

The background of the entire page is a photograph of a protest. Several people are holding up white banners with blue and orange text. The most prominent banner in the foreground reads "fighting motor neurone disease". Other banners in the background also feature the MND logo and the text "motor neurone disease association". The scene is brightly lit, suggesting an outdoor daytime event.

mnda

motor neurone disease
association

Improving MND Care Survey Results

March 2018

Introduction

I'm pleased to share the results of our Improving MND Care survey. We asked people living with motor neurone disease to share their experiences of receiving care as well as asking carers to give us an insight into looking after someone living with MND.

We had our highest response ever with over 1,300 completed. This helps us greatly as we use the outcome of the survey to help shape our plans and inform our actions. We've collated some of the key findings across the five areas of healthcare, social care, diagnosis, costs and communication, equipment and voice banking.

As well as the detail, I'd like to share some points that really stood out.

Key insights from people living with MND;

- The support offered by social care for people with MND is perceived as consistently worse than health care. For those that answered the question 'overall I am satisfied with the care I receive' only 63% felt this for Social Care vs 86% for Health Care.
- A wide range of Social Care problems were identified in the survey. For example, only 45% of people know how to access an advocate.
- There is a lack of awareness of voice banking. Based on the responses, 40% of those people who had not banked their voice, were not aware they could do this.
- We will continue to support NHS services to use our Transforming MND Care Audit Tool to benchmark and improve their services for people with MND. We are also recruiting Voice Banking Volunteers so that we encourage more people living with MND to bank their voice.

Key insights from carers;

- Carers for people with MND spend a very high proportion of their time caring. More than half of carers (59%) spend more than 50 hours per week caring. That's more than an average week's full time job.
- Many carers are not getting carer's assessments. Only 38% have been assessed or are in the process of being assessed.
- Nearly half of carers receive no benefits at all.

I hope you find this information useful. I would like to take this opportunity to thank everybody who completed the survey.

Nick Goldup

Director of Care Improvement

There are major problems with social care services.



More than a third of people with MND (**37%**) are not satisfied with their social care.

Around a third (**33%**) of people with MND do not agree that social care professionals understand that their needs will change over time, and that the change may be rapid.

29% feel that they are not able to receive their social care in a setting of their choice.

Many people with MND do not know they have a right to an advocate (**40%**).

What we are doing:

- Social care advocacy on behalf of people with MND through MND Connect and care volunteers
- Influencing local authorities through our Champion the Charter Campaign
- Working with coalitions such as the Care and Support Alliance (CSA) to highlight and raise awareness of the issues affecting social care services



Almost half (**46%**) of people with MND said that they did not receive a contribution towards their social care* from the local authority.

What we are doing:

- Working directly with people with MND through focus groups to better understand the impact of social care services
- Working with the national government to develop a sustainable long term funding solution for social care informed by our focus groups



More than half of unpaid carers (**59%**) spend longer each week (50 hours+) caring for a person with MND than the average for working full time.

What we are doing:

- Engaging with Government and holding them to account in the development of a carer's action plan to improve the support available to unpaid carers
- Offering grants for carers to improve their quality of life

 **58%**

of people with MND do not have a personal care plan, a written document setting out the care and support they can expect to receive, with their own involvement and approval.

33% 

Fewer than a third of unpaid carers have taken any planned breaks, even for as short time as two hours.



Around three quarters (**72%**) of unpaid carers would like a carer's assessment but only **38%** have been assessed or are in the process of being assessed.

What we are doing:

- Signposting carers to their entitled assessment through MND Connect and via our care volunteers

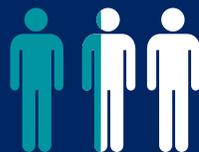
People affected by MND often experience significant financial costs due to the impact of the condition.



Almost half of people (**46%**) with MND do not receive financial contributions from their local authority towards the cost of their social care.

What we are doing:

- Producing original research on the financial impact of MND and the cost of care
- Working to improve access to Continuing Healthcare (CHC) funding for all those eligible
- Engaging with assessment provider organisations to ensure that people can receive the benefits that they are entitled to



The most common benefit received is Personal Independence Payment (PIP) which is claimed by over a third of people with MND. Employment and Support Allowance (ESA) is received by **12%** of people with MND.

What we are doing:

- Researching the effectiveness of the benefits system in supporting people affected by MND
- Working with the Department of Work and Pensions (DWP) to achieve improvements in the benefits system, including the recent exemption from reassessments for people with MND claiming ESA
- Campaigning to raise awareness of benefits issues amongst members of the government, members of parliament and other key decision makers

The MND Association is the most common source of information about benefits and allowances (**34%** of people with MND receive information from MND Association sources).

What we are doing:

- Promoting the availability of advice and support directly via our Benefits Advice Service covering England, Wales and Northern Ireland

Almost half of carers of people with MND (**47%**) do not receive any benefits or allowances.

What we are doing:

- Lobbying the Government to better support carers
- Promoting the availability of carers benefits

Being diagnosed with MND impacts on every aspect of the person's life. They not only have to cope with the physical and mental challenge, but also the logistical challenges of day to day life.



The majority (**64%**) have already been forced to or plan to move or adapt their home.



Patients diagnosed at MND Association funded facilities had a better experience than those diagnosed elsewhere.

Long waits during diagnosis still occur:

- Referral from first seeing a GP to seeing a neurologist is more than a year for **17%** of people
- The time from first seeing a neurologist to getting confirmed diagnosis is more than a year for **25%** of people

What we are doing:

- Continuing to promote and distribute the Red Flags tool to support GPs and other health professionals in making timely referrals to neurology
- Working with NICE to support GPs to refer people more effectively

People diagnosed at MND Association funded facilities had a more positive experience than at non-MND Association funded services:

- Those who received their diagnosis at MND Association Care Centres or Networks were more likely to agree that the explanation was given in a way that they could understand **(88% vs. 80%)**.

- They were also more likely to think that the clinicians who provided the diagnosis understood how they might be feeling **(86% vs. 73%)**.
- More patients felt supported by the clinicians who provided the diagnosis **(83% vs. 69%)**.



What we are doing:

- Funding 22 Care Centres and Networks across England, Wales and Northern Ireland
- We continue to expand this coverage. Our latest Care Centre opened in Norwich in 2017
- Opening the North Midlands Care Network based in Stoke in 2018
- In 2018 we launch our affiliation scheme to support and promote these high standards of care in non MND Association funded services



People diagnosed with MND less than three years ago were much more likely to be advised about the support the MND Association can offer **(45% vs. 35%)**.

What we are doing:

- Raising awareness and making more people aware of the care and support that we can offer



Our drive to improve services is having an impact - people who were diagnosed less than three years ago were significantly more likely to agree that they were supported throughout their diagnosis **(80% vs. 72%)**.

People with MND are more satisfied with the healthcare they receive than their social care, but many problems still exist

People with MND are significantly more satisfied with their healthcare than their social care:



63%
Social Care



86%
Healthcare



The majority of people with MND know who they can talk to if there is a problem with their healthcare. **(88% vs. 66% for social care)**



There is a strong level of agreement that healthcare professionals understand the needs of people with MND will change over time and that the change may be rapid. **(87% vs. 67% for social care)**



People with MND commonly receive an explanation of the different choices for their healthcare in a way that they understand. **(83% vs. 56% for social care)**

What we are doing:

- Supporting NHS services to use our Transforming MND Care Audit Tool to benchmark and improve their services for people with MND
- Regional Care Development Advisers are working with healthcare services to ensure the needs of people with MND are met
- Working with NHS England to improve commissioning of services for people with MND
- Engaging with NICE to develop guidance on improving MND services – such as the NICE guideline on MND
- Providing healthcare information for people with MND, their families and carers through MND Connect and support volunteers



Fewer people with MND completing the survey could identify a named person responsible for co-ordinating their care and support in 2017 than in 2015.



81%
2015



56%
2017

What we are doing:

- Funding more care coordinators, there is research evidence that suggests people with MND who have coordinated care have a significantly better quality of life*
- Supporting/testing designated posts committed to ensuring people get better coordinated care in areas where there is most need

People with MND are more satisfied with the healthcare they receive than their social care, but many problems still exist



A notable number of people with MND have not been given the opportunity to make plans for their future:

36%

Have not been given the opportunity to make an Advance Care Plan.

36%

Have not been given the chance to make Advance Directive Decisions.

19%

Have not discussed end of life issues.

What we are doing:

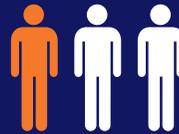
- Informing people with innovative resources – such as our award winning End of Life Guide
- Working as part of the End of Life Coalition to ensure the delivery of the Government's National Commitment on end of life care
- Supporting people directly through MND Connect
- Continuing to work with clinicians to promote these discussions, when the time is right for each individual



Around half of people with MND receive help with their breathing and more than a quarter have had surgery to insert a feeding tube.



The most common form of help that people with MND receive with their breathing is non-invasive ventilation (accessed by **49%** of those receiving help).



Almost one in three people with MND have regularly experienced difficulties getting help with their breathing when they needed it (**29%** of those who answered the question find that this happens regularly).

What we are doing:

- Researching the benefits of invasive ventilation for people with MND through qualitative interviews
- Closely monitoring access to respiratory support in different areas of the country and campaigning for improvements where services are poor

There are key equipment and home adaptation needs for people with MND that are not sufficiently funded by the NHS or Social Services.

The most common equipment or home adaptation needed by people with MND are:

 **61%**
Manual wheelchairs

 **54%**
Bathroom adaptations

 **53%**
Riser recliner chairs

 **52%**
Laptops/tablets

What we are doing:

- Loaning equipment which is needed by people with MND
- Providing grants for equipment and adaptations from central and Branch and Group funds

Whilst the NHS or Social Services are most likely to fund manual wheelchairs, people are less likely to receive laptops/tablets and bathroom adaptations.



Laptops/tablets for communication: used by **52%** of people. **87%** of these are not funded by the NHS or social services.



Bathroom adaptation: more than half of people have bathroom adaptations. **73%** of these are not funded by the NHS or social services.

A third of people who had a riser recliner chair had them funded by the MND Association. **88%** of people said they received this help when they needed it and **87%** said this met their needs (up from 81% in 2015).

What we are doing:

- Piloting a Wheelchair Champions project to recognise and promote best practice in Wheelchair Services
- Influencing statutory services to help people get the equipment that they need
- Focusing our efforts on housing adaptations and Disabled Facilities grants (DFGs)

People with MND can benefit from a range of environmental controls.

The most commonly needed controls are equipment to call for help – needed by **43%** of people and offered to **34%**.



Many people also need equipment to allow them to make and receive telephone calls – needed by **21%** of people & offered to **13%**.



What we are doing:

- Identifying and raising awareness of emerging technologies
- Providing a range of environmental controls to people with MND who need them

A third of people with MND are unaware that they can create a personal synthetic voice which may be used if their ability to speak deteriorates in the future.



13% of people with MND who responded have banked their voice.

What we are doing:

- Piloting a voice banking project to train volunteers to help people with MND bank their voice
- Increasing our information and advice around voice banking, including in video format in 2018