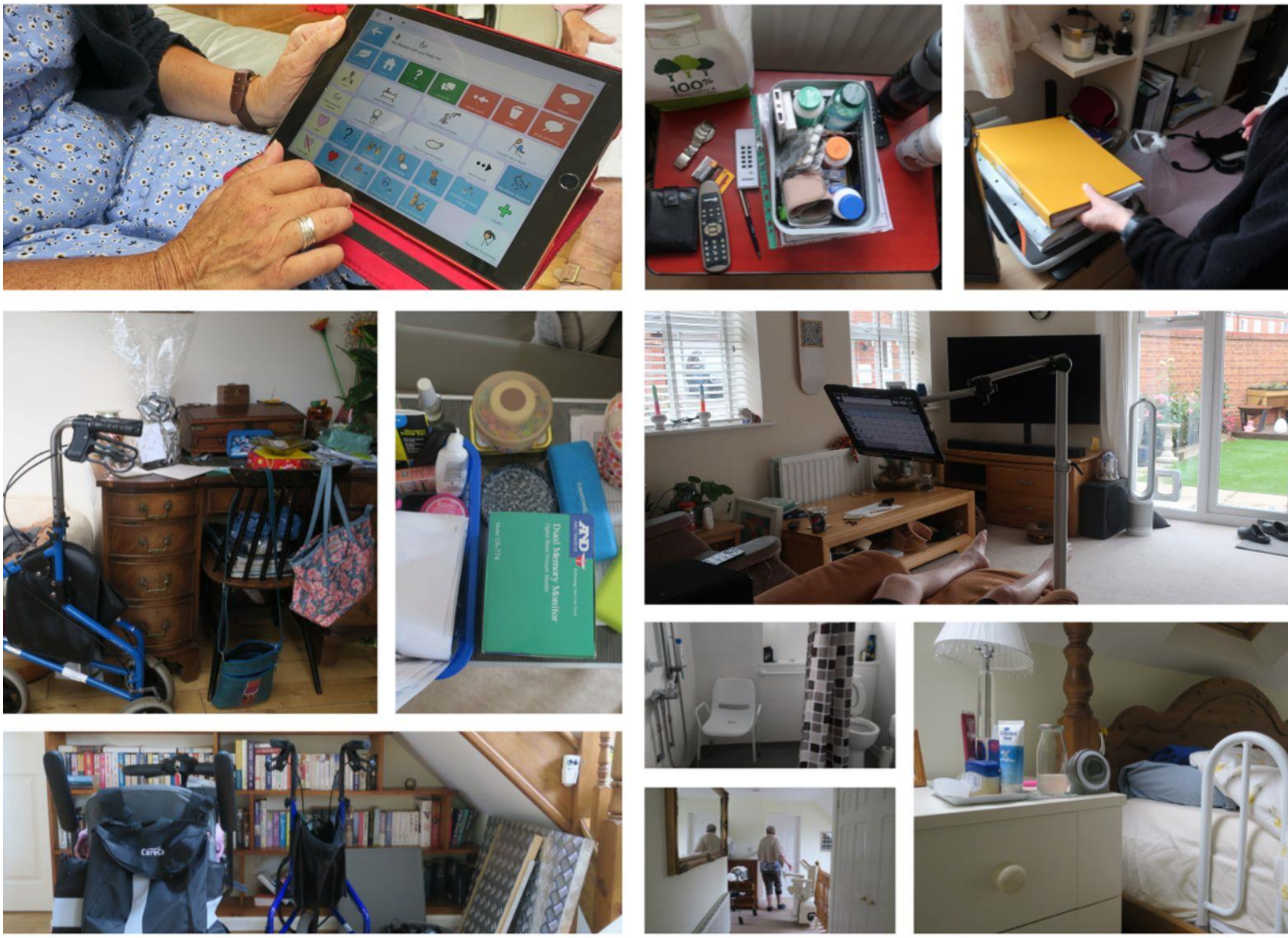
My MND, My Needs

Executive Summary
Revealing Reality



REVEALING REALITY

mnda
motor neurone disease association

Introduction

Up to 5,000 adults in the UK are living with motor neurone disease (MND) at any one time.[1] The MND Association focuses on improving access to care, research, and campaigning for those people living with or affected by MND in England, Wales and Northern Ireland.

How MND affects people and their lives varies greatly, reflecting the need for personalised information and support from the MND Association and wider healthcare professionals. While a myriad of support is available through the MND Association and through other support systems, some gaps in the provision and services available have meant that certain needs are not being met.

Along with these unmet needs, there are some groups of people who are not accessing support equally or accessing all the support available to them, either because they do not know about this support and how to access it, or because they do not think they are eligible for it.

To explore these needs, Revealing Reality was commissioned to explore and understand the unmet needs of people living with MND across the UK. First, researchers completed a literature review which explored the existing information available on the needs and experiences of people with MND, as well as identifying areas of information and support which were relatively unexplored. These findings were developed into a framework of ‘needs’, which reflected different areas of people’s lives that may be impacted by a MND diagnosis. This shaped the qualitative stage of the research, whereby researchers interviewed 15 people living with MND across England, Wales, and Northern Ireland, exploring individuals’ satisfaction with different areas of their lives (for example, their mobility, their relationships, their finances). The findings from these interviews fed into the quantitative stage of the research, resulting in a survey which was distributed nationally, and received 928 responses from people living with MND.

These were the five key findings from the research:

1. Many people living with MND highlighted their need for autonomy, independence and self-expression.
2. There is demand for more financial support, with a third not feeling confident about what they are entitled to.
3. Isolation and loneliness was felt more by those living with other adults and children
4. Younger people and those living with children have more unmet needs
5. Making peace with a MND diagnosis enabled some to find more day-to-day joy

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[1] Motor Neurone Disease Association, ‘About MND’ - www.mndassociation.org/about-mnd

1) Many respondents highlighted their need for autonomy, independence and self-expression

MND was affecting many participants' autonomy and independence, with loss of independence being a commonly reported concern among survey respondents. The survey explored these needs through five statements and participants reported struggling with things like keeping on top of tasks around the home, doing things that they enjoy, and maintaining their personal hygiene.

The qualitative interviews also highlighted that regardless of how advanced an individual's MND symptoms were, maintaining a degree of independence was a priority, for example being able to leave home spontaneously.

Among the 29% of survey respondents who indicated they lacked the necessary aids and adaptations to confidently leave their home, 82% wanted more support. Such experiences were raised in the qualitative interviews as well, for example by Liz, who spent most of her time in bed and relied on a series of carers, her family, and some serious organising to be able to leave her flat.

Autonomy and independence referred to more than just physical mobility. For some in the qualitative stage of the research, this meant having the physical ability to work, to help around the house, and to go out when and where they wanted. For others this included self-expression, and the ability to be oneself.

2) A third of people with MND did not feel confident about what they were entitled to

The financial impact of MND was reported as a challenge by survey respondents, due to the increased costs associated with managing the condition, including equipment, housing adaptations, and care costs. In the survey, of those who reported struggling to afford the costs associated with managing their MND, 91% said they wanted more support, with only 8% saying they already had all the support they needed.

The survey showed that those who struggled to afford the extra costs associated with MND had higher levels of unmet needs across other areas of their life, suggesting that increased financial support would be a wide-reaching measure to improve people's lives. A third of survey respondents said that they wouldn't know where to go for financial support and what kind of support was even available to them, meaning they were not accessing the support they are entitled to.

Even if people with MND knew where to access additional financial support or advice, not everyone felt like they would or could make use of those resources. For example, one interview respondent, Megan, and her family, had some reservations about using the grants available to them to pay for the adaptations to their house. Some of their friends and family had offered to help with the work for no charge and they worried that there may be others with more urgent needs.

3) People living with children and other family reported experiencing the most isolation and loneliness

Living alone was not necessarily a predictor for loneliness. Both the qualitative and quantitative elements of the research highlighted that people with MND living with other adults and children seemed to be experiencing higher rates of loneliness. One potential explanation for this is that those living with other adults and children experienced the most disruption to daily life following a MND diagnosis.

Approximately one-third of survey respondents reported feeling isolated and lonely in the past month. This group also reported higher numbers of unmet needs overall, especially in maintaining relationships and community connections. Specifically, 22% of respondents reported they did not feel capable of maintaining a sense of connection to their community or social groups.

4) Younger people and those living with children said they needed more support

The survey showed that younger people with children, or other family members to take care of, faced unique challenges. The quantitative research showed that those living with family and children under the age of 18 reported a greater number of unmet needs across their lives. Making lifestyle changes in line with MND symptoms, such as moving to appropriate accommodation, often meant making difficult decisions within families.

For Liz, staying in her basement flat meant she could not leave her home without the support of a team of carers. One option was for her to move to a wheelchair-accessible home, however, there was a serious tension between having appropriate accommodation and being able to live with or even be near her family.

Younger people and those living with children also experienced greater financial strain, contributing to more unmet needs across other areas of their life.

5) Making peace with a MND diagnosis enabled some to find more day-to-day joy

Acceptance of the diagnosis and peace with the future were vital but often unmet needs. Many of those who had reached a level of acceptance reported better coping mechanisms and more day-to-day joy despite advanced symptoms.

For some people with MND, it understandably took a while to accept the diagnosis and make a plan for the future. One interview respondent, Paul, reflected on his and his wife's initial shock when he received his diagnosis, which seemed to be impacting him from making and actioning decisions about necessary adaptations at home.

Younger interview respondents and those struggling financially were less likely to have accepted their diagnosis, indicating a need for more tailored support in these areas. In the survey, 29% of those under 60 disagreed with having accepted their diagnosis, compared to 18% of those aged 61–75 and 15% of those aged 76 and above.

Some were not able to or willing to talk about dying or end-of-life care at all. Due to the sensitivity of the topic, survey respondents had the choice to answer questions relating to death, meaning they could skip these questions entirely if they wished. Overall, those who reported a higher number of MND-related needs in their lives were the most likely to answer questions about death and dying, suggesting that those with more advanced symptoms had come closer to making peace with their MND diagnosis.

About Revealing Reality

Revealing Reality is an independent research agency who work with regulators, government, charities, and private sector organisations. Revealing Reality is experienced in conducting research with vulnerable groups in society, particularly for charities involved in health and social care, to ensure the experiences and perspectives of different people are placed at the heart of health and care policy.

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