# Key messages

Psychological support is an essential component to the overall care of a person with MND. The realities of being diagnosed with the disease, its poor prognosis and rapid progression, as well as its deterioration of physical and cognitive function, may place profound psychological challenges on people with the condition. People affected by MND should have full and effective access to specialist psychological care and support, which is essential to the acceptance of an MND diagnosis and management of the impact of the disease.

Recognising the unmet need for psychological support for people affected by MND, the MND Association has funded eight specialist psychology posts in MND Care Centres across the UK. It is unsustainable, however, for the voluntary sector to continue to use charitable funds for vital services that should be available within the NHS without a longer-term ambition that meets patients’ need for mental health support.

Government, national policymakers, and local commissioners need to recognise the importance of, and need for, mental health care and support for people affected by MND and put in place effective measures to expand access. This includes revising national healthcare guidance, ensuring psychology and neuropsychology are key components of MND services, and addressing current psychologist workforce shortages by expanding salaried posts to achieve ambitions set out in the Optimal Clinical Pathway for MND.

# Background

The psychological impact of motor neurone disease (MND) can be characterised as a continuous series of losses.[[1]](#endnote-2) Firstly, disease progression from initial diagnosis of MND can produce repeated feelings of loss. The condition significantly shortens life expectancy – a third of people with MND will die within a year from diagnosis and more than half within two years – meaning people are required to reevaluate their original plans and wishes for the future.[[2]](#endnote-3)

Secondly, losses can also be experienced through the symptoms of MND. Physically, for example, the condition attacks the nerves that control movement so muscles no longer work, leaving people locked in a failing body, unable to move, talk and eventually breathe. People’s cognitive function can also be affected – up to half of people experience changes to thinking and behaviour and this increases to eight out of ten people in the later stages of the condition.[[3]](#endnote-4)

It is therefore no surprise that a diagnosis of MND commonly gives rise to negative emotions such as fear, denial, frustration, and grief.[[4]](#endnote-5) These emotions can often result in feelings of anxiety and depression, with 44% and 30% of the MND population experiencing these mental health conditions, respectively.[[5]](#endnote-6)[[6]](#endnote-7)[[7]](#endnote-8) People diagnosed with the condition are also at greater risk – a six-fold increase – of suicide in comparison to the general population.[[8]](#endnote-9) Moreover, carers of people with MND are also at risk of negative psychological outcomes such as anxiety and depression, with these conditions often correlating with their loved ones’ increasing level of functional impairment.[[9]](#endnote-10)

MND is a terminal disease and its profound impact on physical and cognitive function requires access to specialist psychological support. The rapid progression of MND also means that people will need to routinely access this support as the condition progresses.

Psychological support for MND involves practices and techniques to manage the psychological impact of the condition. This can include Acceptance and Commitment Therapy (ACT), Cognitive Behavioural Therapy (CBT), other talking therapies as well as further mindfulness techniques that help mitigate stress, anxiety, and depression.[[10]](#endnote-11)

# The challenge

## Access to generic mental health services

In England, people affected by MND have a right to mental health support, as laid out in the NHS Constitution, which prescribes that services are designed to treat both physical and mental health equally.[[11]](#endnote-12) In Wales, the quality statement for neurological conditions prescribes that 'neurological rehabilitation services including physical, communication, cognitive and psychological support are consistently accessible for those affected by a neurological condition’.[[12]](#endnote-13) In Northern Ireland, the Mental Health Strategy 2021 – 2031 prescribes ‘consistency and equity of access to [mental health] services’ and that ‘the specific needs of particularly at-risk groups of people, and the barriers they face in accessing mental health services, should be recognised and supported.’

In England, people can access mental health support through primary care via NHS Talking Therapies such as CBT-based services. However, research suggests that NHS Talking Therapies services are not adequately set up to cater for some patients with complex needs.[[13]](#endnote-14) Additional research has found that people with MND report a lack of understanding and knowledge of the condition from non-MND healthcare professionals, which acts as a significant barrier to the delivery of psychological interventions for this patient group.[[14]](#endnote-15)

Waiting times for NHS Talking Therapies are also an issue. While the majority of people (91%) who were referred for, and completed, treatment had their first appointment within six weeks of referral, the average time between first treatment and second treatment was 50 days in 2021/22.[[15]](#endnote-16) Moreover, there is significant variation across England – between 4 days and 229 days for waiting times for first treatment, and 32 days and 291 days for average waiting time between first and second treatment.[[16]](#endnote-17)

In Northern Ireland, there were 2,000 people waiting more than nine weeks for adult mental health services in 2021, and 1,800 people were waiting more than 13 weeks for psychological therapies.[[17]](#endnote-18) In Wales, data from June 2023 finds that just 71% of patients started their therapeutic intervention within 28 days following an assessment.[[18]](#endnote-19) These waiting times are completely unacceptable for people living with MND, a condition where one-third will die within one year of diagnosis.

People may also be referred to mental health services by their specialist MND team. However, current waiting times for mental health services are concerning. They are often fraught with capacity issues and long waiting lists – almost one-quarter (23%) of patients with a rare disease stated that long waiting lists at mental health services prevented them from accessing psychological support.[[19]](#endnote-20)

Local mental health services are also often unsuitable or reluctant to accept neurology patients.[[20]](#endnote-21) Due to the generality of mental health services, staff may not have the requisite knowledge and experience of working with people with progressive and life-limiting conditions. The Neurological Alliance’s 2022 neurological patient experience survey found that two-thirds (67%) of people with a neurological condition said their mental wellbeing needs are being met to a small extent or most often, not at all.[[21]](#endnote-22)

Moreover, over one-third (36%) of adult neurology patients said they would like to be signposted or referred to support for their mental wellbeing by a healthcare professional but haven’t. Similarly, more than six in ten (61%) said they would like counselling but haven’t been offered this.[[22]](#endnote-23)

Due to the unsuitability of, and long waiting lists for, generic mental health services for people affected by MND, there is a need to provide psychology interventions in a more direct and integrated way. The provision of psychology services as a core part of MND multidisciplinary teams (MDT) is necessary to facilitate more timely and appropriate access to vital mental health support.

## Lack of prioritisation of psychology in MND pathways

Current guidance for MND prescribes that, at routine appointments, specialist multidisciplinary teams should ask the person with MND and their carer/family whether they have any psychological or support care needs. The guidance does not prescribe psychologists or neuropsychologists to be a core part of the MDT but rather they should have established relationships with, and prompt access to, these specialists.[[23]](#endnote-24)

This may explain why formal psychology services are not routinely available in, or part of standard care within, specialist MND Care Centres in the UK.[[24]](#endnote-25) An impact of this is that many patients will face an inequity in having their psychological needs identified and addressed – around 60% of adult neurology patients reported not being asked about their mental wellbeing by a healthcare professional in the last three years.[[25]](#endnote-26) More specifically, MND Association’s ‘Improving MND Survey 2019’ found that just 26% of MND patient respondents accessed adequate psychological support (11% to some extent). For those who did access psychological support, for almost one-quarter (23%), it took three months or more to access it.

In Northern Ireland, the Mental Health Strategy 2021 – 2031 denotes a clear aim to improve access to mental health care and support for people living with physical ill health.[[26]](#endnote-27) However, it also prescribes that this aim ‘does not mean the provision of dedicated mental health resources within physical health services.’ Anecdotally, we have heard there is no dedicated neuropsychology service for people living with MND and referrals are accepted under a general neuropsychology service, which is fraught with capacity issues leading to extremely long waiting times for neuropsychological support for people living with MND.

Delivering psychological support within a specialist MND service has many benefits. For example, people with MND are regularly assessed – usually every two to three months – by their specialist MDT throughout the course of their illness.[[27]](#endnote-28) As per national guidance, this therefore provides regular and consistent opportunities for psychological needs to be identified and to provide interventions.[[28]](#endnote-29)[[29]](#endnote-30) The British Psychological Society’s guideline on psychological interventions in MND recognise the importance of MDT approaches to psychological care, given the imperative to respond promptly to rapidly changing health needs.[[30]](#endnote-31)

For example, some people may refuse to engage in psychological support initially, but this pathway of care offers opportunities to revisit people’s needs and wants from psychological care.[[31]](#endnote-32) This is supported by findings of one MND Association-funded psychology post in South Wales that found differing levels of psychological need depending on the time elapsed since diagnosis (57% of patients have psychological needs at 0–6 months post diagnosis, 100% between 24–36 months, and 25% at 48 months or longer).[[32]](#endnote-33)

Moreover, the delivery of psychological care in a specialist MND service facilitates care continuity for people and their carers when accessing services. Requiring a referral for mental health support currently segments people’s experience of care and unnecessarily separates the physical and mental health aspects of MND from one another, preventing the delivery of holistic care. Research suggests that mental health problems have a greater physical effect on quality of life than physical co-morbidities and should therefore be considered in the healthcare provision for patients with all health conditions.[[33]](#endnote-34) It may also drive cost-savings by addressing mental health needs and limiting their further negative effect on physical health resulting in increased service utilisation. For example, a person with MND who is depressed may be less motivated to take care of their physical health, i.e., taking medication routinely.

Corollary, around one-third (34%) of people with a neurological condition said their condition made their mental wellbeing much worse.[[34]](#endnote-35) Further research suggests that health perception by people living with MND is more closely linked to psychological wellbeing than physical function.[[35]](#endnote-36) It is suggested that specially designed services that bring together neurology and mental health are often required to achieve the best outcomes for patients.[[36]](#endnote-37)

These benefits, therefore, necessitate the need for direct access to psychological support for people affected by MND, namely, by requiring psychologists and/or neuropsychologists to be a core part of MND MDTs. There is a need for national action to expand access and the National Institute for Health and Care Excellence (NICE) should explicitly identify the psychology profession as a core part of the MND MDT in their next iteration of MND guidance. It is also important to recognise that, even outside specialist settings, every person living with MND should have sufficient access to psychological support should they need it.

This will help achieve the ambitions set out in the Optimal Clinical Pathway for MND, which denotes psychology/neuropsychology as core occupations and support provision functions within an MND MDT.

While responsibility for the development of service specifications will be held nationally by NHS England, it is important that the value of psychology and neuropsychology is translated into local commissioning arrangements and delivery of care. NHS England, supported by the Specialised Adult Neuroscience Transformation Programme and regional Clinical Reference Groups, should identify psychology and neuropsychology as key service components in updated service specifications for neurology.

This will help patients to access mental health support, as well as satisfy requirements set out in the England Rare Disease Action Plan 2023, which demands all new and revised service specifications for patients with a rare disease to consider user’s psychological needs and ensure coordinated pathways to mental health support.

Similarly, the design, implementation and delivery of a new Integrated Care System in Northern Ireland is underway, bringing commissioning functions within the scope of five Area Integrated Partnership Boards (AIPB), with expected completion in April 2024. It is important that the new Integrated Care System supports access to psychology support for people living with MND by identifying neuropsychology as key service specification for neurology services. The Executive Board for Neurology in Wales should similarly look to do the same. Across all nations, policymakers should ensure there is requisite funding for these posts.

## Lack of psychology workforce

To realise fully integrated, specialist psychological care and support for people affected by MND, the psychology workforce must be addressed. Psychology, across every specialism, is listed on the Shortage Occupation List in all UK countries.[[37]](#endnote-38) Health Education England reports that psychology professions need to expand by 60% on 2019 levels by 2024 to meet patient need, equating to an additional 10,640 full-time equivalent psychological professionals.[[38]](#endnote-39)[[39]](#endnote-40) Similar workforce issues exist in Northern Ireland and Wales.

There has, however, been significant work to increase the clinical psychology workforce in recent years. In 2020, Health Education England announced a 25% increase in the number of training places. More recently, the NHS Workforce Plan – published in June 2023 – plans to increase psychologist training places for clinical psychology by 26%.[[40]](#endnote-41) It is positive the Plan will be reviewed every two years, and it is essential that the next review continues to expand clinical psychology training places to meet patient need.

A limited workforce has an impact on the capacity of services which, in turn, has an impact on the availability of care and support for people affected by MND. A survey by the British Medical Association found that 57% of clinical psychologists said that on their last shift or day worked there was a shortage of one or more clinical psychologists.[[41]](#endnote-42)

It is important that people affected by MND can access psychologists with an interest in MND. These professionals have the requisite knowledge and experience to ensure that psychological interventions are flexible and tailored to the needs of people with the condition. For example, speech and communication difficulties – commonly associated with MND – may be better considered by specialists when delivering psychological interventions compared to non-MND healthcare professionals.[[42]](#endnote-43) A service evaluation of a psychology post in an MND Care Centre found that psychology intervention provided a more appropriate, tailored, and patient-centred approach to care which, in turn, prevented additional primary and secondary care resource.[[43]](#endnote-44)

Neuropsychology is important, too, since it can address mental health care needs as well as the cognitive and behavioural challenges of MND. The Neurological Alliance prescribes that every person with a neurological condition should have access to specialised neuropsychological assessment, care, and treatment in addition to local mental health services.[[44]](#endnote-45) However, 62% of patients with a neurological condition said that they would find neuropsychology helpful but haven’t been offered this.[[45]](#endnote-46)

The specialism is particularly important for the 15% of people with MND who develop frontotemporal dementia and where the specialism can help manage the cognitive and behavioural symptoms of this patient group.[[46]](#endnote-47) One MND Association-funded psychology post within an MND Care Centre in Sheffield found that a dedicated MND neuropsychology service led to improved detection of behavioural and cognitive change in patients attending the clinic, as well as better identification of low mood and anxiety.

However, neuropsychology is part of clinical psychology, a profession that has a 12% vacancy rate and lengthy training pathway. It requires a necessary undergraduate degree, clinical experience, and doctorate, equating up to nine years in education and experience.[[47]](#endnote-48)[[48]](#endnote-49) A review of The Specialist Register of Clinical Neuropsychologist finds that there are only a small number – 118 – of clinical neuropsychologists for neurodegeneration in the UK.[[49]](#endnote-50) However, an even smaller number will have specialist knowledge of MND.

While there has been significant work to increase the number of training places in clinical psychology over recent years, without the requisite expansion of salaried posts within the NHS there is a risk that unmet psychological need will not be addressed.[[50]](#endnote-51) It’s imperative that ICBs in England, Area Integrated Partnership Boards (AIPBs) in Northern Ireland and Local Health Boards in Wales should look to commission salaried posts for clinical psychology, including neuropsychology, within MND MDTs in accordance with the Optimal Clinical Pathway for MND to match patient need.

This will support the broader national call from The Neurological Alliance’s #BackThe1in6 campaign which calls on governments across the UK to establish a Neuro Taskforce. This Taskforce would bring together relevant departments, health and social care bodies, professional bodies, people affected by neurological conditions and the voluntary sector to, amongst other things, assess the current neuroscience workforce and set out plans to ensure it is fit for the future.[[51]](#endnote-52)

In light of psychological support gaps within the NHS, MND Association has provided funding for eight specialist psychology posts across the UK. However, it is unsustainable for the voluntary sector to continue to plug gaps in support which should be routinely available on the NHS. It is also inappropriate that sufficient access to psychological care and support are only being met because of voluntary sector funding, and not by statutory bodies themselves. Where these voluntary-funded posts are due to end, ICBs in England and commissioning bodies in Northern Ireland and Wales should commit to their ongoing funding if they are found to create positive outcomes for patients and services.

# What changes do we want to see?

**From Government:**

* Governments across the UK should establish a Neuro Taskforce to assess the current neuroscience workforce and set out plans to ensure it is fit for the future.

**From policy makers:**

* NICE should explicitly include psychology and/or neuropsychology as a core occupation of the MND MDT in the next iteration of MND guidance.
* NHS England, supported by the Specialised Adult Neuroscience Transformation Programme and regional Clinical Reference Groups, the Integrated Care System in Northern Ireland, and the Executive Board for Neurology in Wales, should identify psychology and/or neuropsychology as a key service component in service specifications for neurology and ensure requisite funding for this workforce.
* NHS England should look to maintain increases in the number of training places for clinical psychology, as committed to in the Long Term Workforce Plan, in order to match demand. Commensurate workforce plans should also be developed in Northern Ireland and Wales.

**From commissioners:**

* ICBs in England, AIPBs in Northern Ireland and Local Health Boards in Wales should look to commission salaried posts for clinical psychology, including neuropsychology, within MND MDTs in accordance with the Optimal Clinical Pathway for MND to match patient need.
* ICBs in England, AIPBs in Northern Ireland and Local Health Boards in Wales should commit to ongoing funding for current voluntary sector-funded psychology posts, where these are in place.

# What MND Association is doing

* Recognising the unmet need for psychological support for people affected by MND, the Association has funded eight specialist psychology posts across the UK, including Sheffield, Bristol, Merseyside, Oxford, and South Wales. As part of these funding posts, evaluation of service and sharing of best practice has been undertaken to ascertain the ongoing benefit of integrated psychology services for people affected by MND.
* Directly funding research including the COMMEND trial (COMmitment therapy for people with Motor nEuroN Disease), iDeliver MND (Improving delivery of psychological care in MND) study and MiNDToolkit, a novel psychoeducational research platform, developing to support carers in the management of behavioural changes in motor neurone disease.
* Raising awareness of the impact and value of specialist psychology through MND care networks by delivering study days, webinars, master classes, published information and developing an MND psychologist network to share best practice and service development.
* Providing MND Connect – MND Association’s information and support service – that supports people affected by MND through the provision of emotional and practical support as well as information about, and signposting to, health and care services.
* Providing funding for counselling for people with MND through our Quality-of-Life grant and carers through our Carers Grant, with young people up to the age of 25 able to access counselling free of charge via our partnership with Barnardo’s.
* Providing X Association Visitors who, as part of their core role, offer vital emotional support to people with MND and their families for as long as it is required, as well as providing broader care coordination across health and social care for families.

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