# Key messages

Motor neurone disease (MND) is a rapidly progressing neurological condition which affects an individual’s ability to walk, talk, eat, breathe, and move. Social care is therefore a vital source of support for many people affected by MND. Effective social care enables people living with MND to prolong independence and maintain wellbeing, dignity, and quality of life as the disease progresses. It also supports unpaid carers to continue in their caring role.

Everybody affected by MND should receive the care and support they need, when they need it. This includes having choice and control over their care. However, decades-long of chronic underfunding, a depleting workforce, and a lack of will to progress long-term reform has led to a sector that is collapsing on its knees.

Government must grasp the nettle and move away from a sticking plaster approach that only keeps the system afloat to funding that is sufficient, sustainable, and well planned to ensure all people can access the support they need. It must act urgently to address damaging gaps in the social care workforce by publishing a long-term social workforce strategy. Finally, it must not continue to kick the can of reform down the road, and should immediately bring forward social care reform proposals, including those on charging.

# Background

Adult social care encompasses a wide range of support, including personal and nursing care, help maintaining independence, access to specialist equipment, information, and advice, as well as financial support. This support can be draw upon from different types of providers including residential and nursing homes, domiciliary care services, day care services, reablement services as well as local authorities themselves.

In 2021/22, local authorities in England received almost two million requests for adult social care support from nearly one and a half million new service users.[[1]](#endnote-2) In Wales, around 150,000 requests for information, advice and assistance from statutory social care services are made each year.[[2]](#endnote-3)

There is no national government budget for adult social care in England. Instead, publicly funded social care is mainly financed through local government revenue, although authorities do receive a grant from central government. Net local authority expenditure on adult social care in 2021/22 in England was £19bn.[[3]](#endnote-4) In Wales, social care is funded by both local revenue raising and a block grant from central government and local authorities spend around £2.4bn a year on social care services.[[4]](#endnote-5)[[5]](#endnote-6) In Northern Ireland, social care is integrated with health care and the five Health and Social Care Trusts manage their own budget allocated by the Northern Ireland Executive.

# The challenge

## Funding

Social care is chronically underfunded, and many local authorities struggle to meet the care needs of their populations. The Health Foundation has suggested that an additional £14.4bn a year is required by 2030/31 to meet future demand, improve access to care, as well as pay for more care. The Levelling Up, Housing and Communities Committee recommended the Government needs to allocate at least £7bn a year for adult social care.[[6]](#endnote-7) In 2022, Government announced £7.5bn of funding for social care up until the end of the 2024/25 financial year, which falls well below the predictions made needed to address the sector’s funding pressures.

An impact of inadequate social care funding is that it results in a lack of system capacity and market sustainability, e.g., ensuring there are enough social care providers to manage the needs of local populations. Service closures and disruptions, provider rates, workforce challenges, and local provider capacity all drive poor market sustainability.

In the six months between November 2022 and May 2023, 44% of councils in reported closures of local nursing and residential care providers. This equates to a total of 2,235 people being affected or 35 people, on average, per local authority in England. Similarly, 36% reported homecare provider closures in their area, equating to 2,066 people being affected or 48 people, on average, per local authority.[[7]](#endnote-8) This is an ongoing challenge for local authorities and does not appear to be slowing down. 63% of Directors of Adult Social Services in England reported that they are not confident their 2023/24 budgets will meet their statutory duty around market sustainability.[[8]](#endnote-9)

A lack of system capacity leaves people unable to have their needs assessed and met. Since November 2021, the number of people waiting for an assessment by their local authority in England increased by 10% from 204,241 to 224,978 in March 2023. Of those waiting for an assessment, 82,087 – or 36% - have been waiting for six months or more, an increase of 30% since April 2022 and nearly double (99%) since November 2021.[[9]](#endnote-10)

Similarly, between 2019 and 2021, two million requests for formal care and support for adults over 18 were turned down by their local authority, equivalent to around 21,000 requests being turned down each week, or 3,000 every day.[[10]](#endnote-11) While it is difficult to estimate the current levels of unmet need, Age UK and Care and Support Alliance estimate that over two and a half million people aged 50 and over have unmet social care needs.[[11]](#endnote-12)

Given the large symptom burden of MND, we expect that most people with MND have social care needs. However, our 2019 Improving MND Care Survey found that only a quarter (26%) of people living with MND said they received social care.[[12]](#endnote-13) This may be driven in part by a lack of appropriate providers to undertake the complex care packages related to MND. We have heard of providers and agencies handing back care packages to the local authority as they did not have the requisite skill-base within their workforce to safely provide the necessary care to the person with MND.

There is currently a sizeable gap between the funding required to meet the needs of the sector and what is currently available. In 2022/23, two-thirds (63%) of local authorities in England overspent on their adult social care budgets, with a total national overspend of £73.6m.[[13]](#endnote-14) These fiscal pressures are often the result of the challenge local authorities face in upholding their statutory duties to meet the needs of their populations and the legal requirement to balance their budgets. Just 6% of local authorities in England say they are ‘fully confident’ that they can meet their statutory duties relating to adult social care from their budget for the 2023/24 financial year.[[14]](#endnote-15)

Decades of neglect and hesitancy to address the key challenges of social care by successive governments has led to a sector that is collapsing on its knees. Government must grasp the nettle and move away from a sticking plaster approach that only keeps the system afloat to funding that is sufficient, sustainable, and well planned to ensure all people can access the support they need.

## **Workforce**

While the social care workforce is extensive – 1.79m posts in total in England in 2021/22 – there are significant gaps. In 2021/22, there were 165,000 vacant posts which had risen from 110,000 in 2020/21 – or by one half (52%).[[15]](#endnote-16) Driving a wedge in the social care workforce gap is the inability of the sector to recruit and retain the requisite number of staff needed to provide care to those who need it.

Recruitment has been particularly affected by Brexit. While recruitment challenges existed well before leaving the European Union, it has contributed to a greater difficulty in recruiting oversees workforce. It is estimated that the social care workforce gap will increase between 350,000 to 1.1 million people as a direct result of Brexit by 2037.[[16]](#endnote-17)

10% of homecare providers report Brexit and migration policy has negatively affected their ability to recruit care workers.[[17]](#endnote-18) While it is positive that social care workers were included on the Shortage Occupancy List in early 2022, just half (52%) of Directors of Adult Social Services agreed that this policy resulted in a positive impact on local recruitment and retention in 2023.

Additionally, 87% of homecare providers state it is harder to recruit new care workers compared to before the pandemic. Moreover, 91% agree that an inability to recruit care workers has resulted being unable to meet the demand for care locally.[[18]](#endnote-19)

Similarly, there are extensive retention issues across the sector, which are partly driven by pay conditions. The median hourly rate for care workers in 2021/22 was £9.50, £1 an hour lower than a healthcare assistant new to the role within the NHS (£10.50).[[19]](#endnote-20) Research finds that 36% of homecare providers agree that pay conditions for care workers has resulted in a negative ability to retain staff. It also finds that 69% state their existing workforce leaving has resulted in them not being able to meet demand for care locally.[[20]](#endnote-21)

Poor recruitment and retention within social care has led to a high turnover of staff and unfilled vacant posts. An impact of this is that there is an insufficient workforce to manage the needs of people who draw on social care. Data from the first three months of 2023 (January to March) shows that half a million (564,584) homecare hours were unable to be delivered due to staffing capacity in England.[[21]](#endnote-22) The Government’s White Paper on social care, published in 2021, did little to address the issue of low pay.

There is also a lack of appropriately skilled staff within the sector. People with MND often have complex needs which requires requisitely skilled staff to administer care packages. In particular, we have heard of families being unable to safely leave their loved one in the care of domiciliary care workers as they were not sufficiently trained on non-invasive ventilation. As a result of such limited skilled staff, we have heard of people with MND unable to get the care they need, resulting in them being left in hospital or going into nursing care facilities prematurely.

While we welcome Government intervention to make social care a more attractive sector to work by implementing a care workforce pathway for adult social care, more must be urgently done to address the current recruitment and retention challenges.[[22]](#endnote-23) We hope that this measure will provide the necessary development for care workers to ensure they are sufficiently skilled enough to cater for the complex needs of people with MND.

However, currently, unpaid carers are often left to fill the gaps in the sector, unfairly shouldering the burden of care for a complex disease – our research shows that almost half (43%) unpaid carers of people with MND spend 100 hours a week or more caring but just 13% received respite care following an assessment of their needs.[[23]](#endnote-24)

Carers are at particular risk of burnout and breakdown, which not only places themselves at risk but also their loved one with MND. 64% of unpaid carers of people with MND reported feeling physically exhausted because of their caring responsibilities, as well as mentally exhausted (66%).[[24]](#endnote-25) Data shows that, in 2022/23, 91% of Directors of Adult Social Services reported they are seeing unpaid carers coming forward for support with increasing levels of need.[[25]](#endnote-26)

Government must be bolder and act urgently to address the damaging gaps in the social care workforce. It is insufficient to continue to pass off the national social care workforce crisis as problem for individual local authorities to solve. If social care is to finally receive parity of esteem with the NHS, then it should be afforded a proper, long-term workforce strategy, in line with the recent workforce plan for the NHS. Only then can the benefits of fully, integrated health and social care be realised and people with MND are able to get the care and support they need.

## **Social care reform**

The Government’s White Paper on social care – *People at the Heart of Care* – which was published in 2021 put forward some positive proposals for people affected by MND. In particular, we were pleased to see proposals to introduce higher maximum grants for home adaptations and a review of the disabled facilities grant means test, which we have long campaigned for through our [#ActToAdapt](https://www.mndassociation.org/get-involved/campaigning/take-action/act-to-adapt) campaign. Additional financial support to improve services for unpaid carers was also promised within the White Paper.[[26]](#endnote-27)

In 2022, Government announced a tranche of funding to move forward with the proposals set out in the White Paper, including a £500m investment into the social care workforce.[[27]](#endnote-28) However, in April 2023, Government had slashed this by a half to just £250m.[[28]](#endnote-29) In a similar fashion, Government committed to consult on changes to the disabled facilities grant in 2022 but, as of July 2023, it is yet to be published. We urge Government to recommit to providing the pledged social care funding in full and urgently bring forward promised proposals around broader social care reform.

How social care users pay for their care has been subject to extensive debate. While we were pleased to see Government willing to tackle the issue through their proposals set out in September 2021, little progress has been made since. Government announced £7.5bn of funding for broader social care reform up until the end of the 2024/25 financial year in late 2022, but a portion of the funding was recycled from budgets used to introduced reforms for social care charging, which have now been delayed for two years.

Government must not continue to kick the can of reform down the road, and we urge them to bring forward social care reform proposals, including those on charging.

# What changes do we want to see?

**From Government**

* Government should commit to social care funding that is sufficient, sustainable, and well planned to ensure all people can access the support they need.
* Government should implement a long-term social care workforce strategy to give the sector parity of esteem with the NHS and ensure people can access the right care, at the right time.
* Government should commit to original funding and immediately bring forward previous proposals for broader social care reform, as set out in the White Paper for social care.

# What MND Association is doing

* Engaging with local councillors and other local decision makers, in partnership with our Campaign Volunteers, to raise awareness of local social care issues.
* Influencing national policy through consultations, campaigns, and meetings, either directly or through coalitions such as the Care and Support Alliance, on the experience of social care for people affected by MND.
* Lobbying MPs and other parliamentary stakeholders and groups ensuring that the experience of people affected by MND accessing social care remains high on government agendas.

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