

# State of Carers' Assessments 2023



## Executive summary

Carers' Assessments are a mandatory duty placed on local authorities to ensure that carers within their populations are able to receive the support they require. Evidence from MND Association in 2022 showed that only 25% of carers of people with MND had either received a carer's assessment or were in the process of having one.<sup>1</sup> This illustrates that too many carers are being denied access to further support to enable them to continue in their caring role.

Through Freedom of Information requests (FOIs) to local authorities in England, Wales and Northern Ireland, this briefing details four key areas where local authorities are not adequately delivering for carers with MND:

- 1) **Identification** – Local authorities are not fully aware of the carer populations they serve, with almost one third (31%) not holding a register of carers. In all, over half a million (636,373) carers are on local registers, amounting to between 6-13% of the estimated carer population in the UK.
- 2) **Quality** – Where Carers' Assessments are being delivered, there are areas of good practice; three-quarters (75%) of local authorities have a Single Point of Access for carers to facilitate access to information and support on assessments and nearly all (97%) use a standardised form which ensures consistency of assessment. However, quality of assessment also relies on maintaining these standards over time and 71% of local authorities do not provide routine reassessment for people with severe progressive diseases like MND.

- 3) **Timeliness** - Between 2018 and 2023, carers have been waiting, on average, between 40 and 50 days for an assessment. There is also a postcode lottery for how quickly people will receive an assessment, ranging over a year depending on where people live. In addition, 82% of these local authorities do not have fast-track routes to assessment in place. For severe, progressive diseases like MND, this is far too slow especially given that MND kills a third of people within a year of diagnosis and more than half within two years.
- 4) **Prioritisation** – 85% of local authorities do not have ringfenced budgets for Carers' Assessments. Increasing demand and restricted funding may mean the social care system will be less able to support carers.

These headline issues reveal the myriad of difficulties local authorities are facing conducting Carers' Assessments and they are likely not exhaustive. Further work needs to be done to establish not simply what the issues are but why they are occurring because the system is currently failing people with MND.

## Introduction

The Care Act 2014 in England gives anyone aged 18 years and over - who is looking after another adult who is disabled, ill or elderly - the right to a carer's assessment.



In Northern Ireland, the Carers and Direct Payments Act (Northern Ireland) 2002 gives carers the right to an assessment. In Wales, the right to a carers assessment is provided through the Social Services & Well-being (Wales) Act 2014.

These assessments cover topics such as carers' mental and physical health, their ability and willingness to care, and their relationships with others. They are the responsibility of local authorities in England, Wales, and of Health and Social Care Trusts in Northern Ireland.

**25%**



of carers of people with MND had either received a carer's assessment or were in the process of having one

The 2022 report 'Understanding the experiences of unpaid carers of people living with MND'<sup>2</sup> laid out the issues people with MND were having with Carers' Assessments. It found that just 25% of carers of people with MND had either received a carer's assessment or were in the process of having one and 40% were unaware of their right to one. It was also revealed that there

is a lack of understanding of MND amongst assessors and the full impact of providing care on the carer.

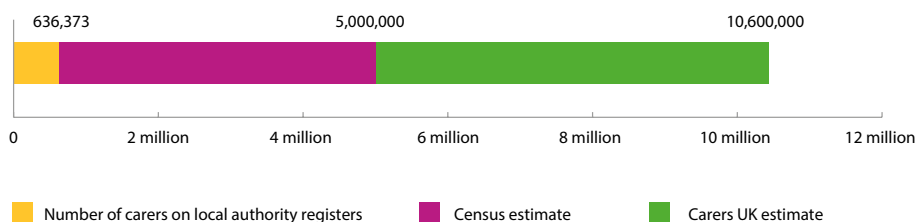
This briefing has used FOI requests to each local authority/health and social care trust within England, Wales and Northern to uncover the issues local authorities are experiencing delivering these assessments and be used for future improvements in Carers' Assessments.

## Theme: Identification

Too many local authorities are not collecting important data on carers in their local populations. Almost one-third of local authorities (31%) do not hold a register of carers in its area, with 55% holding a register and 13% holding some form of records for carer identification.<sup>3</sup> Without this data, local authorities are not able to fully map their carer population and provide support to those who require it.

According to these registers, local authorities are aware of 636,373 carers. Therefore local authorities are only identifying between 6-13% of carers in their local area.<sup>4 5 6</sup> (Figure 1). This means that, at the very least, 87% of carers and their needs are going unnoticed by local authorities. It is essential that local authorities are aware of their unpaid carer populations so that they can provide the support they need.

**Figure 1: Number of carers on registers compared to estimated number of carers**




## Theme: Quality

Just over half (52%) of local authorities conduct Carers' Assessments in-house using their own social care teams, 35% commission an external organisation to conduct assessments and 12% operate a mixed or blended model between the two.<sup>7</sup>

Regardless of how they are provided, there are examples of good practice within the system. Almost all local authorities (97%) use a standardised form for undertaking Carers' Assessments. Standardised forms allow for the process of assessment to be replicated across different assessments, so that outcomes have consistency.<sup>8</sup>

It is also positive that three-quarters (75%) of local authorities have a Single Point of Access for information and guidance on Carers' Assessments.<sup>9</sup> A Single Point of Access is integral for ensuring that people can access Carers' Assessments with ease and not go down 'rabbit holes' to get the support they need. For local authorities, a Single Point of Access provides a centralised gateway by which carers can be triaged more effectively.



**75%**  
of local authorities have a Single Point of Access for information and guidance on Carers' Assessments

Quality of assessment also relies on maintaining these standards over time. However, seven in ten (71%) local authorities do not conduct routine reassessments for people with severe, progressive conditions.<sup>10</sup> Many local authorities only reassess at the regular 12-month intervals as is mandated in the Care Act 2014, followed by light touch reviews. This reactive approach does not consider the rapidly progressive nature of MND which means people with the condition deteriorate quickly and therefore the needs of their carers increase considerably as a result.

In many cases, the responsibility of requesting a reassessment is put on the carer who may already be facing a high care burden— half (52%) of MND carers report spending over 75 hours a week providing unpaid care to their loved ones, and eight in ten (79%) spend over



**36%**

**of unpaid carers of  
people with MND are  
also working**

an average working week (35 hours) providing care.<sup>17</sup> They may also be contending with family commitments or work as 36% of unpaid carers of people with MND are also working (part or full time).<sup>12</sup>

## Theme: Timeliness

MND is a severe, progressive condition. This means that family members providing unpaid care will often continually and rapidly need local authority support to enable them to care for their loved one. Given this, it is integral that the gap between request and completion of assessment is as short as possible.

However, Figure 2 shows a stagnant pattern of waiting times for completion of assessments.



**An average  
wait of 42 - 47  
days between  
2018 and 2023**

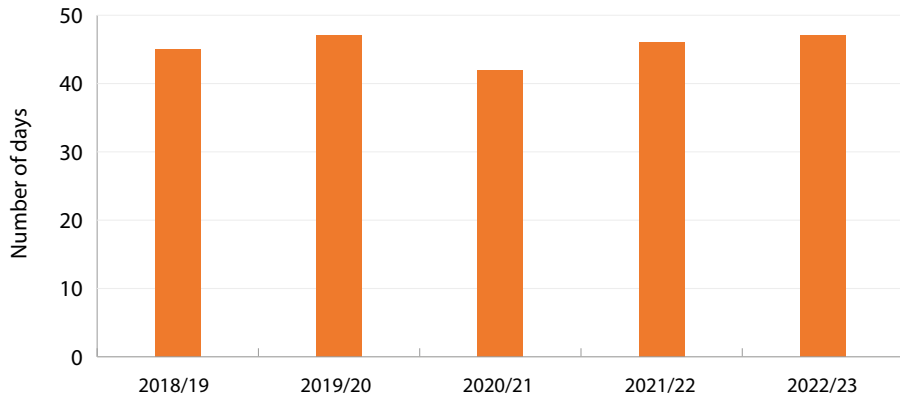
Between 2018 and 2023, the average wait was between 42 and 47 days.<sup>13</sup> In the context of a disease like MND, a lot can change over this period for carers and support is often needed promptly.

The situation worsens when looking at the range of waiting times across the country. Figure 3 shows the range of waits between

the local authorities with the shortest waits and longest waits for Carers' Assessments. This illustrates that the length of time carers wait for an assessment is heavily dependent on where they live. The range between the longest and shortest waits rose to 455 days in 2022/23. This can lead to a situation whereby for the carers of the the one third of people with MND who die within a year, they will never have received an assessment.

It is also concerning that 67 local authorities (40%) are not able to provide data on the length of time people are waiting for an assessment. This has improved from 101 local authorities who collected no data in 2018/19 (60%).<sup>14</sup>

**Figure 2: Average waiting time between request for assessment and completion of assessment for all Carers' Assessments**

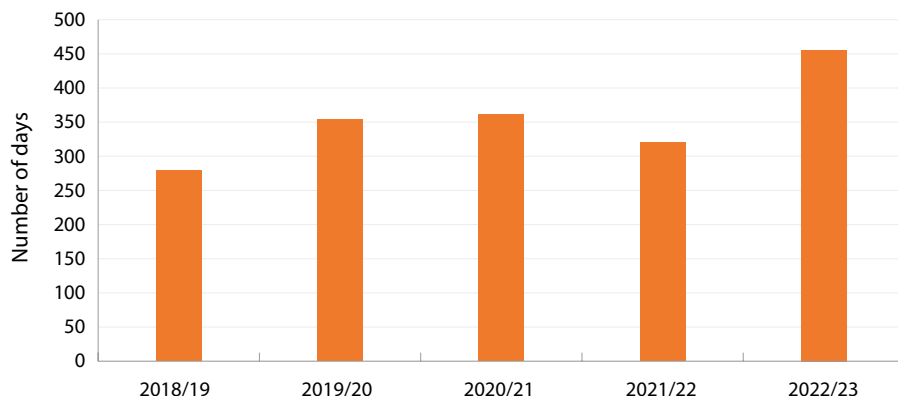


To bring down waits for people with severe, progressive diseases who have the greatest needs, a fast-tracking process can ensure that those who require support most receive it more quickly. However, 82% of local authorities have no formal fast-track process for the delivery of Carers' Assessments for carers of people with severe, progressive conditions.<sup>15</sup> Many local authorities stated that they prioritise based on risk and need, but had no specific measures in place to meet the needs of people with MND which, on average, kills a third of people within a year and more than half within two years of diagnosis.

**82%**  
of local authorities have no formal fast-track process for the delivery of Carers' Assessments for carers of people with severe, progressive conditions

The icon consists of a white rectangular box at the top right, with several parallel orange lines sloping downwards and to the left from the bottom right corner of the box, resembling a ramp or a fast-track path.

**Figure 3: Range between longest and shortest average waiting time between request for assessment and completion of assessment for all Carers' Assessments**



## Theme: Prioritisation

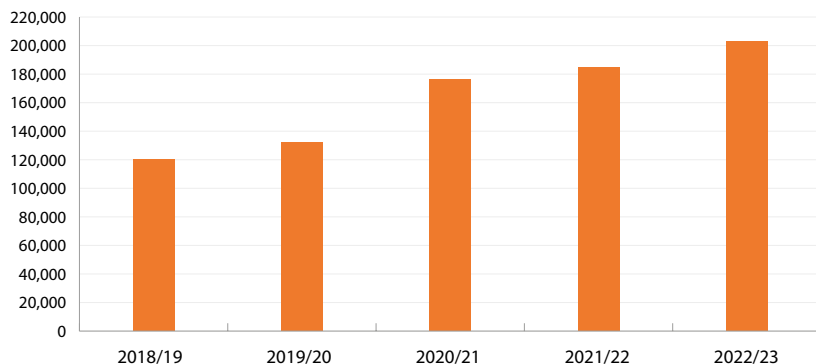
Local authority social care budgets are under major pressure with competing parts of the system requiring funding. Due to this, in many cases Carers' Assessments do not present themselves as a high priority and can be neglected. A means by which to prioritise assessments is to provide ringfenced budgets for them.

Having a specific budget allows local authorities to better plan and arrange activities and duties set out in the Care Act 2014. However, 85% of local authorities do not allocate a specific budget for Carers' Assessments.<sup>16</sup> This means

that local authorities are using funding from their broader adult social care budget, which is often spread thinly across other competing priorities.

The *Spring 2023 Adult Directors of Social Services (ADASS)* survey found that just 6% of local authorities were 'fully confident' their budgets were enough to meet their statutory duties in 2024/25. Concerningly, the survey also found that, of all duties local authorities are statutorily required to provide, 38% said they are least confident in being able to provide assessments, both for carers and people using services.<sup>17</sup>

**Figure 4: Average local authority budget for Carers' Assessments**



Of the 12% of local authorities that do provide a specific budget, Figure 4 illustrates the median amount spent on the budget. From 2018/19 to 2021/22 there has been a 68% increase in median budgets which may show the increasing demand for Carers' Assessments.<sup>18</sup> This is supported by the Spring 2023 ADASS survey which found that 91% of Directors of Adult Social Services reported they are seeing increasing levels of need among unpaid carers, compared to the last survey.<sup>19</sup>

A major barrier to successfully budgeting for Carers' Assessments is not knowing how many carers are in the population (see above) and the cost of conducting the assessment. This was a common theme with 127 local authorities (74%) not knowing the cost of a Carer's Assessment.<sup>20</sup>

For the 39 local authorities who did measure the cost of a carer's assessment (23%), the mean average cost was £118.53.<sup>21</sup> If this cost was applied for all 10.6 million carers who need to be assessed, this would amount to a cost of £1.232 billion for one assessment per year for each carer. Although high, it is under 1% of the estimated £164 billion value of unpaid care in the UK.<sup>22</sup> For carers of people with MND, this cost would amount to £592,650. This is just 0.3% of the annual savings MND carers save the health and social system every year (£185 million).<sup>23</sup> This means that

investing in Carers' Assessments brings a 100 to 1 return on investment for local health and care systems – through the identification of needs, as well as the delivery of subsequent support – to enable carers to continue in their caring role.

It is important to note the potential of cost savings for local authorities in delivering Carers' Assessments – the recent Spring 2023 ADASS survey found that over two-thirds (68%) of local authorities reported an increase in referrals relating to carer breakdown, with the main drivers in carer breakdown burnout, lack of access to health support and the inability to find the right services, something which a carer's assessment seeks to identify and address.<sup>24</sup>

## Methodology

12 questions concerning the state of Carers' Assessments were drawn up with assistance from the wider sector on their content. In July 2023, these were then sent to all upper tier local authorities in England and Wales, as well as Health and Social Care Trusts in Northern Ireland. The 174 responses received were then coded, analysed, and presented thematically by the MND Association policy team to produce this briefing.



## References

- 1 MND Association (2022). Understanding the experiences of unpaid carers of people living with MND. Available: <https://www.mndassociation.org/sites/default/files/2022-12/Carers-Report-External-version.pdf>
- 2 MND Association (2022). Understanding the experiences of unpaid carers of people living with MND. Available: <https://www.mndassociation.org/sites/default/files/2022-12/Carers-Report-External-version.pdf>
- 3 "Does the local authority/health and social care trust hold and maintain a register of carers in its area?" 173 responses; 56% said yes, 31% said no and 13% said they hold some records.
- 4 "If yes to 1, how many carers have been identified in the local authority area at the time of receipt of this FOI?" 118 responses; 56 did not respond. Of those who responded and held a register of carers, a total of 573,836 unpaid carers were registered.
- 5 Office for National Statistics. (2021). Unpaid care, England, and Wales: Census 2021
- 6 Carers UK (2022). Carers Week 2022 Report. Available: [https://www.carersweek.org/media/qf0p5u4t/carers-week-2022-make-caring-visible-valued-and-supported-report\\_final.pdf](https://www.carersweek.org/media/qf0p5u4t/carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf)
- 7 "Does the local authority/health and social care trust commission an external organisation(s) to be responsible for and conduct Carers' Assessments on its behalf?" 174 responses; 35.06% said yes, 52.30% said no, 12.07% mixed
- 8 "Does the local authority/health and social care trust – or the commissioned organisation responsible for Carers' Assessments – use a standardised form for undertaking Carers' Assessments?" 174 responses, 97.13% said yes, 1.15% said no and 1.72% held no records
- 9 "Does the local authority/health and social care trust have a Single Point of Access for information and guidance on Carers' Assessments?" 174 responses; 75.86% said yes, 23.56% said no
- 10 "Following initial Carers' Assessments, does the local authority/health and social care trust – or the commissioned organisation responsible for Carers' Assessments – conduct routine reassessments for carers of people with severe, progressive conditions?" 174 responses, 27.57% said yes, 70.69% said no and 0.57% held no records
- 11 MND Association. (2022). Understanding the experiences of unpaid carers of people living with MND
- 12 MND Association (2022). Understanding the experiences of unpaid carers of people living with MND. Available: <https://www.mndassociation.org/sites/default/files/2022-12/Carers-Report-External-version.pdf>
- 13 "What is the average (mean) waiting time between request for assessment and completion of assessment for all Carers' Assessments in 2018/19, 2019/20, 2020/21, 2021/22 and 2022/23" Mean average 2018/19 – 45 days, 2019/20 – 47 days, 2020/21 – 42 days, 2021/22 – 46 days, 2022/23 – 47 days
- 14 "What is the average (mean) waiting time between request for assessment and completion of assessment for all Carers' Assessments in 2018/19, 2019/20, 2020/21, 2021/22 and 2022/23" Number of local authorities without data: 2018/19 – 101, 2019/20 – 91, 2020/21 – 82, 2021/22 – 72, 2022/23 – 67
- 15 "Does the local authority/health and social care trust – or the commissioned organisation responsible for Carers' Assessments – have a formal fast-track process in place for the delivery of Carers' Assessments for carers of people with severe, progressive conditions?" 174 responses, 10.34% said yes, 82.18% said no, 5.75% said partly
- 16 "Does the local authority allocate a specific budget for Carers' Assessments?" 23 responses, 12.35% said yes, 85.88% said no, 1.21% said information not held
- 17 ADASS (2023). ADASS Spring Survey 2023, Available: <https://www.adass.org.uk/media/9751/adass-spring-survey-2023-final-web-version.pdf>
- 18 "Does the local authority allocate a specific budget for Carers' Assessments?" 170 responses, 12.35% said yes, 85.88% said no, 1.21% said information not held
- 19 ADASS (2023). ADASS Spring Survey 2023, Available: <https://www.adass.org.uk/media/9751/adass-spring-survey-2023-final-web-version.pdf>
- 20 "What is the cost of conducting one single Carers' Assessment?" 41 responses, Mean - £118.53, Median - £93.25
- 21 "What is the cost of conducting one single Carers' Assessment?" 41 responses, Mean - £118.53, Median - £93.25
- 22 M. Petrillo & M. Bennett (2023). Valuing Carers 2021. Available: [https://centreforcure.ac.uk/wp-content/uploads/2023/05/Valuing\\_Carers\\_WEB2.pdf](https://centreforcure.ac.uk/wp-content/uploads/2023/05/Valuing_Carers_WEB2.pdf)
- 23 Carers UK. (2020). Unseen and Undervalued
- 24 ADASS (2023). ADASS Spring Survey 2023, Available: <https://www.adass.org.uk/media/9751/adass-spring-survey-2023-final-web-version.pdf>