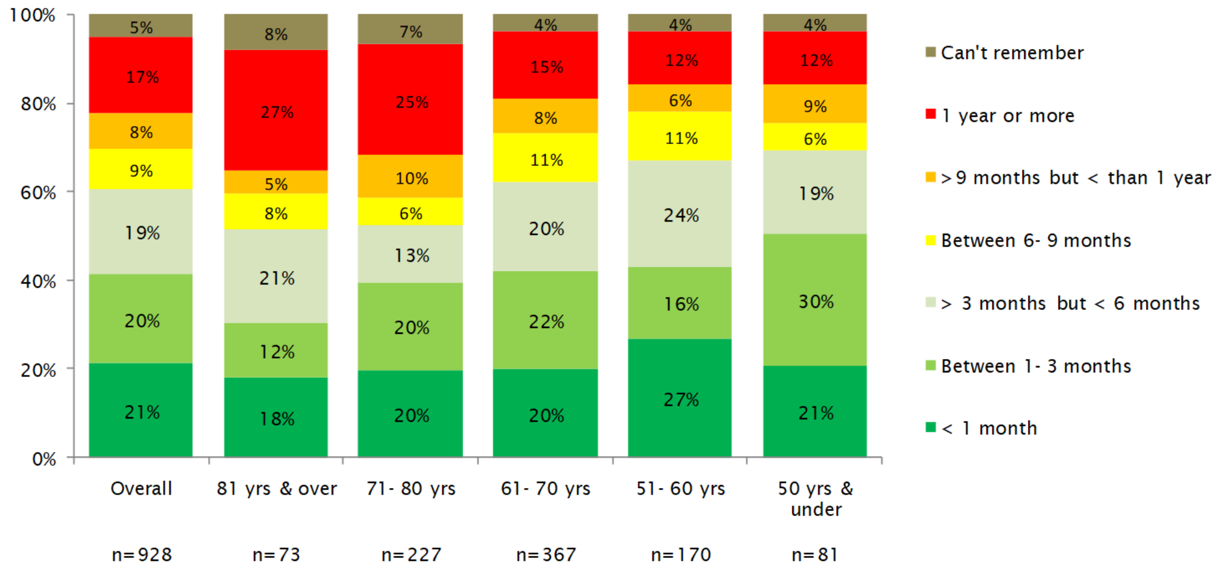
(answered by 928 respondents)



*Note – Percentage does not add to 100% due to rounding

Respondents aged 71 years and above were significantly more likely to wait more than a year for referral compared with younger respondents – see chart below:

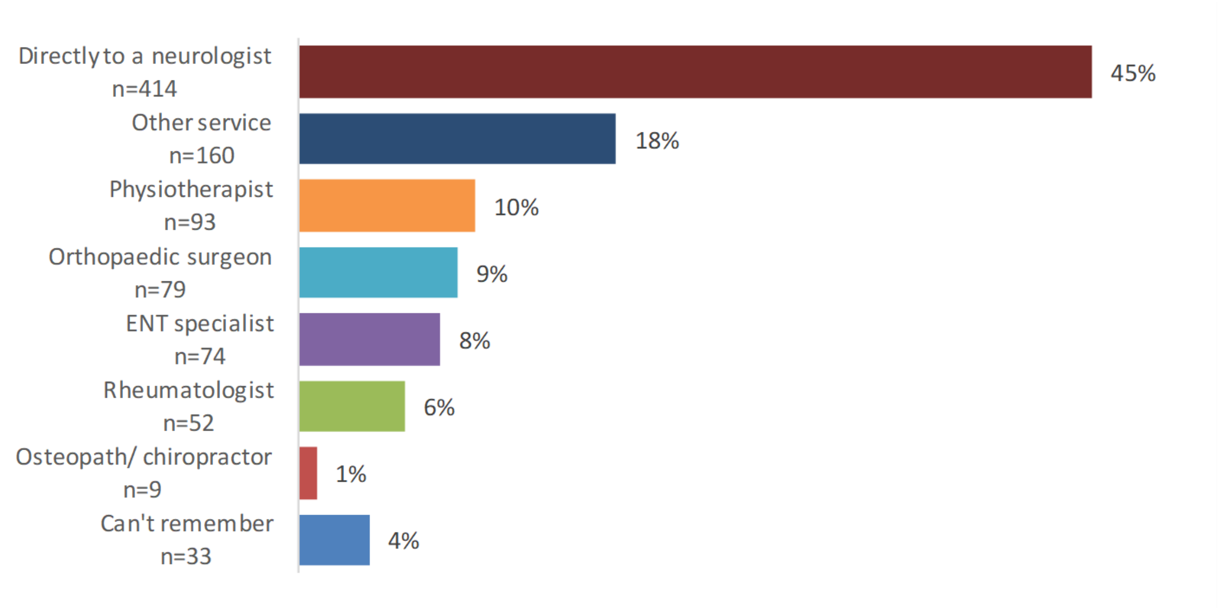
Q2. How long was it from when you first consulted your GP until you were referred to a Neurologist by age?



Over a third of respondents (37%, n=348) felt that the referral to a Neurologist '*definitely*' happened as soon as they would have liked, with 27% (n=255) stating that it had '*to some extent*'. However, 32% (n=302) reported that it was not as soon as they would have liked.

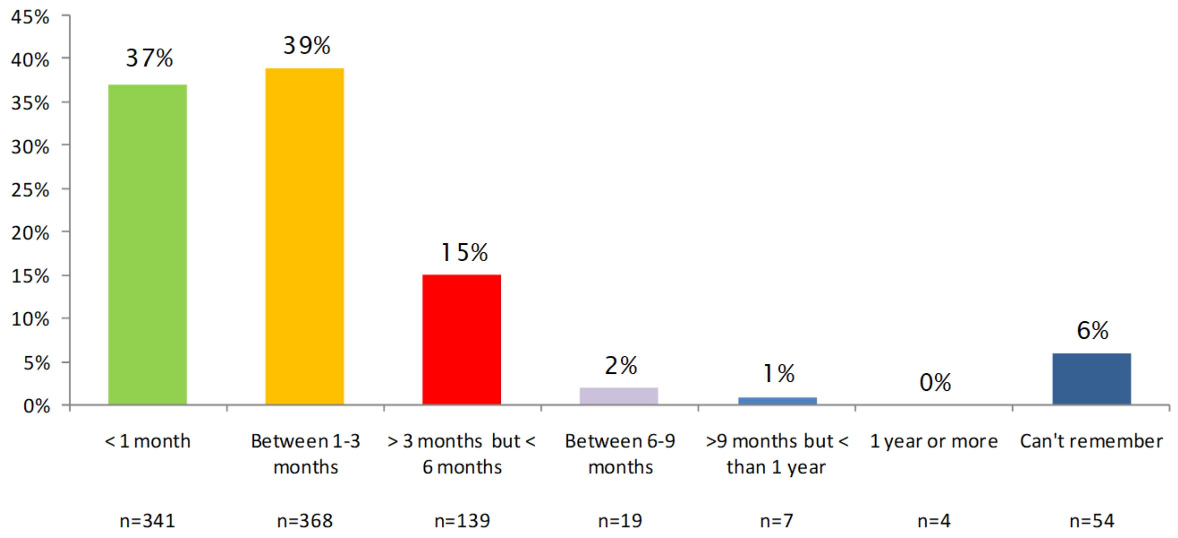
Over half of respondents (52%; n=467) stated that they had been referred to other healthcare practitioners before being referred to a Neurologist.

Q3. Were you referred to anybody else before seeing a neurologist?
(answered by 914 respondents)



When asked how long after the referral that they were actually seen, three-quarters of respondents (76%, n=709) were seen within three months (37%, n=341 reporting within one month and 39% n=368 between one to three months).

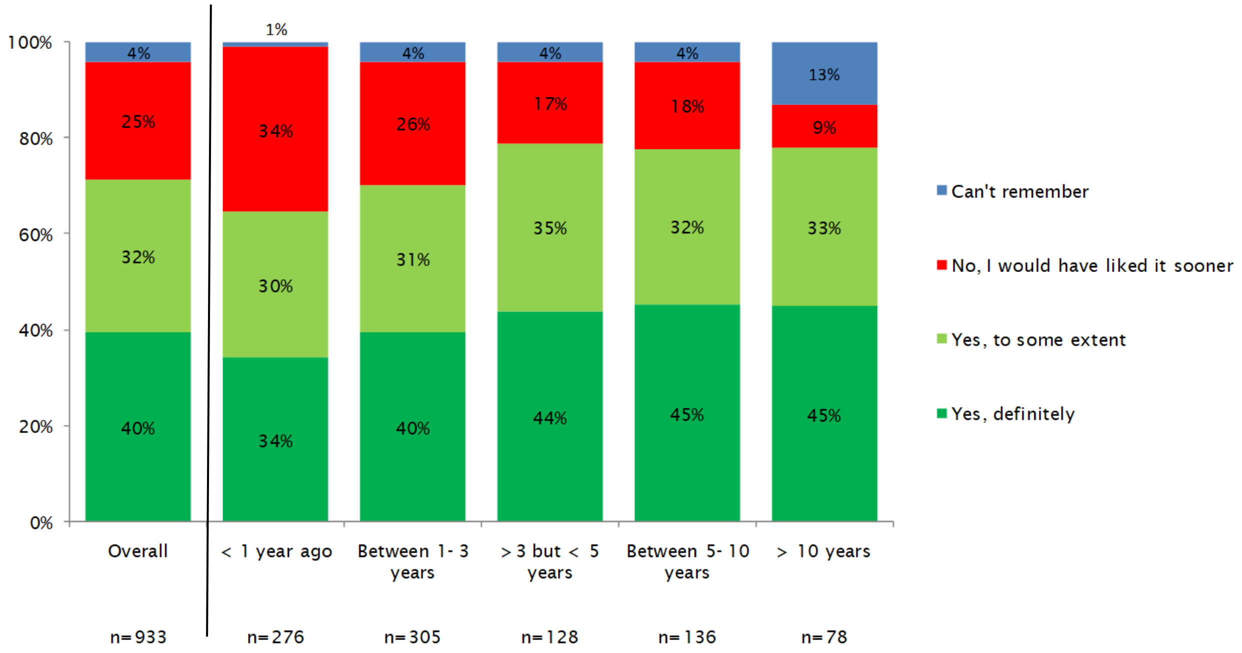
Q4. After you were referred to a neurologist, how long was it before you were actually seen?
(answered by 932 respondents)



Respondents were asked if the appointment with the Neurologist was as soon as they would have liked, 40% (n=373) said '*yes, definitely*', with a third (32%, n=295) saying '*yes, to some extent*'. A quarter of respondents (25%, n=229) felt that the appointment should have been sooner.

Respondents who had received their confirmed diagnosis within the last year (34%, n=95) were significantly more likely to feel that they should have been seen earlier compared to those who had received their diagnosis over a year ago (1-3 years ago 26% (n=78), 3-5 years ago 17% (n=22), 5-10 years ago 18% (n=25) and more than 10 years ago 9% (n=7).

Q4b. Was the appointment with the Neurologist as soon as you would have liked?
by time since diagnosis

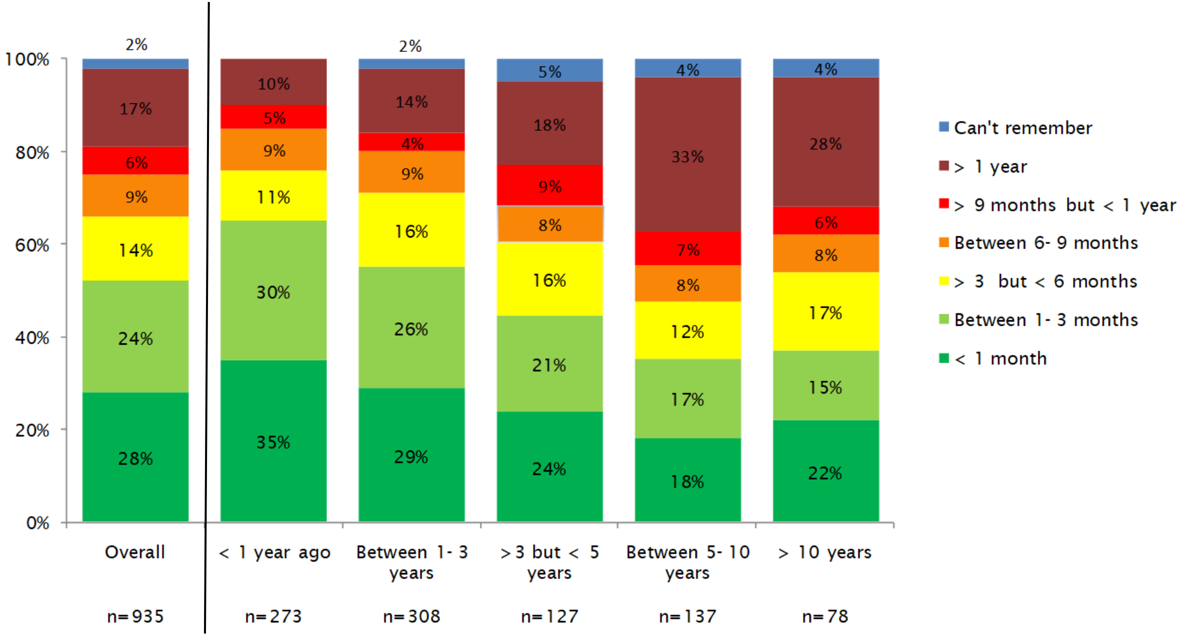


Following the appointment with the Neurologist, half of all respondents (52%, n=484) reported they received a confirmed diagnosis within 3 months (28%, n=257 received it within one month and 24%, n=227 received their diagnosis between one and three months). A third of respondents (29%, n=263) stated they waited between three months and one year for the diagnosis, whilst nearly a fifth (18%, n=164) waited over a year.

Those who were diagnosed more than five years ago where significantly more likely to have waited a year or more for their diagnosis compared with those diagnosed within the last three years.

Those who received their confirmed diagnosis at an Association-funded MND Care Centre (22%, n=100) are more likely to have waited a year or more for their diagnosis than those receiving it at a non-Association funded MND clinic (16%, n=39).

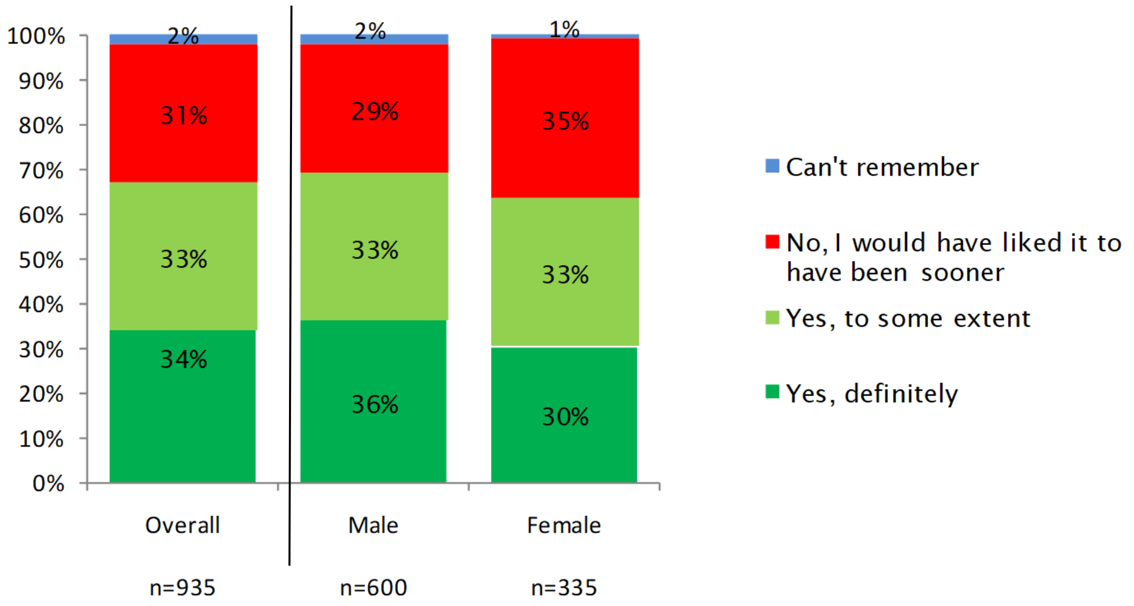
Q5a. How long after you first saw a Neurologist were you given the diagnosis of MND? by time since diagnosis



The majority of respondents felt they '*definitely*' (34%, n=317) or '*to some extent*' (33%, n=310) received the diagnosis as soon as they would have liked. However, a third (31%, n=292) that they would have liked it sooner.

Females were significantly more likely to say that they would have liked their diagnosis earlier (35%, n=118) compared with males (29%, n=174).

Q5b. Did you receive the confirmed diagnosis as soon as you would have liked? by Gender

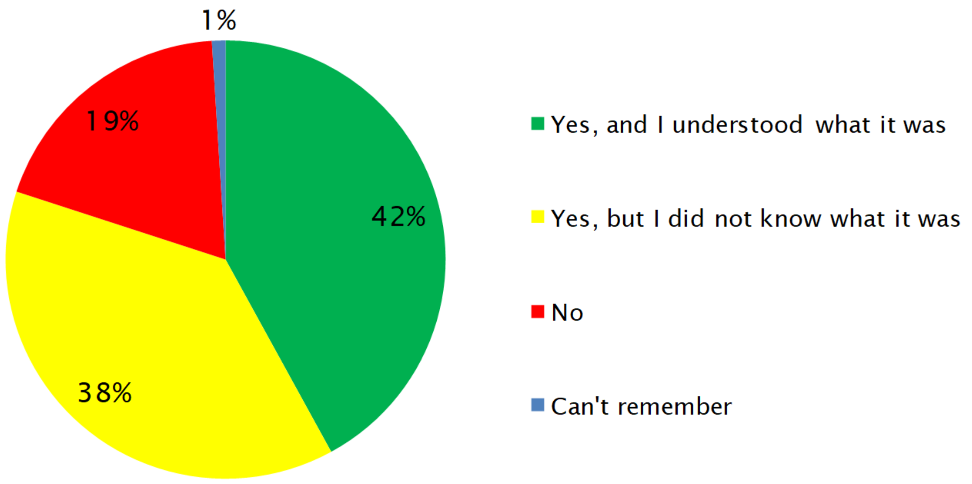


Just over half of all respondents (58%, n=543) felt that the various tests and investigations were '*definitely*' explained to them in a way they could understand. A third (32%, n=298) agreed they had been '*to some extent*', whilst 9% (n=85) felt they had not been explained in a way they could understand. Those receiving their diagnosis at an Association-funded MND Care Centre are more likely to say the tests and investigations are explained (59%, n=270) than those receiving the diagnosis at a non-Association funded MND clinic (50%, n=127).

Day of confirmed diagnosis

Before receiving their confirmed diagnosis, 42% (n=396) reported that they had heard of Motor Neurone Disease and understood what it was, whilst 38% (n=351) had heard of MND but **did not** know what it was. A fifth of respondents (19%, n=181) had not heard of MND prior to receiving their confirmed diagnosis.

Q7. Before receiving your confirmed diagnosis had you heard of Motor Neurone Disease?
(answered by 933 respondents)



The majority of respondents (93%, 859) who completed the survey received their diagnosis '*in person, during an appointment with a neurologist*', 45 respondents (5%) reported that they had received their diagnosis '*in person, during an appointment with another doctor or healthcare professional*'. A very small number of respondents (n=4) received their diagnosis over the telephone, with 2% (n=18) reporting that they received theirs by letter.

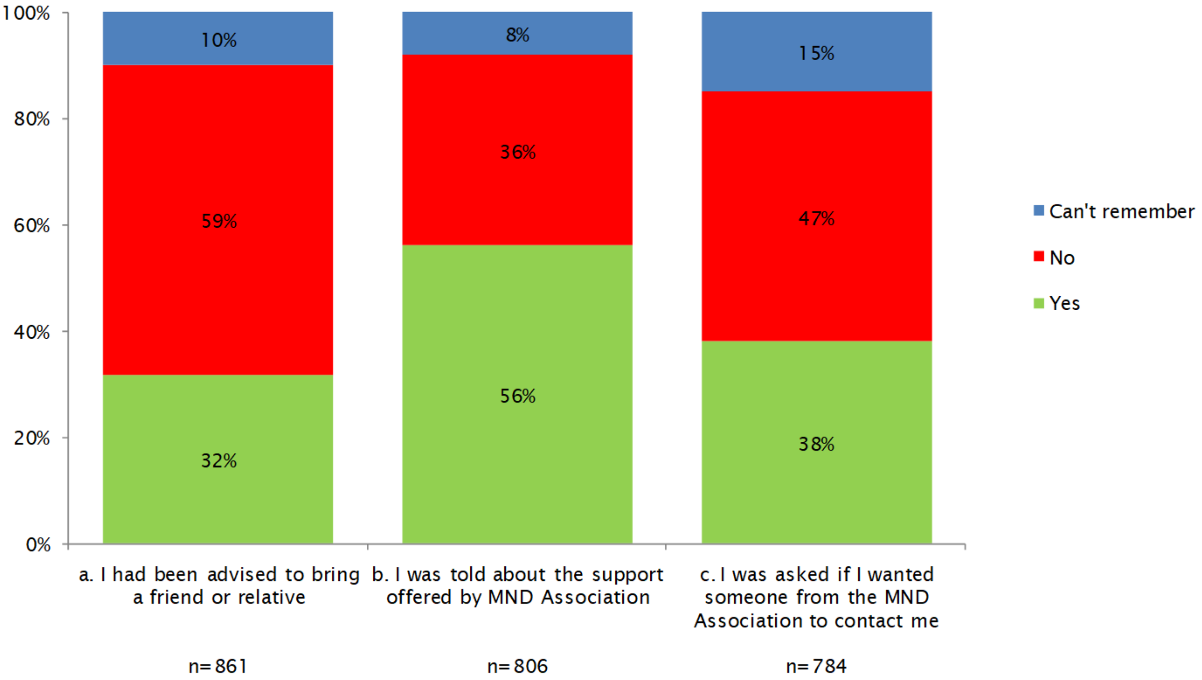
Respondents were asked to think about the appointment in which they were given their confirmed diagnosis and consider a selection of statements around advice and support.

When asked if they had been advised to bring a friend or relative, the majority (59%, n=505) reported '*No*', with a third (32%, n=273) saying '*Yes*' they had been advised to do so. Those receiving their diagnosis at an Association-funded MND Care Centre are significantly more likely to be advised to bring a friend or relative (35%, n=153) than those receiving their diagnosis from a non-Association funded MND clinic (27%, n=62).

Just over half of respondents (56%, n=455) said '*Yes*' they had been told about the support offered by the MND Association, with just over a third (36%, n=288) reporting they had not been told.

Just under half (47%, n=366) reported that they were not asked if they wanted someone from the MND Association to contact them, with 38% (n=300) saying '*Yes*' they had been asked. Those receiving their diagnosis at a non-Association funded MND clinic are significantly more likely to be say they had not be asked if they wanted somebody from the MNDA to contact them (51%, n=107) compared with those receiving their diagnosis from an Association-funded MND Care Centre (39%, n=159)

Q9. Thinking about the appointment in which you were given your confirmed diagnosis…



The majority of respondents (86%, n=771) reported that they were given their confirmed diagnosis in a private place behind closed doors, 9% (n=77) agreed that this had happened '*to some extent*'. A small number (3%, n=27) said that was not the case but they did not mind, however, for 2% (n=17) they were not told in a private place behind closed doors but would have like this.

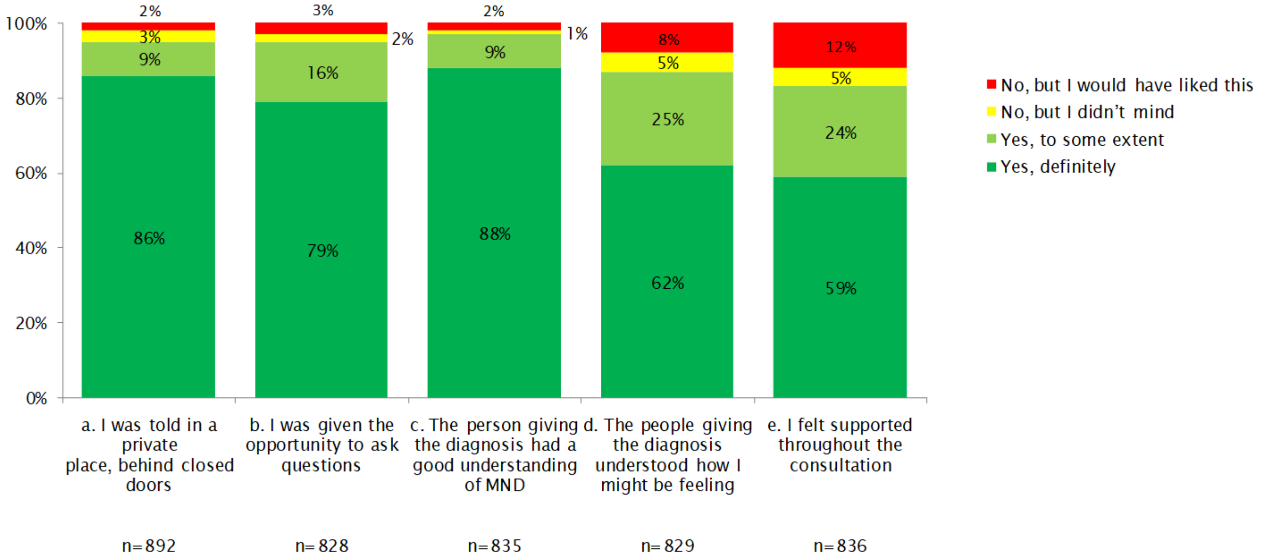
Four-fifths of respondents (79%, n=656) felt they were given the opportunity to ask questions, 16% (n=132) agreed to some extent that they had been given the opportunity. Again, a small number of respondents reported that this was not the case for them, 2% (15) said '*no, but I didn't mind*' while for 3% (n=25) they were not given the opportunity to ask questions, but would have liked to have been.

We can see a similar response pattern from respondents when they were asked if they felt the person giving the diagnosis had a good understanding of MND with 88% (n=733) saying '*Yes, definitely*' and a further 9% (n=79) agreeing '*to some extent*'.

When asked if they felt the people giving the diagnosis understood how they might be feeling, there is more variation in the responses given. Just over half of respondents 62% (517) reported '*Yes, definitely*', with a quarter of respondents (25%, n=209) agreeing '*to some extent*'. Just under a tenth of respondents said this did not happen with 5% (n=38) stating '*no, but I didn't mind*', and 8% (n=65) reporting that this had not happened but they would have like it to.

Over half of respondents (59%, n=493) said they had '*definitely*' felt supported throughout the consultation, with a quarter (24%, n=199) saying they had felt supported '*to some extent*'. We see the largest number of respondents replying negatively to this statement with 5% (n=44) saying they had not felt supported but they did not mind. However, just over a tenth of respondents (12%, n=100) said they had not felt supported throughout the consultation but they would have liked to.

Q10. Still thinking about the appointment in which you were given your confirmed diagnosis…



The majority of respondents (50%, n=459) received their diagnosis at an Association-funded MND Care Centre however, of those diagnosed within the last year, significantly more (34%, n=86) received their diagnosis in a non-Association funded MND Clinic compared with those receiving it at an Association-funded MND Care Centre (26%, n=119).

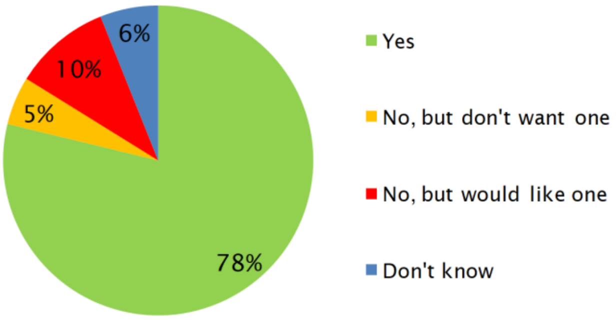
At the end of this section, respondents were asked if they had any further comments to make around the day of confirmed diagnosis, 591 respondents made a comment. The word cloud below has been produced to give an idea of what is being mentioned.


tests
hospital
told
time
gp
symptoms
years
long
consultant
appointment
months
thought
given
took
first
confirmed
shock
doctor
waiting
saw
felt
referred
private
condition
day
might
think
see
wrong
weeks
treatment
support
disease
many
one
like
stroke
knew
specialist
several
seemed
year
received
wife
shocked
know
already
made
came
taken
nhs
prior
carried
scan
left
confirmation
good
husband
explained
done
information
appointments
speech
problems
opinion
brother
lot
asked
now
blood
results
treated
seen
another
get
things
find
different
lost
still
went
later
dr
clinic
may
care
neurology
foot
visit
motor
second
g.p
work
idea
yes
back
due
got
period
suspected
found
really
referral
earlier
london
days
test
way
also
brain
health
doctors
difficult
probably
privately
least
kings
positive
something
muscle
serious
consultation
quicker
delay
m.n.d
emg
died
confirm
ward
initially
local
just
centre
although
since
genetic
fact
illness
paid
anything
help
late
news
nerve
come
wait
sent
quickly
seriously
never
questions
staff
team
people
finally
legs
surgeon
home
short
times
etc
well
far
little
various
mentioned
following
expected
make
take
feel
month
slow
insisted
suffering
surgery
worst
tried
parkinson's
available
working
visited

After confirmed diagnosis

Three quarters of respondents (78%, n=718) report that they currently have a named person in either health or social care who is responsible for co-ordinating their care and support, whilst10% (n=92) said they did not have a named person but would like one; a small number of respondents (5%, n=47) did not have a named person but report that they did not want one.

Q15. Do you currently have a named person in either health or social services who is responsible for co-ordinating your care and support?
(answered by 915 respondents)



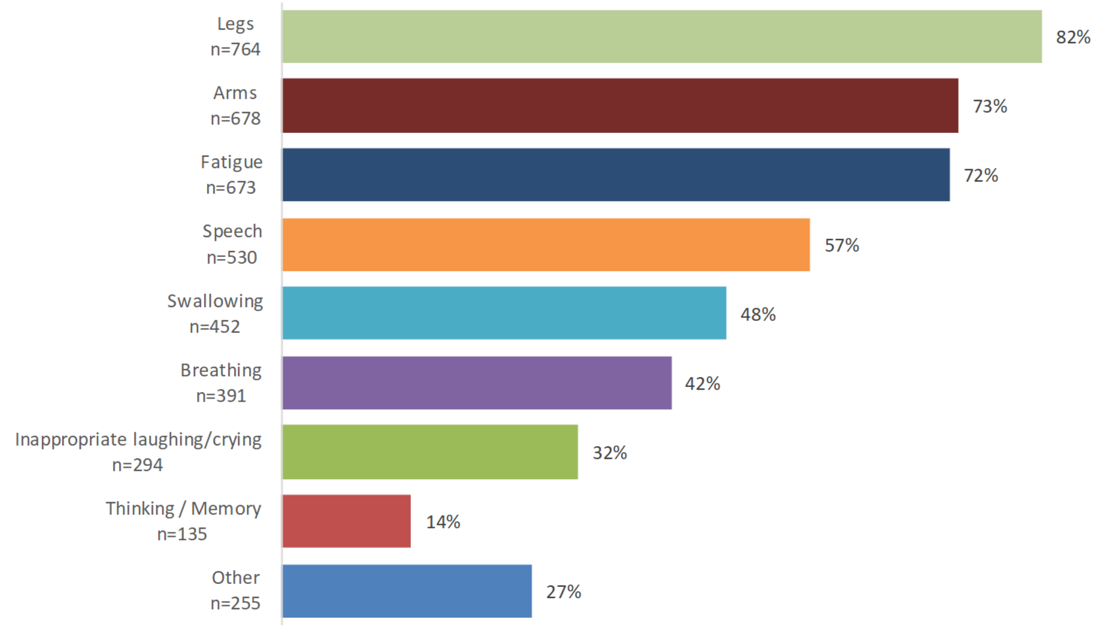
Of the 718 respondents who do have a named person responsible for co-ordinating their care and support, the majority (95%, n=679) felt that relationship either works '*very well*' (69%, n=492) or '*fairly well*' (26%, n=187) with only a small number of respondents reporting that it wasn't working '*very well*' or '*not at all well*' (3%, n=21 and 1%, n=5 respectively).

Respondents aged 81 years and over are significantly more likely to say the relationship works very well (88%, n=52) compared with younger respondents.

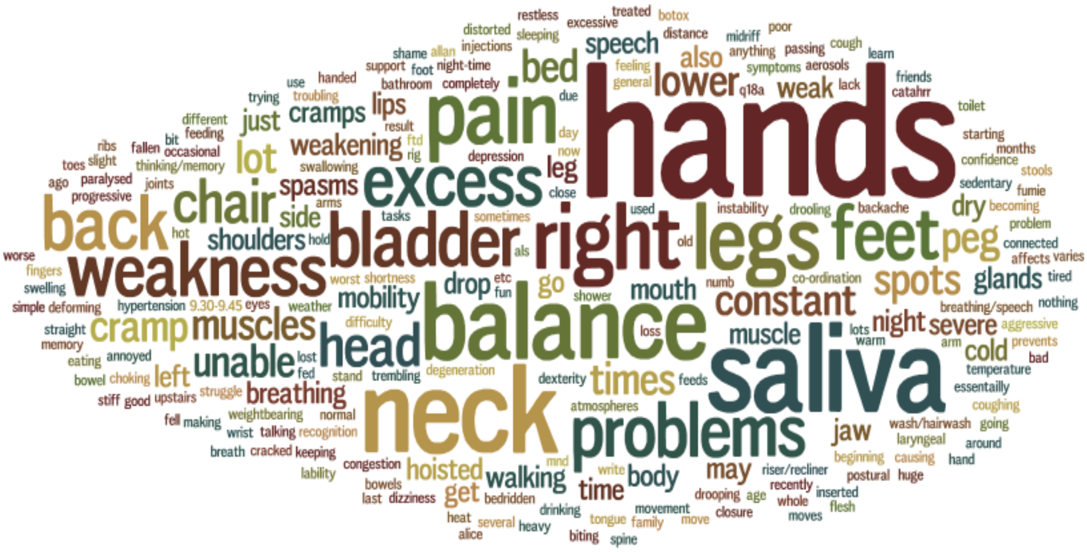
When asked if there were any additional comments concerning the co-ordination of their ongoing care, 523 respondents gave a comment:

Respondents were asked to indicate how they were affected by MND, the majority (82%, n=764) reported that their legs were affected, while three quarters said MND affected their arms and caused fatigue (73%, n=678 and 72%, n=673 respectively). The chart below shows how all respondents were affected:

Q18. Please indicate how you are affected by MND?
(answered by 929 respondents)



Other areas/ comments around areas affected by MND are shown in the following word cloud:



The table below indicates the number of respondents affected by MND in multiple areas:

Number of areas affected by MND	Number of respondents (n=)	Percentage of respondents (%)
1	35	4%
2	101	11%
3	170	18%
4	157	17%
5	175	19%
6	164	18%
7	87	9%
8	34	4%
9	6	1%

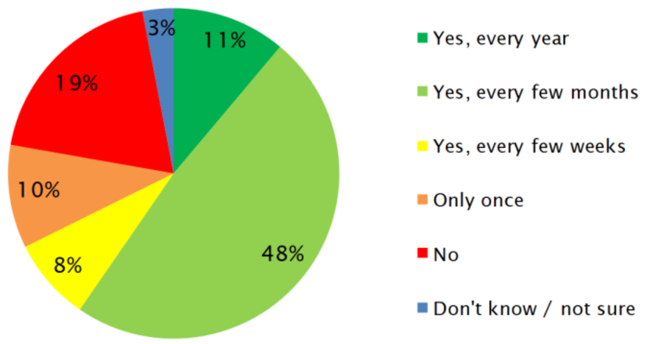
*Note – Percentages add to more than 100% due to rounding

Just over half of respondents (57%, n=517) said that they had not needed surgery to insert a feeding tube to help with breathing, while nearly a third (27%, n=134) said they had been offered and had surgery to insert a feeding tube. Just over a tenth of respondents (15%, n=134) said they had been offered surgery but decided against it.

Females were significantly more likely (33%, n=107) to choose surgery compared with males (23%, n=134).

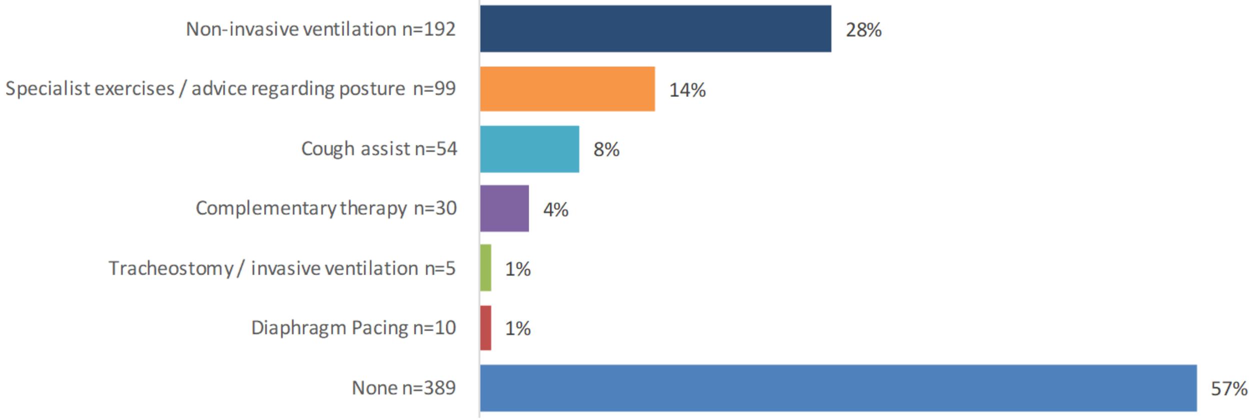
Having their breathing monitored was an annual occurrence for a tenth of respondents (11%, n=103). For nearly half of all respondents (48%, n=442) breathing assessments and monitoring happened every few months, and occurred every few weeks for 8% (n=72) of respondents. A tenth of respondents (10%, n=93) said this had only happened once and 19% (n=178) reported that their breathing was not monitored or assessed.

Q20. Is your breathing monitored and assessed?
(answered by 913 respondents)



Respondents were asked if they received any special help with their breathing to which just over half (57%, n=389) replied they received 'none', nearly a third of respondents (28%, n=192) received non-invasive ventilation, with just over a tenth (14%, n=99) had specialist exercises/ advice regarding posture.

Q21. What special help do you have with your breathing?
(answered by 779 respondents)



And when asked if they had experienced any difficulty in obtaining help with their breathing, three-quarters of respondents (76%, 218) reported that they '*rarely or never*' experienced difficulties, however a tenth of respondents reported that they had either '*regularly*' (2%, n=7) or '*a few times*' (8%, n=22) had difficulties in obtaining help with their breathing.

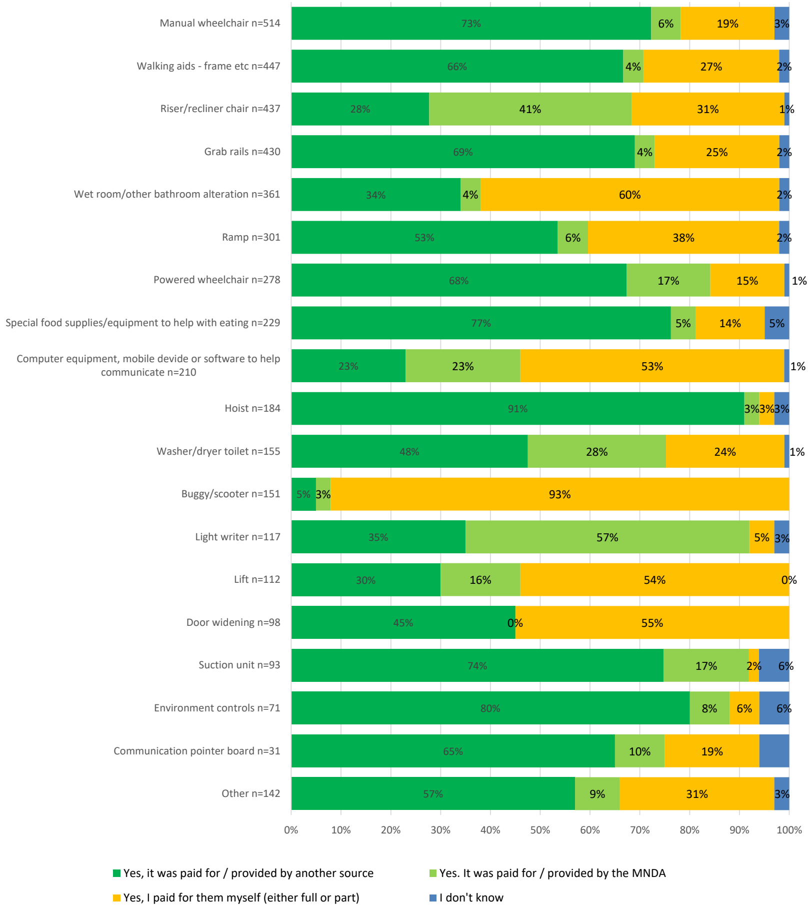
Specialised equipment

Respondents were asked to identify which items of specialised equipment they used and to select how this was provided/funded;

The items have been charted in order of those most used and highlight the following:

- The manual wheelchair (n=514) is mainly funded by another source (73%)
- The hoist (n=184) is the item mainly funded by others (91%)
- Buggies/ scooters (n=151) are mostly (93%) self-funded(either in whole or part)
- Of those using a light writer (n=117), just over half (57%) are provided by MNDA
- When home adaptations are required (wet room, lift or door widening), the majority of respondents (60%, 54%, 55% respectively) self-fund (either in whole or part)

Q23c. For each item you have, do you know who provided/ paid for it?
(answered by 846 respondents)

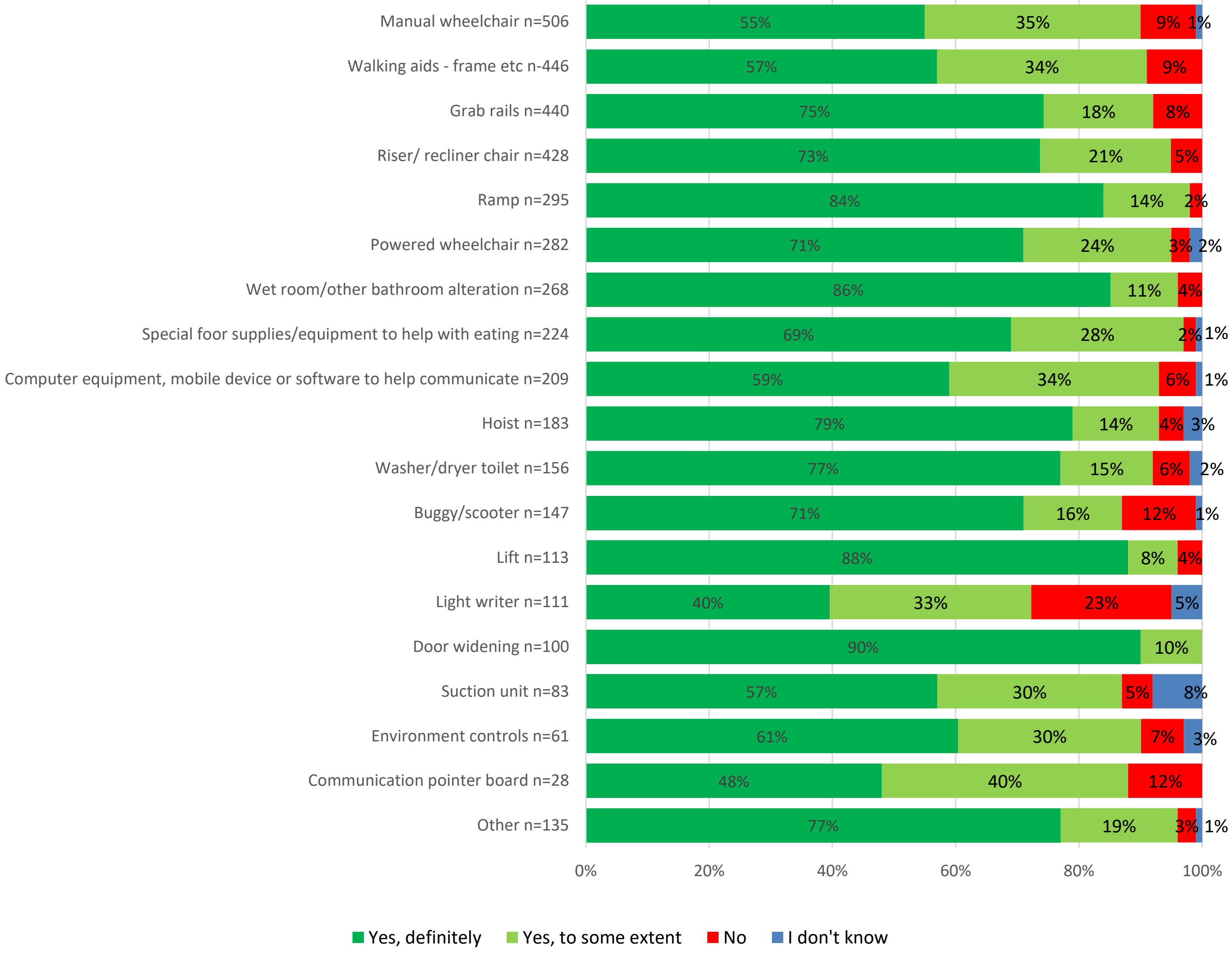


Respondents were then asked if the equipment they were using met their needs;

Again, the items have been charted in order of those most used and highlight the following:

- The light writer (n=111) is the item that least meets respondents needs with a nearly a quarter of respondents stating '*no*'(23%), followed by buggy/ scooter (n=147) and communication pointer board (n=28) both with just over a tenth (12%) of respondents stating '*no*'
- Unsurprising the items that most meet respondents needs are those which the majority self-fund – door widening (90%), lift (88%) and wet room (86%) reporting '*yes, definitely*'
- Just over half (55%) of manual wheelchair users said theirs 'definitely' met their needs, compared with nearly three-quarters (71%) of powered wheelchair users

Q24. For each item/ adaptation you have, does it meet your needs?
(answered by 854 respondents)



When asked to consider a series of statements about their care and treatment since diagnosis, the majority of respondents either '*agreed strongly/*'*agreed*' with all statements. The statements with the highest level of agreement (agree strongly/ agree), 88%, were 'I am treated with dignity and respect' and 'when receiving health care services, I feel my independence/ autonomy is respected'. However we see a few where disagreement is high:

- A fifth of respondents (18%, n=156) disagreed that all the different services are co-ordinated well
- Almost a fifth of respondents (16%, n=142) feel that their family members and carers are NOT well supported
- A tenth of respondents (13%, n=112) 'disagreed'/ 'disagree strongly' that they get the social care service they need when they need them
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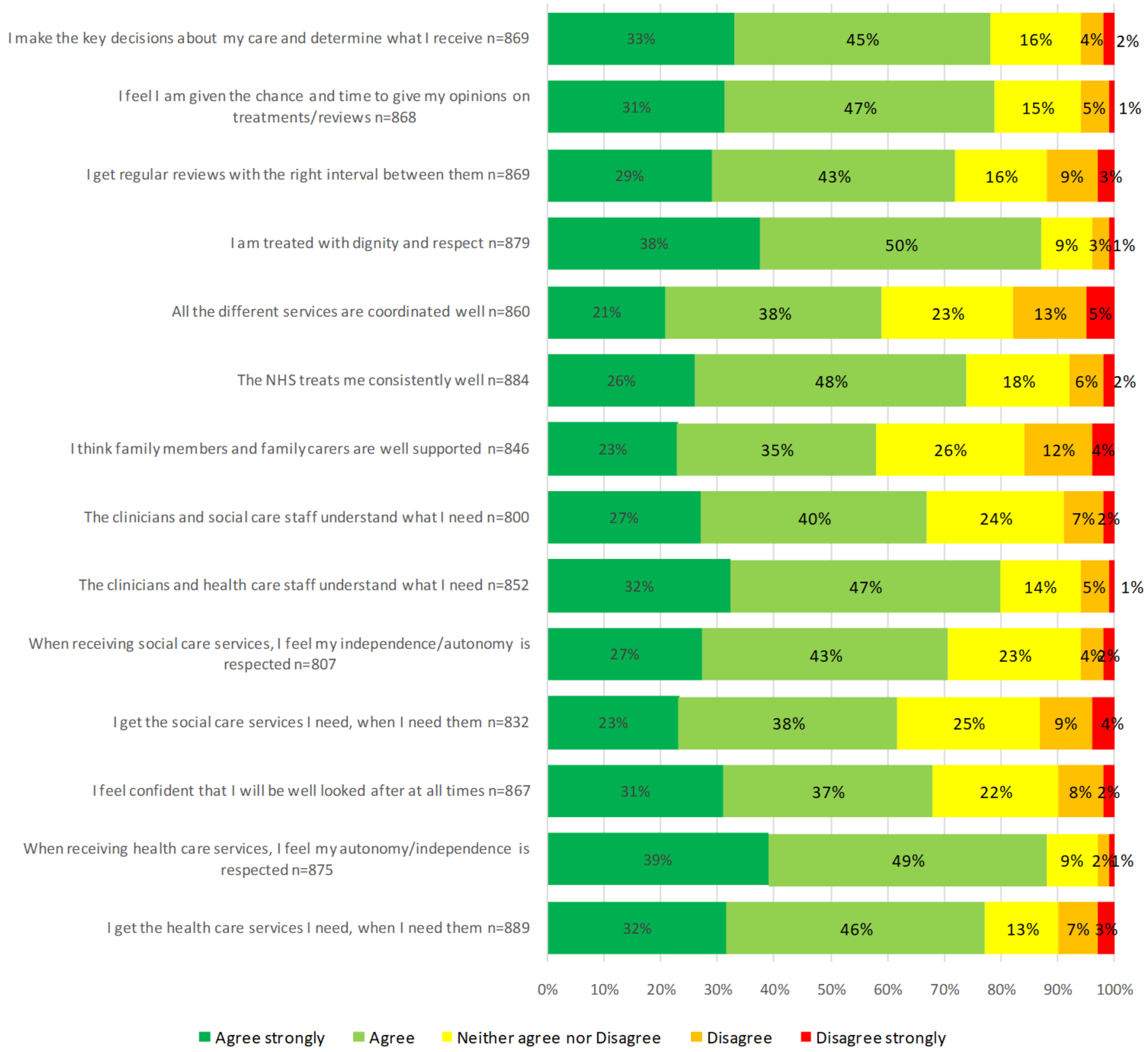
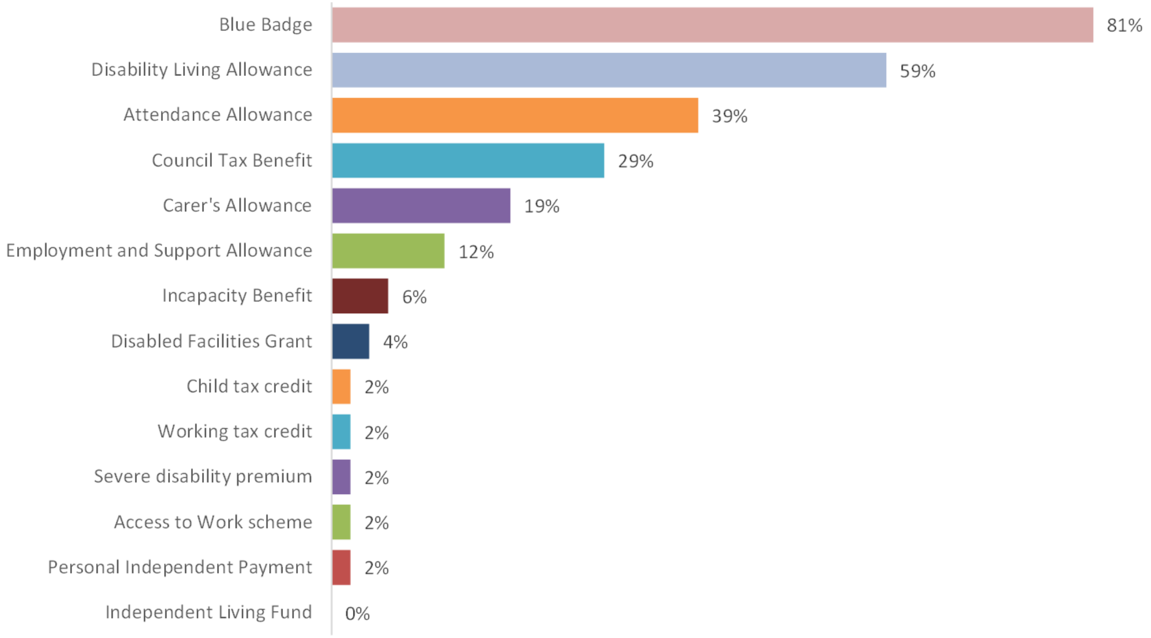
Q25. Please indicate the extent to which you agree or disagree with each of the following statements?



Blue badge (81%, n=695), Disability Living Allowance (59%, n=504), Attendance Allowance (39%, n=33), Council Tax Benefit (29%, n=252) and Carer's Allowance (19%, n=166) are the benefits received by the majority of respondents.

Q26. Please tell us which of these benefits and funding you currently receive?

(answered by 856 respondents)



When asked if the process of obtaining the benefits caused difficulty, nearly three-quarters (68%, n=580) reported they had not, while a third (32%, n=276) said they experienced difficulties. Respondents aged 50 years and younger (49%, n=38), 51-60 years (42%, n=67) or those age 61-70 years (35%, n=117) were more likely to experience difficulties obtaining benefits than those aged 71-80 years (22%, n=45) or those aged 81 years and over (11%, n=8).

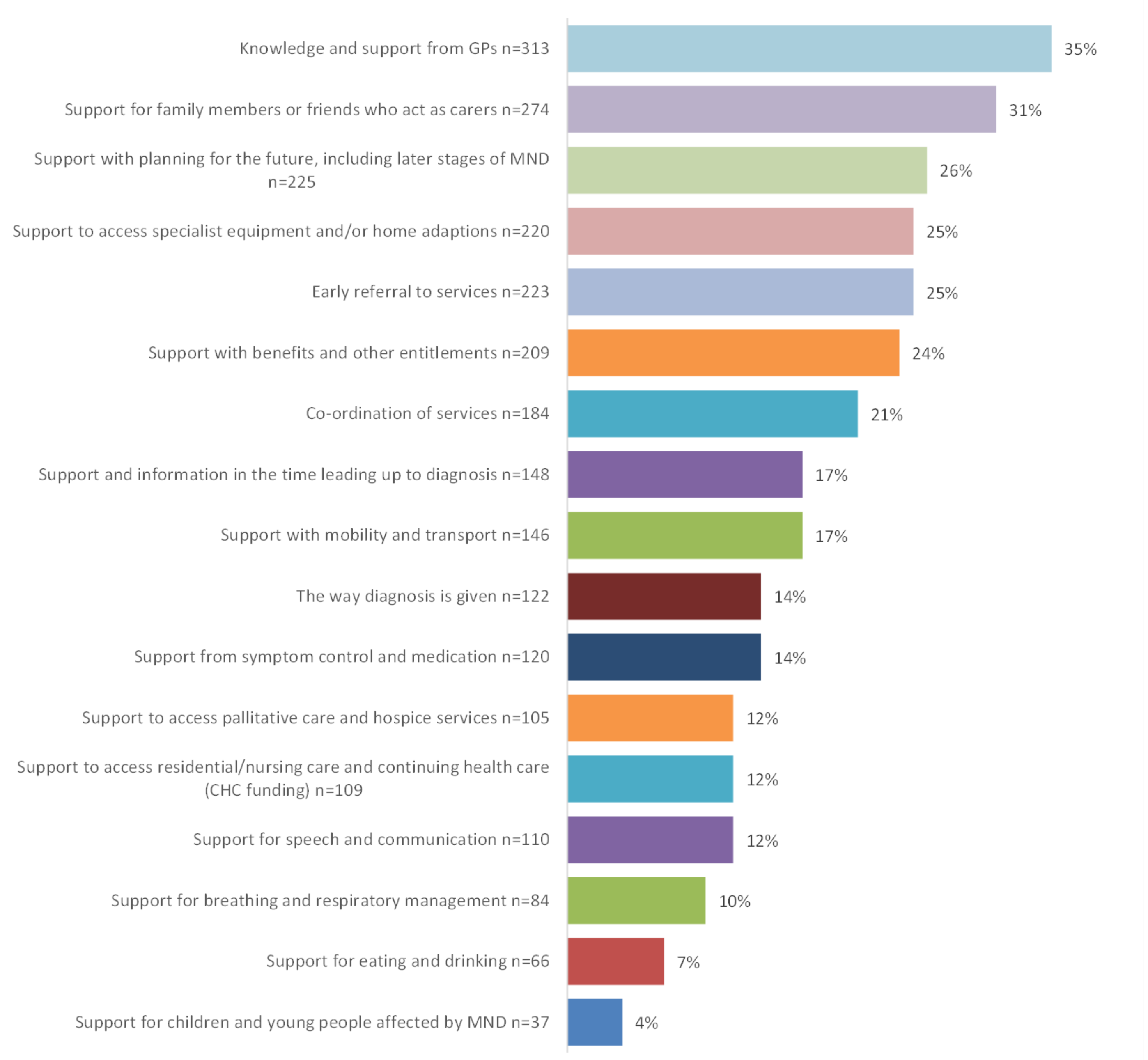
Respondents were asked to consider 17 different areas of support that the MND Association should address or improve, they were instructed to select up to three areas that they considered to be most important.

The most important area that respondents feel needs addressing/ improving is 'knowledge and support from GP' 35% (n=313), closely followed by 'support for family members or friends who act as carers' 31% (n=274).

The third most important area is 'support with planning for the future, including later stages of MND' 26% (n=225).

'Support to access specialist equipment and/ or home adaptations' and 'early referral to services' were selected at the fourth most important area by a quarter of respondents (25%, n=220 and n=223 respectively).

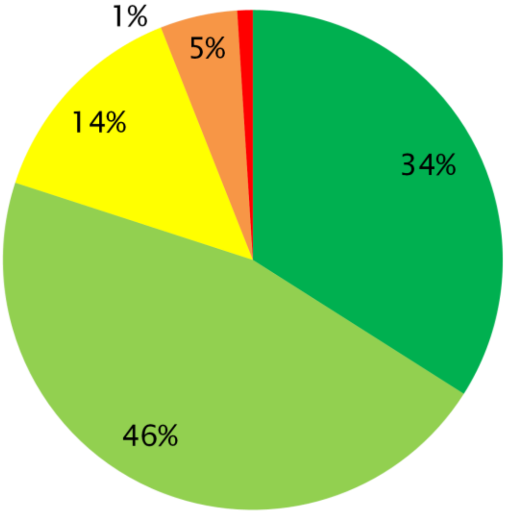
Q28. Thinking about MND care in general, which of following areas do you think should be addressed or improved as a priority?
(answered by 882 respondents)



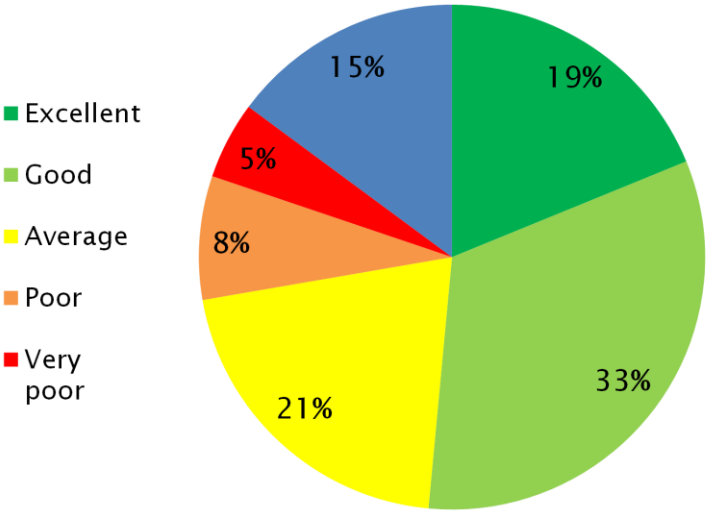
Thinking overall about the care received from the NHS for the disease, the majority of respondents rated their care as either ‘excellent’ 34% (n=309) or ‘good’ 46% (n=417). A fifth of respondents rating their care as ‘average’ 14% (n=125), ‘poor’ 5% (n=45) or ‘very poor’ 1% (n=13).

Although the majority of respondents (61%, n=453) who receive care from social services rated their care as either ‘excellent’ 22% (n=163) or ‘good’ 39% (n=290), we see smaller numbers rating their care as positive, compared with the care provided by the NHS with over a third rating their care as either ‘average’ 24% (n=180), ‘poor’ 9% (n=66) or ‘very poor’ 6% (n=48).

Q29. Overall, how would you rate the care you receive for your disease from the NHS as a whole?
(answered by 909 respondents)



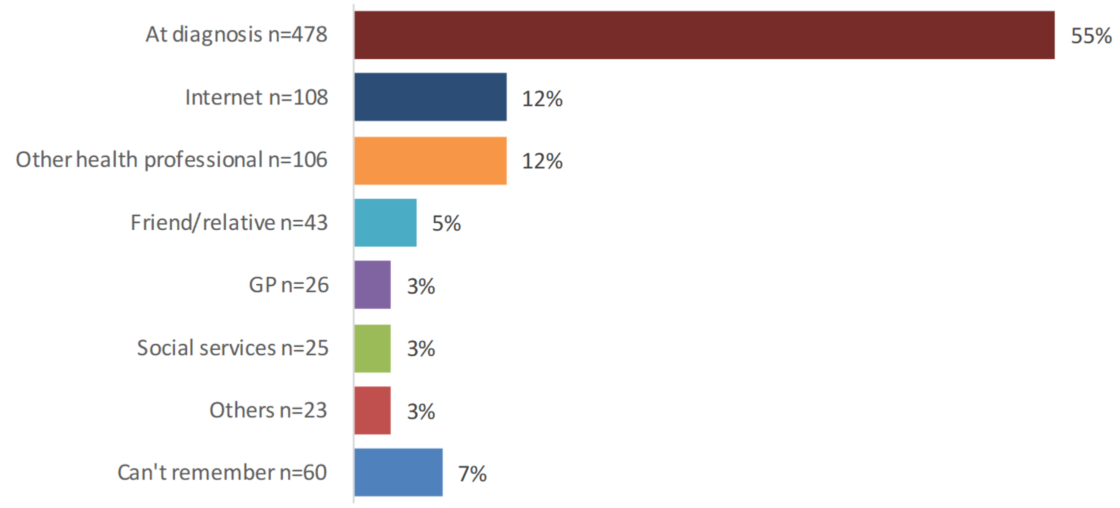
Q30. Overall, how would you rate the care you receive for your disease from the Social Services as a whole?
(answered by 875 respondents)



MND Association services

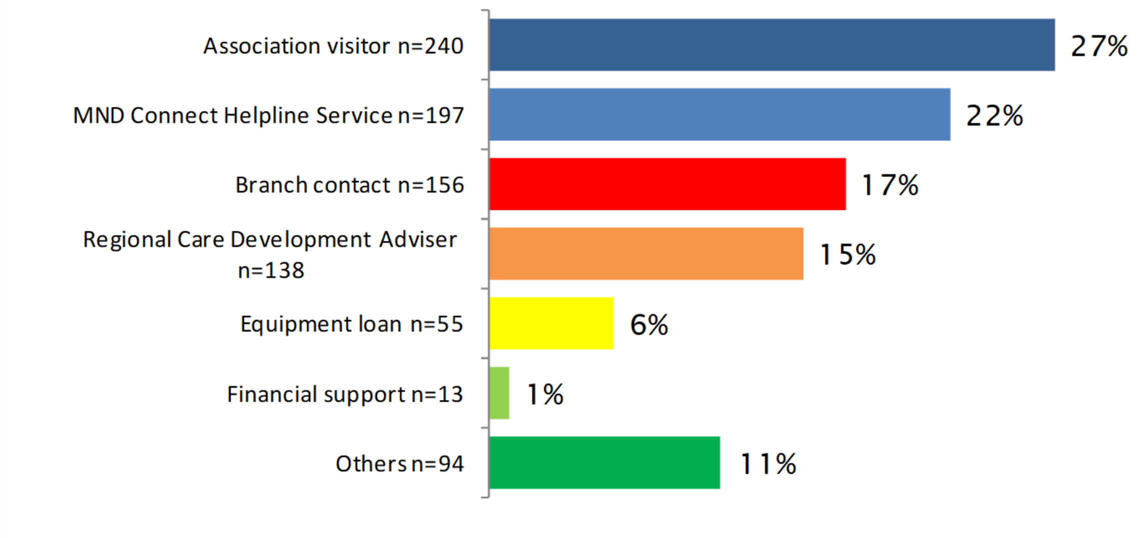
Just over half of respondents (55%, n=478) first heard about the MND Association at the time of their diagnosis, via the '*internet*' and via '*other health professionals*' were the joint second most common mentions (n=108 & 106 respectively).

Q31. How did you first hear about the MND Association?
(answered by 869 respondents)



Association visitors were most often (27%, n=240) the first contact that respondents had with the association, followed closely by MND Connect Helpline Service (22%, n=197) and Branch contact (17%, n=156)

Q32. Which part of the Association did you first have contact with?
(answered by 893 respondents)



- Respondents aged 50 years and younger (30%, n=23) and 51-60 years (31%, n=51) are more likely to contact the Association via the MND Connect Helpline Service than those aged 61-70 years (19%, n=68) or those aged 71-80 years (19%, n=42)
- For respondents aged 61-70 years (29%, n=105) 71-80 years (30%, n=67) or those aged 81 years and over (37%, n=26), first contact with the Association is more likely be via the Association visitor than those aged 50 years and younger (13%, n=10) and 51-60 years (19%, n=30)

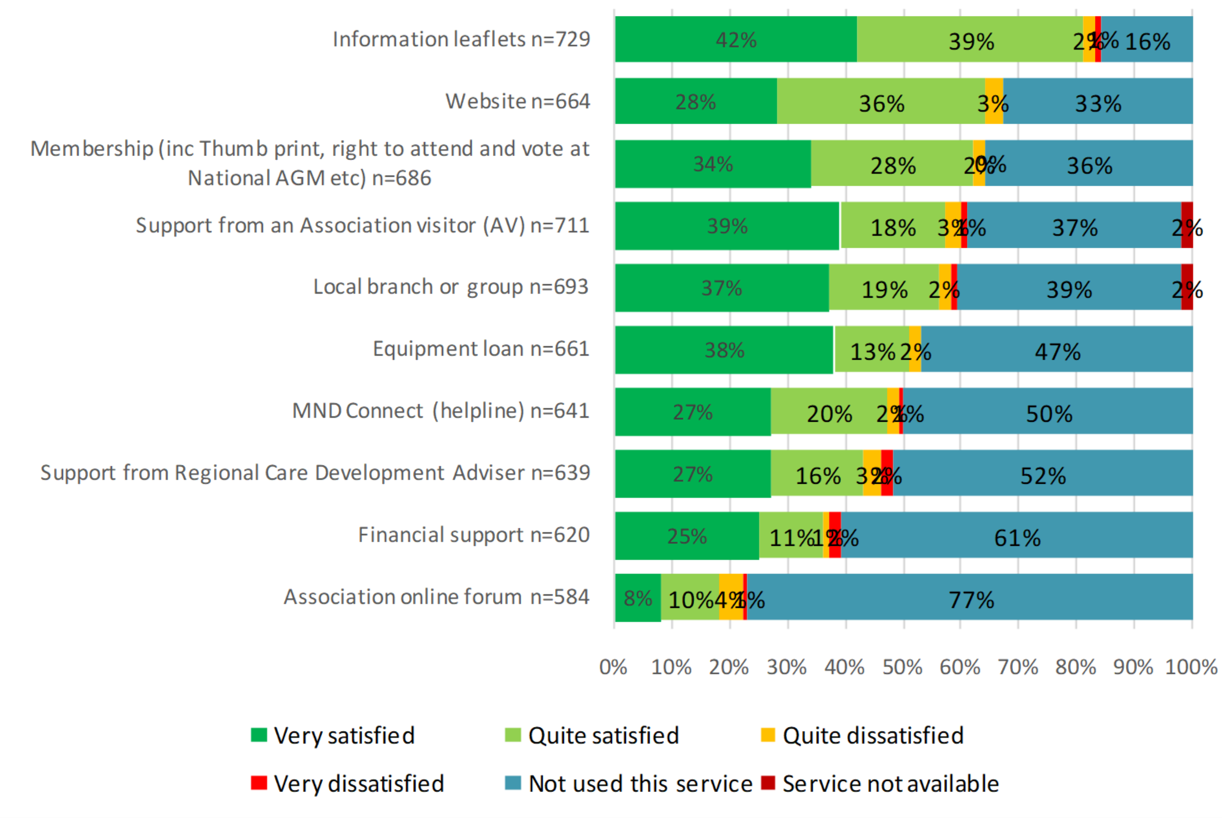
When thinking about the services and support from the MND Association, the most used resource was ‘information leaflets’ (n=612), second most used resource was the MND website (n=448). The least used resource is the Association online forum, only used by (n=132). Financial support and support from Regional Care Development Advisors are resources where the majority of respondents report they do not use the service.

Males are significantly are less likely to receive support from an Association visitor (40%, n=181), when compared with females (31%, n=80).

Respondents aged 61-70 years (54%, n=144), 71-80 years (54%, n=71) or those aged 81 years and over (71%, n=25) are less likely to make use of the MND Connect helpline than those aged 50 years and younger (31%, n=22) and those aged 51-60 years (43%, n=58).

Respondents aged 61-70 years (83%, n=200), 71-80 years (86%, n=101) or those aged 81 years and over (97%, n=35) are less likely to make use of the Association Online forum than those aged 50 years and younger (56%, n=36) and those aged 51-60 years (64%, n=78).

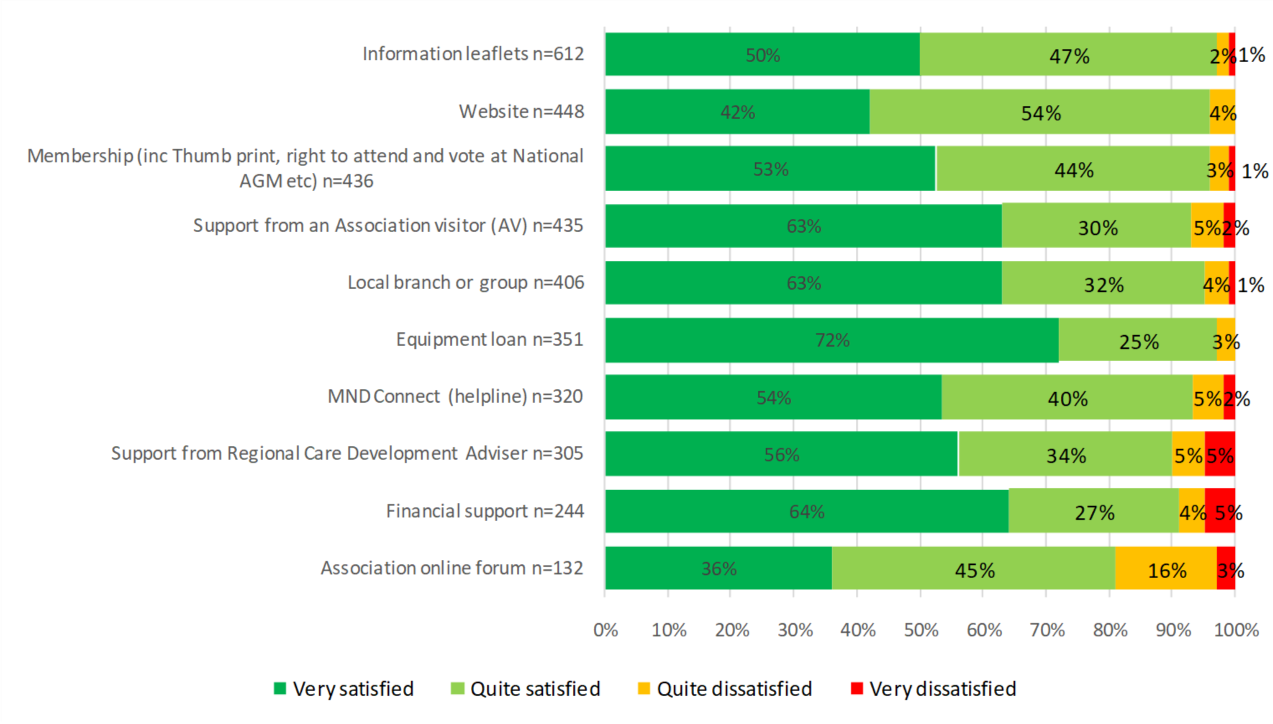
Q33. Please tell us how satisfied you are with each service you use?



When we look at the responses from those who use the service we see a different picture:

- Equipment loan is the service users are most satisfied with, 72% (n=272) '*very satisfied*'
- Nearly three-quarters of those accessing 'financial support' 64% (n=155) are '*very satisfied*'
- The resource with the lowest level of satisfaction amongst users is the 'association online forum' 36% (n=48) '*very satisfied*', 45% (n=59) '*quite satisfied*' and nearly a fifth either '*quite dissatisfied*' 16% (n=21) or '*very dissatisfied*' 3% (n=4)

Q33. Please tell us how satisfied you are with each service you use?
(With those who do not use the service/ service not available removed)



Nearly all respondents 85% (n=771) were aware that membership of the MND Association entitles them to benefits including the regular magazine and the right to vote at the national AGM and was free for people with MND and a carer or spouse.

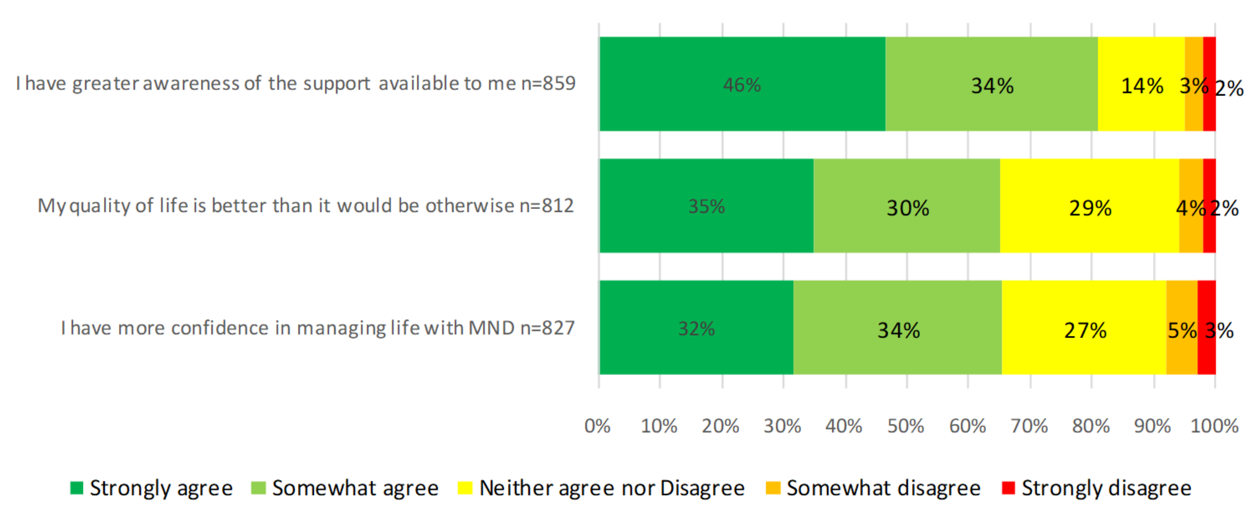
What difference does the MND Association make to you?

As a result of being supported by the MND Association, almost half of respondent (46%, n=395) '*strongly agree*' with the statement 'I have greater awareness of the support available to me'.

A third of respondents (35%, n=281) '*strongly agree*' with the statement 'my quality of life is better than it would be otherwise', although we see a third (29%, n=238) who 'neither agree nor disagree' with this statement.

We see a similar pattern of response for the statement 'I have more confidence in managing life with MND'; 32% (n=265) '*strongly agree*', 34% (n=281) '*somewhat agree*' and 27% (n=221).

Q35. What difference does the MND Association make to you?



Respondents were shown six different functions of the MND Association and asked to select the three functions they felt were most important.

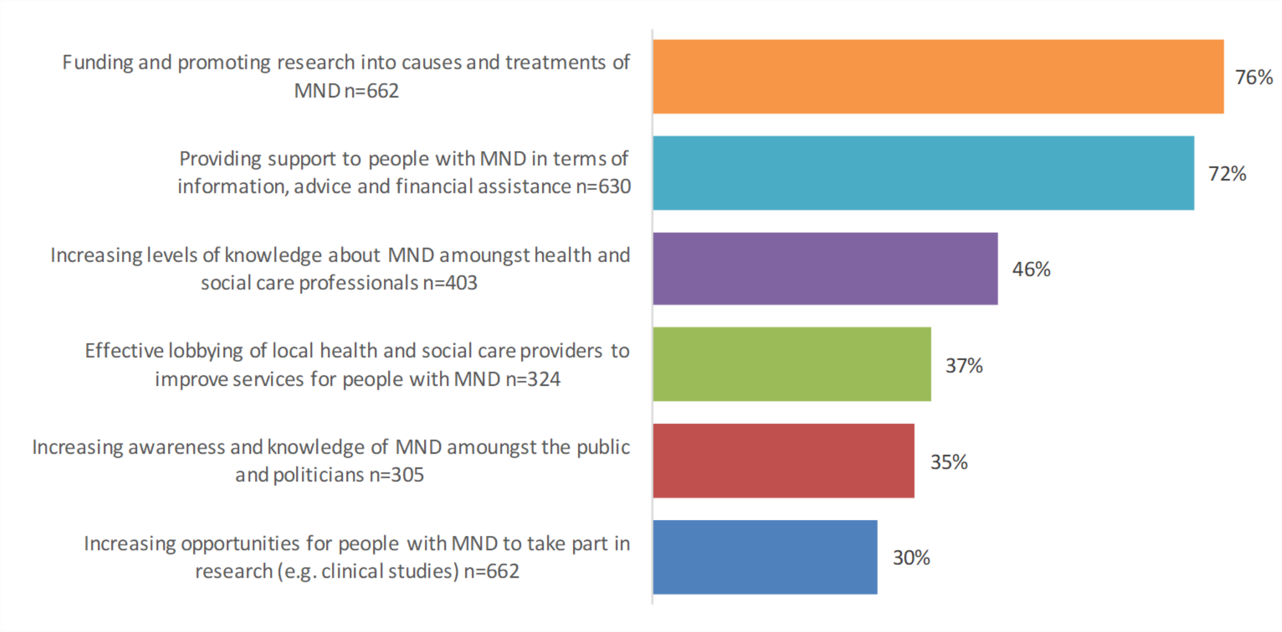
The top three functions were:

- Funding and promoting research into causes and treatments of MND, 76% (n=662)
- Providing support to people with MND in terms of information, advice and financial assistance, 72% (630)
- Increasing levels of knowledge about MND amongst health and social care professionals, 46% (n=403)

Respondents aged ‘61-70 years’ (77%, n=268), ’71-80 years’ (78%, n=165) and those aged ’81 years and over’ (83%, n=57) are significantly more likely to select ‘funding and promoting research into causes and treatments of MND’ than those aged 51-60 years (67%, n=108).

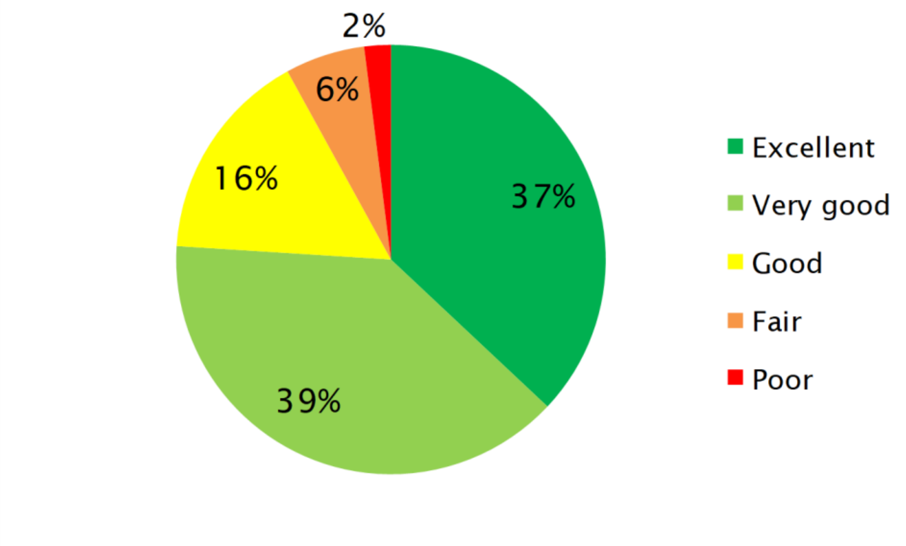
Those diagnosed within the last year (81%, n=207) are more likely to select providing support to people with MND in terms of information, advice and financial assistance than those diagnosed ‘between 1 year and 3 years ago’ (66%, n=188), those diagnosed ‘between 5 years and 10 years ago’ (71%, n=87) and those diagnosed ‘more than 10 years ago’ (64%, n=48).

Q36. Looking at the difference functions of the MND Association, please select the three most important functions?
(answered by 874 respondents)



Overall, a third of respondents (37%, n=322) rated the support received from the MND Association as '*excellent*', 39% (n=340) felt it was '*very good*' while 16% (n=136) only rated the support received as '*good'*. Nearly a tenth of respondent felt the support was either '*fair'* (6%, n=48) or '*poor'* (2%, n=17).

Q37. Overall, how would you rate the support you receive from the MND Association?
(answered by 863 respondents)



When asked what had been particularly good about the service and support they had received from the MND Association, 583 respondents provided a comment. The comments have been shown in the word cloud below:

When asked if there was anything that could be improved about the service/ support received from the MND Association, a fifth of respondents (18%, n=172) suggested areas for improvement:

- Greater awareness of MND
- More contact/ support from AVs/ local contacts
- Better communication between head office and local branches
- More/ better local meetings
- More support for carers
- More information / advice (funding/technology/end of life)
- Improved website (improved forum accessibility/more friendly/include stages of MND to prepare family)
- Continuity of support when staff leave

Thinking in general about the MND care received, 311 respondents gave a response. The comments have been shown in the word cloud below:

Below are a selection of verbatim comments:

“GP's knowledge is poor.”

“Many practitioners don't always know about MND. I am fed up with explaining! When they do understand for some it rarely goes beyond Stephen Hawkin! The fact that it is progressive and can be very fast, is not taken in board by many and this equipment and care needs get v. delayed causing great distress.”

“Thank you for being there!”

“The care from the hospital is very good. I have always had a constant supply of pages and pages of forms to fill in to claim any benefit or because the government have changed the names of benefits. This is hard work”

“I would like to thank all the people who are involved with MND, you have helped me.”

“There is a lack of knowledge within the care agencies of how to deal with this disease. Specialised care is very hard to get.”

Respondents were asked about the different digital technologies they use. The most used technologies were the internet (65%, 578), email (57%, n=513), PCs (44%, n=394) and tablet computers (33%, n=296). Unsurprisingly, those aged 71 years and above are significantly less likely to use digital technologies. A third of respondents (28%, n=256) do not use any digital technologies.

When asked how they communicated with other people living with MND, the majority (61%, n=554) said they didn't use any of the options listed. The most popular way to communicate was via branch/ group meetings, 30% (n=269) attended these. Those aged 51-60 years (35%, n=57) and those aged 61-70 years (34%, n=125) are significantly more likely to attend these meetings compared with those aged 50 years and younger (16%, n=12) and those aged 81 years and over (18%, n=13).

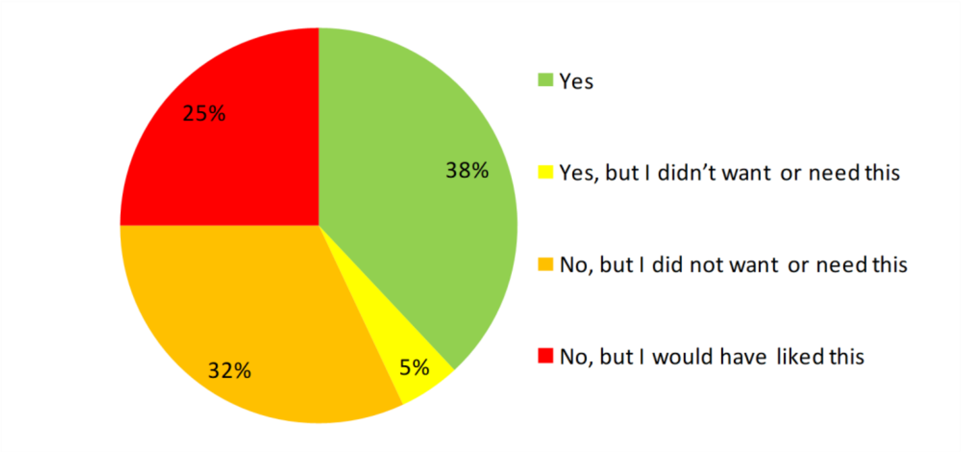
As with digital technology, those aged 70 years and younger are more likely to use digital based methods to communicate (blogs, social media, online forums/ chats) compared to older responders (71 years and above).

Your choices as the disease progresses

To build on the qualitative work conducted in 2012 by the MND Association around choices people with MND face at the end of their lives, questions were developed to capture the voice of members. Great care was taken to ensure that those who would find these questions distressing had the opportunity to avoid this section without having to read any of the questions. Three-fifths of respondents overall (n=589) opted to complete some or all of these questions.

When asked whether they had been offered information about the choices and options available at the end of life, 38% (n=225) reported that they had been; 5% (n=27) said they had been offered the information but that they had not wanted or needed it. However, a quarter of respondents (25%, n=150) reported that they had not been offered information but **would** have liked this; another third (32%, n=187) did not receive information, but did not want or need it.

Q50. Have you been offered any information about your choices and options at the end of your life?
(answered by 589 respondents)



The comments received (n=220) about the information respondents have received are shown in the word cloud below:

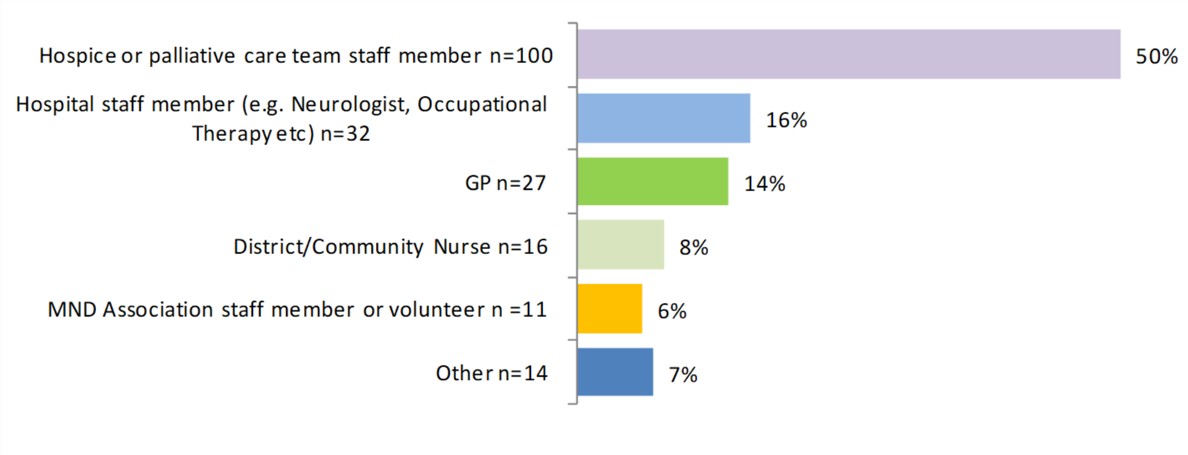
A third of respondents (36%, n=213) have been given the opportunity to, and actually discussed end of life issues with a care professional; 6% (n=37) had been given the opportunity but did not want to discuss this. However, 15% (n=88) were not given the opportunity but **would** have liked to, while 10% (n=60) were neither given, nor wanted the chance to discuss this. A third of respondents (33%, n=193) felt it was too early for them to have these discussions.

Females (42%, n=88) are significantly more likely to choose to have these discussions than males (33%, n=125).

Respondents diagnosed more than 10 years ago (24%, n=12) are more likely than those diagnosed ‘less than a year’ (8%, n=13); between 1 year and 3 years’ (6%, n=12); those diagnosed more than 3 years ago but less than 5 years (11%, n=10); and those diagnosed between 5 and 10 years ago (12%, n=11) to say ‘no, but I did not want to’.

Hospice or palliative care team members were overwhelmingly the most popular choice for most respondents (50%, n=100) to discuss end of life issues with, followed by a member of hospital staff (16%, n=32) and a GP (14%, n=27). Only 6% (n=11) had these discussions with a member of staff from the MND Association.

Q53. Who did you discuss end of life issues with?
(answered by 200 respondents)

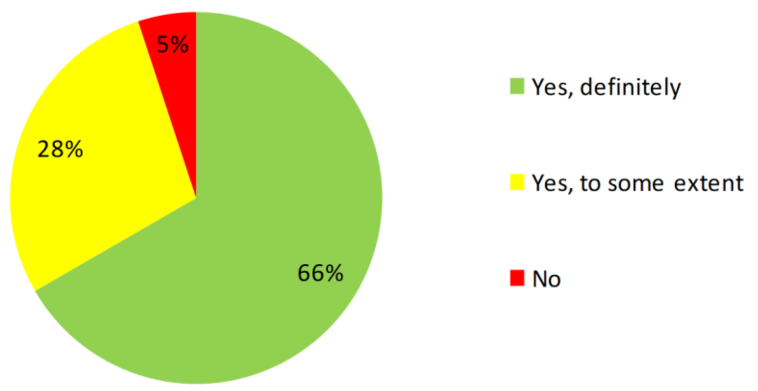


When asked who had begun the discussion about end of life issues, two-fifths (41%, n=84) reported that they had instigated the conversation, whilst 47% (n=96) said that the subject had been raised by a care professional and 7% (n=14) said it was raised by a family member/ carer.

Four-fifth of respondents 83% (n=170) felt that the care professional had put them at ease/ shown sensitivity about discussing these issues. The remaining respondents 14% (n=28) agreed that they had '*to some extent*'. However, 3% (n=6) said they had not been put at ease.

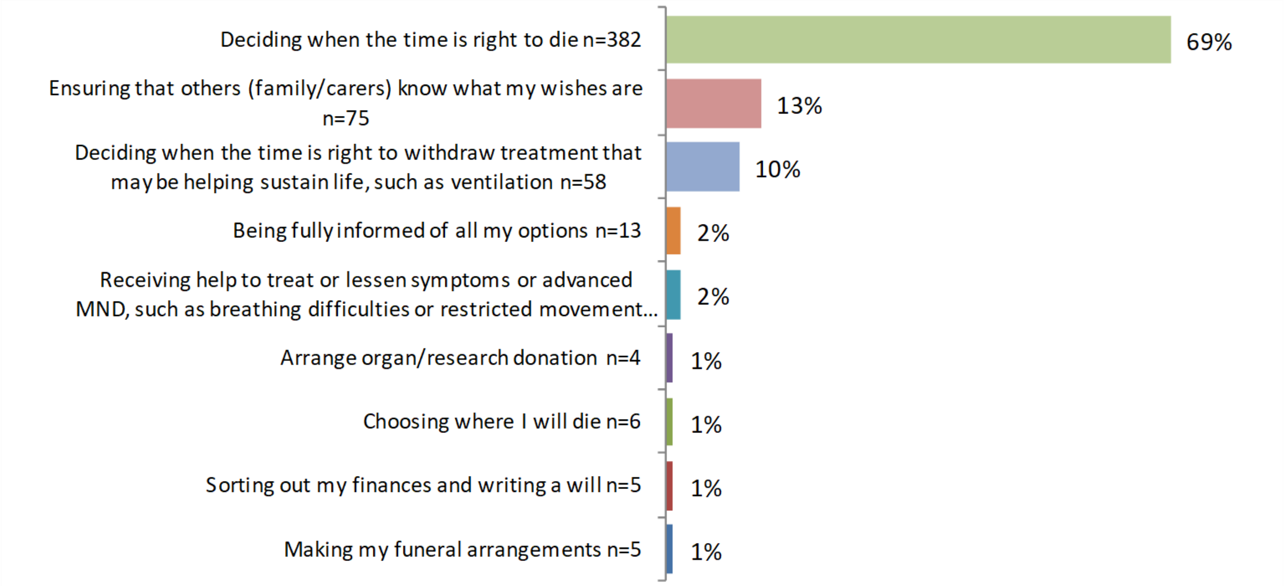
Two-fifths (66%, n=133) of respondents who discussed end of life issues felt it had been helpful, a quarter (28%, n=57) agreed that it had been helpful '*to some extent*'. Only a small number (5%, n=11) commented that it had not been useful for them.

Q56. Was it helpful for you to discuss end of life issues with this person?
(answered by 201 respondents)



Respondents were asked what having control at the end of life meant to them. Just over two-thirds (69%, n=382) said it was 'deciding when the time is right to die'; the second most popular response (13%, n=75) was 'ensuring that others (family/ carers) know what my wishes are'. 'Deciding when the time is right to withdraw treatment that may be helping to sustain life' was the third most selected response 10% (n=58).

Q58. What does having control at the end of life mean to you?
(answered by 557 respondents)

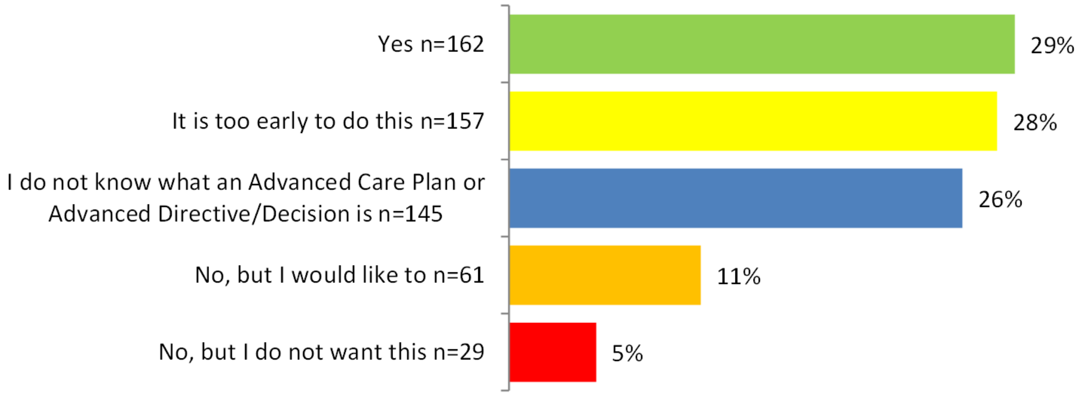


Two-fifths (41%, n=225) of respondents said they had taken steps to ensure they have control/ choice at the end of their life, 16%, (n=87) said '*no, it is not something I wish to think about*'. Nearly half of respondents (44%, n=242) said they '*no, but they will*'.

Females (49%, n=99) are significantly more likely to say they have taken steps to ensure they have control at the end of their life when compared with males (36%, n=126).

A third of respondents (29%, n=162) have made an Advance Care Plan or Advance Directive/ Decision, whilst just a third (28%, n=157) said it was too early to do this. A small number, 5% (n=29) said 'no, I do not want this'; a tenth (11%, n=61) said 'no, but I would like to'. A quarter of respondents (26%, n=145) 'do not know what an Advance Care Plan or Advance Directive/ Decision is.

Q61. Have you made an Advance Care Plan or Advance Directive/ Decision?
(answered by 534 respondents)



Females (34%, n=70) are significantly more likely to have made and Advance Care Plan or Advance Directive/ Decision than males (26%, n=92).

Significantly more males (30%, n=105) do not know what an Advance Care Plan or Advance Directive/ Decision is, compared with females (20%, n=40).

Almost all respondents who have an Advanced Care Plan or Advance Directive/ Decision (98%, n=158) say theirs reflects their current views.

Of those respondents who are aware of Advance Care Plans or Advance Directive/ Decision, half of them (52%, n=127) were offered support/ help making them. A quarter of respondents (26%, n=63) said ‘no, but they did not need this’, while 23% (n=56) report that they were not offered help or support but **would** have liked it.

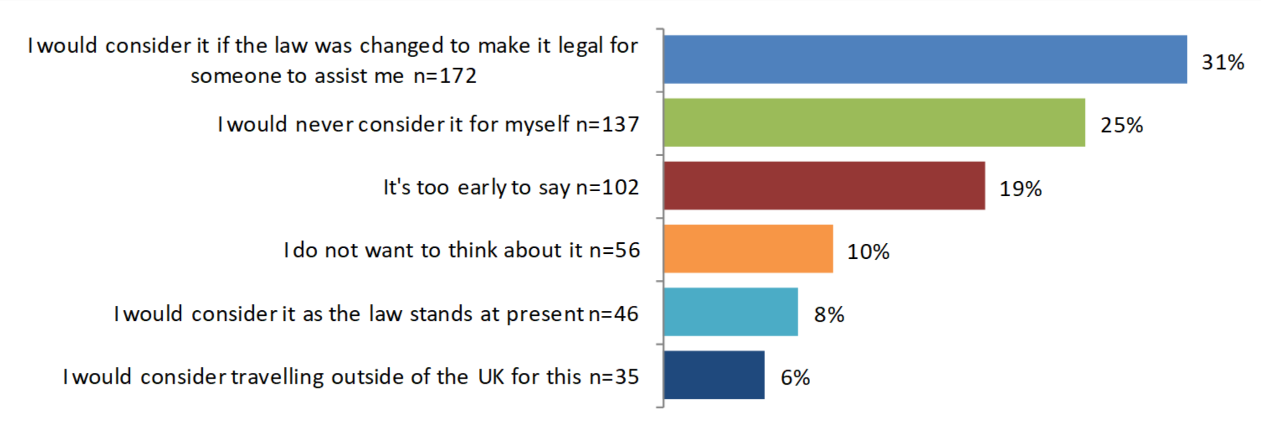
Respondents diagnosed more than 10 years ago (53%, n=10) are more likely than those diagnosed ‘less than a year’ (22%, n=13), between 1 year and 3 years’ (18%, n=13) and those diagnosed more than 3 years ago but less than 5 years (26%, n=13) to say ‘no, but they do not need this’.

Respondents we asked for their views on assisted suicide, an emotive question but one that previous research highlighted as needing to be asked. Respondents were asked the question ‘We know from previous research, that some people with MND have considered assisted suicide, although currently illegal in the UK for anyone to assist someone to take their own life – although not illegal to discuss these issues, what are your views on this?

- Almost half of respondents (46%, n=253) would consider assisted suicide:
    - 31% (n=172) would consider it if the law were changed to make it legal for somebody to assist them
    - 8% (n=46) would consider it as the law stands at present
    - 6% (n=35) would consider travelling outside of the UK for it
- A fifth of respondents (19%, n=102) felt it was too early to say
- A quarter of respondents (25%, n=137) would not consider this for themselves
- A tenth of respondents (10%, n=56) did not want to think about it

Q64. What are your views on assisted suicide?

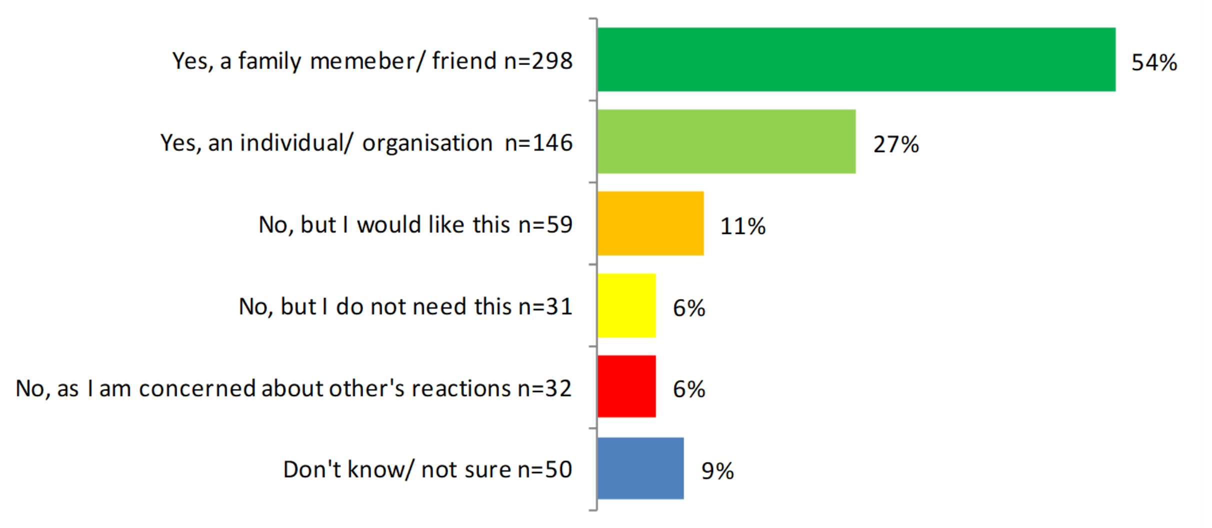
(answered by 548 respondents)



When asked if they wanted to have further discussions or access support around end of life choices, did they feel they had somebody to talk to; the most popular answer was ‘Yes, a family member/ friend’ mentioned by just over half of the respondents (54%, n=298). A quarter of respondents (27%, n=146) responded ‘yes, an individual/ organisation’. However, a tenth of respondents (11%, n=59) said they didn’t have somebody but would like this. A small number (6%, n=32) said no as they are concerned about others’ reaction, while 9% (n=50) were unsure.

Q65. If you wanted to have further discussions or to access support regarding your end of life choices, do you feel you have somebody to talk to?

(answered by 548 respondents)



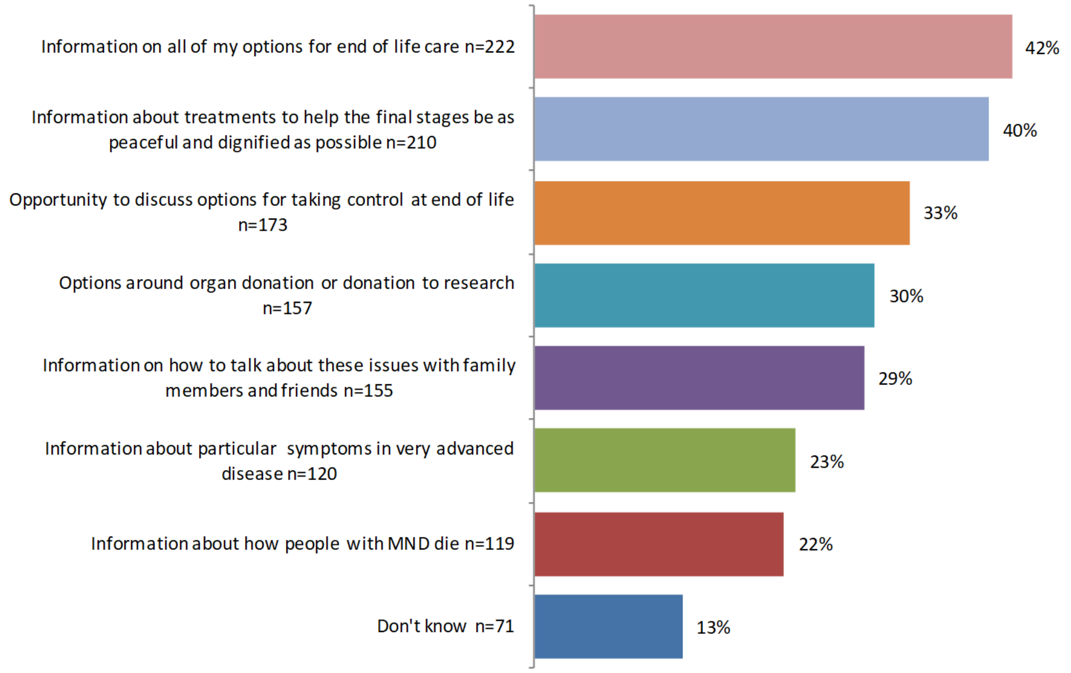
Different information and support options were presented to respondents for them to select which options they would like the MND Association to provide to support them in their thinking about end of life care.

The top five responses were:

- ‘Information on all of my options for end of life care’ (42%, n=222)
- ‘Information about treatments to help the final stages be as peaceful and dignified as possible’ (40%, n=210)
- ‘Opportunity to discuss options for taking control at the end of life’ (33%, n=173)
- ‘Options around organ donation or donation to research’ (30%, n=157)
- ‘Information on how to talk about these issues with family members and friends’ (29%, n=155)

It’s clear, however, that all of the information/support options are important to respondents.

Q66. What kinds of information and support would you like the MND Association to provide to support you in thinking about end of life care?
(answered by 531 respondents)



Conclusion

Diagnosis

This survey is the largest survey (to-date) of people living with Motor Neurone Disease and the findings in this report give a clear understanding of what is important to people living with the disease. Throughout the analysis we found few significant differences amongst sub-groups, which in itself is a strong message, giving a clear unified voice from people living with MND.

A third of those responding had received their confirmed diagnosis within the last year, with a further third stating that is was between one year and 3 years, and the remaining third receiving the diagnosis between 3 years and more than 10 years ago. Of those, significantly more females than males had been diagnosed within the last year.

Getting a diagnosis

The majority of respondents were referred to a Neurologist within six months from first consulting their GP. However, a fifth of respondents waited a year or more with respondents aged 71 years and above significantly more likely to wait more than a year for referral compared with younger respondents. Nearly two-thirds of respondents were happy (definitely/ to some extent) that the referral was as soon as they would have liked; a third would have liked it sooner.

More than half of all respondents were referred to other healthcare practitioners before referral to a Neurologist. But once referred, three-quarters of respondents were seen by the Neurologist within three months. Respondents who had received their confirmed diagnosis within the last year were significantly more likely to feel that they should have been seen earlier.

Following their appointment with the Neurologist, half of all respondents received a confirmed diagnosis within three months. A third of respondents waited between three months and one year for the diagnosis, whilst nearly a fifth waited over a year. Those who were diagnosed more than five years ago were significantly more likely to have waited a year or more for their diagnosis compared with those diagnosed within the last three years. Nearly two-thirds of respondents felt they received the diagnosis as soon as they would have liked (definitely/ to some extent); a third would have liked it sooner. Females were significantly more likely to say that they would have liked their diagnosis earlier compared with males.

Tests and investigations were explained in a way that just over half of all respondents could understand, however two-fifths felt they could have been explained better.

Day of confirmed diagnosis

Four-fifths of respondents had heard of Motor Neurone Disease before their diagnosis, although only half of them understood what it was.

Almost all respondents received their confirmed diagnosis in person, during an appointment with a Neurologist. Over half of the respondents had not been advised to bring a friend or relative with them. Over half were told about the support offered by the MND Association and just under half were not asked if they wanted someone from the MND Association to contact them.

When being given their diagnosis, the majority of respondents were given theirs in a private place behind closed doors. Respondents were generally happy with the way they were given the opportunity to ask questions, and many agreed that the person giving the diagnosis had a good understanding of MND. Over half of all respondents felt the people giving the diagnosis understood how they might be feeling.

Over half of all respondents felt supported throughout the consultation, however, a third of respondents felt they could have been better supported throughout their consultation.

After confirmed diagnosis

Three quarters of respondents currently have a named person in either health or social care who is responsible for co-ordinating their care and support; a tenth of respondents don’t have one, but would like one. For the majority of those with a named person co-ordinating their care, the relationship works well. Respondents aged 81 years and over are significantly more likely to say the relationship works very well compared with younger respondents.

The most affected area of the body for respondents were their legs, while many mentioned their arms (& hands). Fatigue was also something three-quarters of respondents said affected them.

Just over half of all respondents had not needed surgery to insert a feeding tube to help with breathing, while nearly a third have had surgery to insert a feeding tube. Just over a tenth of respondents had been offered surgery but decided against it. Females were significantly more likely to choose surgery compared with males.

Only a tenth of respondents had their breathing monitored annually, nearly half of all respondents had breathing assessments and monitoring at least every few months. Just over half of all respondents do not receive any special help with their breathing, the top three areas of help are; non-invasive ventilation, specialist exercises/ posture advice and cough assist. Three-quarters of respondents rarely or never experienced difficulty obtaining help with their breathing, however a tenth of respondents have had difficulty getting help with their breathing.

The most used items of equipment are the manual wheelchair, walking aids, riser/ recliner chairs and grab rails. The least used are communication pointer board, environment controls and suction units.

- The manual wheelchair is mainly funded by another source
- The hoist is the item mainly funded by others
- Buggies/ scooters are mostly self-funded (either in whole or part)
- Nearly two-thirds of light writers are provided by the MNDA

- Of those provided with riser/ recliner chairs, the MNDA fund almost half of them
- When home adaptations are required, over half of respondents self-fund (either in whole or part)

When looking how well each piece of equipment meets their needs;

- The light writer is the item that least meets respondent needs, followed by buggy/ scooter and communication pointer board
- Unsurprising the items that most meet respondents needs are those which are mainly self-fund – door widening, lift and wet
- Powered wheelchairs better meet the needs of respondents than manual wheelchairs

When asked to consider a series of statements about their care and treatment since diagnosis, the two-thirds to three-quarters of respondents either '*agreed strongly/*'*agreed*' with all statements. The statements with the highest level of agreement (agree strongly/ agree), were 'I am treated with dignity and respect' and 'when receiving health care services, I feel my independence/ autonomy is respected'. However, disagreement is high for:

- All the different services are co-ordinated well
- I think that family members and carers are well supported
- I get the social care service they need when they need them

The benefits received by the most respondents were Blue Badge, Disability Living Allowance, Attendance Allowance, Council Tax Benefit and Carer's Allowance. Two-thirds of respondents had not experienced any difficulty in obtaining their benefits. Respondents aged 70 yrs and younger where more likely to experience difficulties obtaining benefits than those aged 71-80 yrs and over.

The most important area that respondents feel needs addressing/ improving is 'knowledge and support from GP', closely followed by 'support for family members or friends who act as carers'. The third most important area is 'support with planning for the future, including later stages of MND'.

Four-fifths of respondents rated the overall care they received from the NHS for their disease as either excellent or good. The overall rating for care received from social services wasn't quite as favourable, although still mainly positive.

MND Association services

At the time of their diagnosis is where just over half of respondents first heard about the MND Association, via the '*internet*' and via '*other health professionals*' were the joint second most common mentions.

Association visitors were most often the first contact that respondents had with the Association, followed closely by MND Connect Helpline Service and Branch contact. Respondents aged 60 years and younger are more likely to contact the Association via the MND Connect Helpline Service. For respondents aged 61years and over, first contact with the Association is more likely be via the Association visitor.

Information leaflets were the most used resource, the second most used resource was the MND website. The least used resource is the Association online forum, financial support and support from Regional Care Development Advisors. Females are significantly more likely to receive support from an Association visitor. Respondents aged 60 years and younger are more likely to make use of the MND Connect and the Association online forum.

- Equipment loan is the service users are most satisfied with
- Nearly three-quarters of those accessing 'financial support' are '*very satisfied*'
- The resource with the lowest level of satisfaction amongst users is the 'Association online forum'

Nearly all respondents were aware that membership of the MND Association entitles them to benefits including the regular magazine and the right to vote at the national AGM.

As a result of being supported by the MND Association, four-fifths of respondents agree (strongly/somewhat) that they have greater awareness of the support available to me them. Over half of respondents feel their quality of life is better than it would be otherwise and three-quarters feel they have more confidence in managing life with MND as a result of being supported.

The three most important functions of the MNDA are:

- Funding and promoting research into causes and treatments of MND
- Providing support to people with MND in terms of information, advice and financial assistance
- Increasing levels of knowledge about MND amongst health and social care professionals

Respondents aged 61years and over are significantly more likely to select 'funding and promoting research into causes and treatments of MND. Those diagnosed within the last year are more likely to select 'providing support to people with MND in terms of information, advice and financial assistance'

Overall satisfaction with the Association is high with three-quarters of respondents rating them as either excellent or very good. However, a tenth of respondent felt the support was either fair or poor.

Your choices as the disease progresses

To build on the qualitative work conducted in 2012 by the MND Association around choices people with MND face at the end of their lives, questions were developed to capture the voice of members. Great care was taken to ensure that those who would find these questions distressing had the opportunity to avoid this section without having to read any of the questions. Three-fifths of respondents overall opted to complete some or all of these questions and provide a unified voice on the choices they face.

A third of respondents were not given information about the choices and options available at the end of life but would have liked this, although two-fifths had been given this information.

A third of respondents have been given the opportunity to, and actually discussed end of life issues with a care professional, however just over a tenth were not given the opportunity but **would** have liked to. A third of respondents felt it was too early for them to have these discussions. Females are significantly more likely to choose to have these discussions. Respondents diagnosed more than 10 years ago are more likely than those diagnosed less than 10 years ago to say they did not want to discuss these issues.

Hospice or palliative care team members were overwhelmingly the most popular choice for most respondents to discuss end of life issues with, followed by a member of hospital staff and GPs. Only a small number had these discussions with a member of staff from the MND Association. Two-fifths of respondents instigated the conversation, while almost half said it have been raised by a care professional. Four-fifths of respondents felt the care professional had put them at ease/ shown sensitivity about discussing these issues. Two-fifths of respondents who discussed end of life issues felt it had been helpful, a quarter agreed that it had been helpful '*to some extent*'. Only a small number commented that it had not been useful for them.

Two-thirds said that having control at the end of life meant 'deciding when the time is right to die'. The second most popular response was 'ensuring that others (family/ carers) know what my wishes are'. 'Deciding when the time is right to withdraw treatment that may be helping to sustain life' was the third most selected.

Two-fifths of respondents have already taken steps to ensure they have control/ choice at the end of their life whilst nearly half of respondents said they had not yet but they will. Females are significantly more likely to say they have taken steps to ensure they have control at the end of their life.

A third of respondents have made an Advance Care Plan or Advance Directive/ Decision, whilst a third felt it was too early to do this and a tenth plan to make one 'no. Worryingly, a quarter of respondents do not know what an Advance Care Plan or Advance Directive/ Decision is. Females are significantly more likely to have made and Advance Care Plan or Advance Directive/ Decision and significantly more males do not know what an Advance Care Plan or Advance Directive/ Decision is.

Almost all respondents who have an Advanced Care Plan or Advance Directive/ Decision say theirs reflects their current views. Of those respondents who are aware of Advance Care Plans or Advance Directive/ Decision, half were offered support/ help making one. A quarter of respondents were not offered help or support to make one but **would** have liked it. Respondents diagnosed more than 10 years ago are more likely to say 'no, but they do not need this.

When asked for their views on assisted suicide, almost half of respondents said they would consider assisted suicide in some form:

- A third would consider it if the law were changed to make it legal for somebody to assist them
- A tenth would consider it as the law stands at present
- 6% would consider travelling outside of the UK for it

A fifth of respondents felt it was too early to say and a quarter of respondents would not consider this for themselves.

Just over half of respondents feel they have somebody to talk to if they wanted to have further discussions or access support around end of life choices. However, a tenth of respondents said they didn't have anybody but would like somebody and although a small number, 6% said they do not have anybody as they are concerned about others' reactions.

The top five areas for the MNDA to provide information and support in are:

- 'Information on all of my options for end of life care'
- 'Information about treatments to help the final stages be as peaceful and dignified as possible',

- ‘Opportunity to discuss options for taking control at the end of life’
- ‘Options around organ donation or donation to research’
- ‘Information on how to talk about these issues with family members and friends’

It’s clear, that although in many areas half of all respondents report positively, the findings highlight areas for improvement:

- Timely referral directly to a Neurologist
- Improved waiting times for confirmed diagnosis
- Co-ordination of multiple services
- Improved quality of care from social care services
- Provision of social care
- Better support for family members and carers
- Consistency of quality care within the NHS
- Support and information leading up to and during the diagnosis consultation
- Improved levels of respect for independence/autonomy in social care services
- Better understanding of respondents’ needs from clinicians and social care staff
- Provision of regular reviews

Problem Scores

At the Picker Institute, we use the concept of '**problem scores**' to help summarise results. We hope that you will find problem scores a helpful way of targeting areas in need of attention – this in turn can help you to bring about real quality improvement for your respondents.

What is a problem score?

The problem score shows the percentage of respondents for each question who, by their response, indicated that a particular aspect of their care could have been improved. We have found this to be the simplest summary measure that focuses on quality improvement.

How are problem scores calculated?

We calculate the problem scores by combining response categories. Responses such as 'don't know', 'can't remember' 'not answered' etc, were excluded and response percentages were recalculated. The problem score was then calculated by combining the responses that were not the 'best' response.

For example, for the following question 'Did you have confidence and trust in the doctors treating you?' we have combined the responses 'Yes', 'Sometimes' and 'No', to create a single problem score. Asterisks on the frequency tables indicate which response categories have been combined to create the problem score.

EXAMPLE QUESTION ONLY:

C2 - Did you have confidence and trust in the doctors treating you?

All Patients	n	%
Yes, always	459	**82.7**
* Yes, sometimes	85	**15.3**
* No	7	**1.3**
Not answered	4	**0.7**
Problem Score: 16.6%	555	

How should we use problem scores?

As the name suggests, problem scores indicate where there may be a problem within a service, hospital trust or clinic, and may need further investigation. It is useful to keep in mind that **lower scores reflect better performance.** Large problem scores should be highlighted as potential problems that need to be addressed. By targeting these areas, you can hopefully start to bring about real quality improvement for your members.

Problem Score Summary – MNDA 2013

The following problem scores show the percentage of respondents for each question who, by their response, indicated that a particular aspect of their care could have been improved. Therefore, **lower problem scores reflect better performance** whereas a higher score indicates a greater problem.

Problem scores have been rounded up or down to the nearest whole number.

Problem scores 70%+

Q2_a	One month or more from when respondent first consulted their GP until they were referred to a Neurologist	**78%**
Q5_a	One month or more from when respondent saw a Neurologist until they were given a diagnosis of MND	**72%**
Q25_a	Respondent does <u>not</u> strongly agree that all the different services are coordinated well	**72%**
Q30	The care the respondent received for their disease from social services as a whole was <u>not</u> rated as *'excellent'*	**71%**
Q25_d	Respondent does <u>not</u> *'strongly agree'* that they get the social care they need, when they need them	**70%**

Problem scores 60% - 69%

Q25_h	Respondent does not *'strongly agree'* that their family members and family carers are supported well	**69%**
Q25_i	Respondent does not *'strongly agree'* that the NHS treats them consistently well	**68%**
Q5_b	Confirmed diagnosis was not entirely as soon as the respondent would have liked	**66%**
Q9_a	Respondent had not been advised to bring a friend or relative	**65%**
Q25_e	Respondent does not *'strongly agree'* that when receiving social care services, their independence/autonomy is respected	**65%**
Q25_g	Respondent does not *'strongly agree'* that clinicians and social care staff understand what they need	**65%**
Q25_l	Respondent does not *'strongly agree'* that they get regular reviews with the right interval between them	**65%**
Q25_a	Respondent does not *'strongly agree'* that they get the health and social care services when they need them	**64%**
Q33_i	Respondent is not very satisfied with the Association online forum	**64%**
Q25_f	Respondent does not *'strong agree'* that the clinicians and health care staff understand what they need	**63%**
Q25_m	Respondent does not *'strongly agree'* that they are given the chance and time to give their opinions on treatments/reviews	**63%**
Q2_b	Referral to a Neurologist was not entirely as soon as respondent would have liked	**62%**
Q4_a	One month or more from when respondent was referred until they were actually seen by the Neurologist	**61%**
Q25_c	Respondent does not *'strongly agree'* that they are well looked after at all times	**61%**
Q25_n	Respondent does not *'strongly agree'* that they make the key decisions about their care and determine what they receive	**61%**
Q29	The care the respondent received for their disease from the NHS as a whole was not rated as *'excellent'*	**61%**

Problem scores 50% - 59%

Q25_k	Respondent does not *'strongly agree'* that they are treated with dignity and respect	**59%**
Q50	Respondents have not been offered any information about their choices and options at the end of their life	**59%**
Q59	Respondents have not taken any steps to ensure they have control/choice at the end of their life	**59%**
Q4_b	The appointment with the Neurologist was not entirely as soon as the respondent would have liked	**58%**
Q33_a	Respondent is not *'very satisfied'* with the MNDA website	**58%**
Q7	Before receiving a confirmed diagnosis, the respondent had not heard of Motor Neurone Disease or had heard, but *'did not know what it was'*	**57%**
Q25_b	Respondent does not strongly agree that when receiving health care services, their independence/autonomy is respected	**57%**
Q35_c	Respondent does not *'strongly agree'* that they have more confidence in managing life with MND as a result of being supported by the MNDA	**56%**
Q37	Overall, the support the respondent received from the MNDA was not rated as *'excellent'*	**56%**
Q9_c	Respondent was not asked if they wanted someone from the MND Association to contact them	**55%**
Q35_a	Respondent does not strongly agree that their quality of life is better than it would be otherwise, as a result of being supported by the MNDA	**51%**
Q33_c	Respondent is not *'very satisfied'* with the information leaflets	**50%**

Problem scores 40% - 49%

Q33_j	Respondent is <u>not</u> *'very satisfied'* with their membership (including Thumb Print, right to attend and vote at National AGM etc.)	**47%**
Q63	Respondents have <u>not</u> been offered any support/help with making an Advance Care Plan or Advance Directive/Decision	**47%**
Q33_b	Respondent is <u>not</u> *'very satisfied'* with MND Connect (helpline)	**46%**
Q35_b	Respondent does <u>not</u> *'strongly agree'* that they have greater awareness of the support available to them, as a result of being supported by the MNDA	**46%**
Q24_b	The manual wheelchair does <u>not</u> *'definitely'* meet the respondents needs	**44%**
Q33_f	Respondent is <u>not</u> *'very satisfied'* with the Regional Care Development Adviser	**44%**
Q24_a	Walking aids (frame etc.) do <u>not</u> *'definitely'* meet the respondents needs	**43%**
Q6	The various tests and investigations were <u>not</u> *'definitely'* explained in a way the respondent could understand	**41%**
Q10_e	Respondent did <u>not</u> '*definitely'* feel supported throughout the consultation	**41%**
Q33_e	Respondent is <u>not</u> *'very satisfied'* with the financial support	**40%**

Problem scores 30% - 39%

Q9_b	Respondent was not told about the support offered by the MND Association	38%
Q10_d	The people giving the diagnosis did not *'definitely'* understand how the respondent might be feeling	38%
Q33_g	Respondent is not *'very satisfied'* with the support from and Association Visitor (AV)	37%
Q33_h	Respondent is not *'very satisfied'* with their local branch or group	37%
Q52	Respondents have not been given the opportunity to discuss end of life issues with any care professionals	36%
Q27	The process of obtaining benefits has caused the respondent difficulty	32%
Q16	Respondent feels that the relationship with their named person does not work *'very well'*	30%

Problem scores 20% - 29%

Q56	It was not entirely helpful for the respondent to discuss end of life issues with the person they did	29%
Q33_d	Respondent is not *'very satisfied'* with the equipment loan	28%
Q24_h	The riser/recliner chair does not *'definitely'* meet the respondents needs	27%
Q24_q	Grab rails do not *'definitely'* meet the respondents needs	25%
Q65	Respondent does not feel that they have somebody to talk to, if they wanted to have further discussions or to access support regarding end of life choices	22%
Q10_b	Respondent was not *'definitely'* given the opportunity to ask questions	21%
Q20	Respondent's breathing is not monitored and assessed	20%

Problem scores 0% - 19%

Q15	Respondent does not currently have a named person in either health or social care services who is responsible for coordinating their care and support	**16%**
Q34	Respondents were not aware that membership of the MNDA entitles them to benefits	**15%**
Q10_a	Respondent was not *'definitely'* given their diagnosis in a private place, behind closed doors	**14%**
Q10_c	The person giving the diagnosis did not *'definitely'* have a good understanding of MND	**12%**
Q22	Respondent has had difficulty in obtaining help with their breathing	**12%**
Q55	The person who the respondent discussed end of life issues with did not entirely put them at ease/show sensitivity	**9%**
Q19	Respondent has not been offered surgery to insert a feeding tube to help with nutrition, but feels they should have been	**0.3%**

Comparison with previous wave (2009)

The following table shows the problem scores for Wave one (2009) compared to the Wave two (2013) survey data (where possible). Problem scores show the percentage of respondents for each question who, by their response, indicated that a particular aspect of their care could have been improved. Therefore, lower problem scores reflect better performance whereas a higher score indicates a greater problem.

Problem scores have been rounded up or down to the nearest whole number.

Name	Question	2009 Problem Score	2013 Problem Score	+ or - significance
Q2_a	One month or more from when respondent first consulted their GP until they were referred to a Neurologist	77%	78%	
Q2_b	Referral to a Neurologist was not entirely as soon as respondent would have liked	64%	62%	
Q4_a	One month or more from when respondent was referred until they were actually seen by the Neurologist	55%	61%	⊟
Q4_b	The appointment with the Neurologist was not entirely as soon as respondent would have liked	62%	58%	
Q5_a	One month or more from when respondent saw a Neurologist until they were given the diagnosis of MND	72%	72%	
Q5_a	One month or more from when respondent saw a Neurologist until they were given the diagnosis of MND	72%	72%	
Q5_b	Confirmed diagnosis was not entirely as soon as respondent would have liked	70%	66%	
Q6	The various tests and investigations were not '*definitely*' explained in a way the respondent could understand	67%	41%	⊞
Q7	Before receiving a confirmed diagnosis, respondent had not heard of Motor Neurone Disease or had heard, did not know what it was	75%	57%	⊞
Q9_a	Respondent had not been advised to bring a friend or relative	66%	65%	
Q9_b	Respondent was not told about the support offered by the MND Association	36%	38%	

Name	Question	2009 Problem Score	2013 Problem Score	+ or - significance
Q9_c	Respondent was not asked if they wanted someone from the MND Association to contact them	43%	55%	-
Q10_a	Respondent was not '*definitely*' told in a private place, behind closed doors	67%	14%	+
Q10_b	Respondent was not '*definitely*' given the opportunity to ask questions	62%	21%	+
Q10_c	The person giving the diagnosis did not '*definitely*' have a good understanding of MND	47%	12%	+
Q10_d	The people giving the diagnosis did not '*definitely*' understand how the respondent might be feeling	71%	38%	+
Q15	Respondent does **not** currently have a named person in either health or social care services who is responsible for co-ordinating their care and support	22%	16%	+
Q20	Respondents breathing is not monitored and assessed	30%	20%	+
Q25_a	Respondent does not '*strongly agree*' that they get the health and social care services when they need them	68%	64%	
Q25_b	Respondent does not '*strongly agree*' that when receiving health care services, their independence/autonomy is respected	64%	57%	+
Q25_c	Respondent does not '*strongly agree*' that they are well looked after at all times	71%	61%	+
Q25_h	Respondent does not '*strongly agree*' that their family members and family carers are supported well	77%	69%	+
Q25_i	Respondent does not '*strongly agree*' that the NHS treats them consistently well	71%	69%	
Q25_j	Respondent does not '*strongly agree*' that all the different services are co-ordinated well	78%	72%	+
Q25_k	Respondent does not '*strongly agree*' that they are treated with dignity and respect	61%	59%	
Q25_l	Respondent does not '*strongly agree*' that they get regular reviews with the right interval between them	70%	65%	
Q25_m	Respondent does not '*strongly agree*' that they are given the chance and time to give their opinions on treatments/reviews	70%	63%	+
Q33_a	Respondent is not '*very satisfied*' with the website	50%	58%	-

Name	Question	2009 Problem Score	2013 Problem Score	+ or - significance
Q33_b	Respondent is not '*very satisfied*' with MND Connect (helpline)	47%	46%	
Q33_c	Respondent is not '*very satisfied*' with the information leaflets	58%	50%	➕
Q33_d	Respondent is not '*very satisfied*' with the Equipment loan	22%	28%	➖
Q33_e	Respondent is not '*very satisfied*' with the Financial support	42%	40%	
Q33_f	Respondent is not '*very satisfied*' with the Regional Care Development Adviser	50%	44%	➕
Q33_g	Respondent is not '*very satisfied*' with the support from an Association Visitor (AV)	36%	37%	
Q33_h	Respondent is not '*very satisfied*' with their local branch or group	39%	37%	
Q52	Respondents have not been given the opportunity to discuss end of life issues with any care professionals	77%	36%	➕

Benchmarking for non-problem score comparable questions:

Name	Question	2009	2013	% difference	+ or – significance
Q21	What special help do you have with your breathing?	Non-invasive ventilation, 13%	Non-invasive ventilation, 51%	38%	➕
		Specialist exercises, 9%	Specialist exercises, 26%	17%	➕
		Cough assist, 6%	Cough assist, 14%	8%	➕
Q31	How did you originally find out about the MND Association?	At diagnosis, 49%	At diagnosis, 59%	10%	➕
		Internet, 12%	Internet, 13%	1%	
		Other HCP, 22%	Other HCP, 13%	9%	➖

Name	Question	2009	2013
Q36	Three most important functions of the MND Association	**1.** Research in to causes and treatments of MND (n=294)	**1.** Funding and promoting research into causes and treatments of MND (n=662)
		2. Providing support to people with MND in terms of information, advice and financial advice (n=258)	**2.** Providing support to people with MND in terms of information, advice and financial assistance (n=630)
		3. Increasing levels of knowledge about MND amongst health and social care professionals (n=218)	**3.** Increasing levels of knowledge about MND amongst health and social care professionals (n=403)

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Making patients' views count