



# No time to lose

Addressing the housing needs of people with MND

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**MND**  
**Scotland**  
Making time count

# Contents

<b>Executive Summary</b>	<b>i</b>
<b>Introduction</b>	<b>1</b>
<b>Methods and approach</b>	<b>3</b>
Contact us	3
<b>Housing needs and MND</b>	<b>4</b>
<b>Part 1: MND and Housing Adaptations</b>	<b>7</b>
Waiting times for adaptations	10
Reactive adaptations processes	14
Understanding and awareness of MND by local authorities	15
Complex processes	16
Independence and internal adaptations	19
Other concerns raised	20
<b>Part 2: MND and accessible housing</b>	<b>22</b>
Allocating accessible homes	23
A lack of definition	26
Waiting times for accessible housing	29
Target setting	32
Accessible housing and connections to care	34
<b>Part 3: Conclusion and Recommendations</b>	<b>35</b>
Conclusions	35
Recommendations	37
<b>Endnotes</b>	<b>42</b>
<b>Bibliography</b>	<b>43</b>

# Executive Summary

“They are delaying everything they can. I think they are holding out until I pass away so that they don't need to do anything” **person with MND**

For people with motor neuron disease (MND), having an accessible home is critical to being able to live safely, and with dignity. MND is a rapidly progressing terminal illness which can cause a person to lose the ability to walk, talk, eat or breathe unaided. Average life expectancy is just 18 months from diagnosis. Loss of mobility means it can become impossible to use steps and stairs, access a bathroom, or move around safely.

Most people with MND will need adaptations to their homes such as handrails, ramps or wetrooms. If adaptations cannot be made, an alternative accessible home is needed. However, housing processes do not take account of the speed in which MND progresses. Waiting lists can be longer than the average life expectancy with MND, leaving people with an already devastating diagnosis facing debt, physical injury, reduced quality of life and independence. Systems are not acting fast enough, and, tragically, some people are dying before they can get the support they need.

“My husband passed away nine and a half months from diagnosis and the ramp wasn't even begun” **bereaved family member**

Our research into housing and adaptations was carried out during the summer of 2021. 30 out of 32 local authorities and 134 people affected by MND contributed.



## MND and adaptations

Our report reveals that a postcode lottery of support for adaptations continues in Scotland, meaning where a person lives, and the type of property they live in, determines the support they receive. Some people are not told they are eligible for financial support and pay thousands of pounds for adaptations which should be free. Those who do know to seek support find themselves waiting for months for adaptations – time which they simply do not have.

Extensive waiting times exist across local authorities for adaptations. In our survey, 40% of people affected by MND who needed to have handrails fitted reported that they waited 4–6 months for these. Ramp waiting times were also lengthy with one local authority reporting an average wait of 475 days. Another local authority reported an average of 256 days for fitting a wetroom, and 11% of people affected by MND reported waiting more than a year for a wetroom. Several local authorities stated that delays were due to Covid-19 restrictions. However, evidence from our research, and our Advocacy service, indicates that such lengthy delays preceded the pandemic.

“ My husband lived in the living room with no shower facilities at all. We were washing him out on the decking with buckets of water. No dignity in that whatsoever ” **bereaved family member**

Waiting times, and a lack of formal fast-tracking processes for people living with terminal illnesses, are made worse by councils working reactively rather than proactively to fit adaptations which people with MND will likely need as their disease progresses.

“ We got in touch to apply for a ramp and were asked by the local council if he could still walk. He said yes, and so they said, we’ll not look into it until you can’t walk. But then he can’t get out the house. He asked how long the waiting list was and it was 9 months. So, they wanted us to wait 9 months from the point that he couldn’t get out ” **family member**

Over and above excessive waiting times, people with MND face a raft of other barriers to accessing adaptations. This includes inconsistent, complex and inaccessible application processes for some, and expensive contractor monopolies for others.

Some people with MND find they are unable to get internal adaptations fitted if the outside of their home is deemed inaccessible, for example, they live in a tenement flat. Instead, they are added to a waiting list for an alternative accessible home. However, these waiting lists are so long that people reported being stuck in single rooms, unable to move through their homes, and prevented from having a good quality of life in the time they have left.

“ What would make a difference to me is moving round my own home even if I can’t ever actually leave the house again ” **person with MND**

## MND and accessible housing

Less than half of the local authorities who responded to us shared their waiting times for an accessible property. For those that did, the average wait was 635 days – longer than the average life expectancy with MND, from diagnosis. One local authority reported waiting times of over 4 years. Some people with MND will therefore never reach the top of the waiting list. This is compounded by a lack of formal prioritisation processes for people with terminal illness, which only one local authority stated they had.

As mobility becomes affected by the disease, many people with MND will require a wheelchair. However, wheelchair accessible housing stock across local authorities is very low with one authority reporting it at 0.28%. Some local authorities are unable to identify how much stock they have. The majority stated that they have targets for building such homes, however, what these targets look like varies enormously. We also received reports of increased targets being voted down at council meetings, despite local ageing populations.

The situation is complicated further by the fact that there is no common definition of what an accessible home is. Local authorities, individually, determine what they mean by accessible, wheelchair accessible, or other terminology taken from a range of housing documentation. Some local authorities have no definition. This can result in people with MND being allocated unsuitable properties.

**“ Even though it’s an accessible home, I still have three steps at the back door. On the first day of arrival, I fell down the steps and smashed into the fencing ” person with MND**

Some people with MND report being pressurised to accept, or bid on, a property deemed as accessible, which they can see is unsuitable, or takes them away from essential support networks such as their family and care providers. Allocation processes can be hugely problematic for people with MND. Most local authorities use points based waiting lists yet, despite the prognosis of MND, people with the illness are not routinely prioritised. Other local authorities use choice based letting which requires applicants to bid (usually online) for an accessible home. This is highly impractical for people with such a disabling illness.

A scarcity of truly accessible housing, inadequate target setting, and a lack of formal prioritisation processes for those with terminal illness, means waiting times for accessible housing are too long for people with MND. This restricts lives already significantly shortened by the illness, and across our research, people shared stories of being trapped in unsafe homes.

**“ Being trapped in a flat was mentally challenging and the thought of not having much time left and not being able to do the things together that we planned to have taken its toll. To go out and make memories would have meant everything ” bereaved family member**

## There is no time to lose

The Scottish Government has made recent accessible housing commitments through their report 'Housing to 2040'. The identified need to streamline and accelerate adaptations systems, commit to consistent practices, and for more accessible housing processes intersect with several themes discussed in our report.

However, the system as it is, is failing too many people with MND and the need for action is urgent. Immediate 'Housing to 2040' commitments, such as the review of the adaptations system, should not be delayed. It is concerning that previous working groups and consultations around adaptations (Adaptations Working Group 2012) and accessible housing (Scottish Government 2009b) have already identified many of the key issues we present in this report a decade later.

People with MND must receive the adaptations and accessible housing they need quickly. If not, many will continue to spend their final months battling for the support they need. This support may never arrive in time.

The recommendations for Scottish Government and local authorities outlined in detail from page 37, are critical to ensuring people with MND live with the dignity and care everyone is entitled to.

### A summary of our key recommendations are:

#### Adaptations

- Fast-tracking applications for adaptations
- Anticipatory care planning for adaptations
- Clear and publicly available information about the Scheme of Assistance
- Making internal adaptations to a property
- Simplifying contractor and tender processes, but not at any cost

#### Accessible Housing

- A national definition of accessible housing
- 10% minimum accessible housing target
- Fast-tracking for accessible housing
- Direct matching properties with applicants
- Portable care packages

# Introduction

**Housing is key to people's lives. Over the past two years, the Covid-19 pandemic has highlighted more than ever the importance of having somewhere safe and accessible to live. However, in many cases, the pandemic has simply shone a light on more widespread housing issues. For many people affected by motor neuron disease (MND), current processes and practices in Scotland's housing are failing to meet their needs. We need urgent action to ensure that people affected by MND are able to live safely, and with the dignity and care that every person is entitled to.**

MND is a rapidly progressing, muscle wasting, terminal illness. How it affects people varies but it can cause someone to lose the ability to walk, talk, eat, drink or breathe unaided. While there is a diversity in how the disease progresses, the average prognosis after diagnosis is just 18 months<sup>1</sup>. There is no known cure or effective treatment for the disease, and a person's lifetime risk of developing the condition is 1 in 300. In Scotland at any one time, around 400 people are living with MND, and almost 200 people are diagnosed each year.

MND affects every part of a person's life. The speed and severity of the disease mean that accessible and adaptable housing is a cornerstone to being able to live life with dignity, care, and as fully as possible, particularly as the disease progresses. Current housing and adaptations processes are not only failing to meet people's needs, but they are also failing to understand the speed and progression of the disease. The impact is that people are faced with significant financial costs, a reduced quality of life and independence, and waiting lists that are longer than the average life expectancy with MND.

During summer 2021, MND Scotland undertook research to explore the experiences of those affected by MND in relation to adaptations and accessible housing. This explored what housing processes are like for people affected by MND and sought to identify what people felt would help or improve their experiences. We see people affected by MND – whether the person diagnosed, family members and carers or bereaved family members and carers – as the experts of their experiences and therefore best placed to make recommendations. We also examined current local authority practices and asked them questions about key indicators such as average waiting times for adaptations and accessible housing through Freedom of Information requests.

The Scottish Government's (2021a) recent consultations around Housing to 2040 have started to set out a vision for housing in Scotland over the next 20 years. Many of the commitments being made refer to progress in affordable housing. This is important. However, it is essential that this is done in tandem with commitments to accessible housing for those living with progressive and terminal conditions. Housing is a human right. Under the United Nations (2006) Convention on the Right of Persons with Disabilities, disabled people have "the same freedom, dignity and choice and control over their lives as everyone else".

However, as the Scottish Government's (2016) report 'A Fairer Scotland for Disabled People' acknowledges, this has not been the case. Within 'Housing to 2040', the Scottish Government has stated a commitment to support the development of quality homes that adapt as people's needs change. This includes consulting on new housing standards which should ensure that properties are free from serious disrepair, that they can be future proofed, and that they meet minimum space standards (instead of recording properties by room numbers). It also includes a commitment to taking action to streamline and accelerate adaptations systems. As we discuss in the following sections of this report, in the case of MND, there are several questions and considerations around consistent practices, waiting times and investment which also need addressing.

The Equality and Human Rights Commission, hereafter referred to as EHRC (2018), and Horizon Housing (2018) have highlighted the impact of unsuitable housing on disabled people and have made their own calls to action in this area. The findings from our research reflect many similar themes, including a need for concrete commitments to more accessible housing, and for consistent adaptations processes across tenure types and postcodes. Our findings also suggest that MND requires additional commitments in terms of speed and prioritisation, understanding of the disease, and proactive systems and procedures. The recommendations in Section 3 of this report offer a timely contribution to the Scottish Government's attention to adapted and accessible housing systems.



# Methods and approach

This report draws on the experiences and expertise of many people affected by MND across Scotland. We use the term people affected by MND to include those diagnosed, current family members and carers (using the attribution preferred by an individual), and recently bereaved family members and carers. We use this grouping because the impacts of MND and housing needs extend beyond the person diagnosed.

We conducted a survey to capture the needs and experiences of those affected by MND regarding adaptations and accessible housing (118 respondents). In addition, we had in-depth individual conversations on the phone, via email, or via text, with those affected by MND (36). We also held a series of separate focus groups (4) for those diagnosed, for family members and carers, and for bereaved family members and carers. These groups and individual conversations allowed us to explore what people felt were the key barriers in current practices, and to develop a set of suggestions around what would have improved their experiences.

MND Scotland's Advocacy Workers also shared their experiences of navigating housing processes. The advocacy team support people living with MND to resolve issues such as applying for housing, care, entitlement to equipment and accessing services from a local authority.

These conversations were accompanied by a literature review and a desk analysis of current practice for allocating accessible housing and adaptations for each of Scotland's local authorities. As not all information is readily accessible, in the summer of 2021 we also sent a series of questions to local authorities around key statistics such as average waiting times, numbers of applications and prioritisation practices. 30 out of 32 local authorities responded<sup>2</sup>.

## Contact us

If you have any questions about this report, or require it in a different accessible format, please get in touch with Dr Gabrielle King at [gabrielle.king@mndscotland.org.uk](mailto:gabrielle.king@mndscotland.org.uk) or 0141 332 3903.

**We recognise that some of the quotes included in the report might be difficult to read about, particularly if you are someone who has been affected by MND. If this is the case, you may prefer to skip to part 3, on page 35, which outlines the recommendations for local and national government that developed from our research.**

If you have been diagnosed with MND and would like support in navigating adaptations and accessible housing, please get in touch with advocacy on [advocacy@mndscotland.org.uk](mailto:advocacy@mndscotland.org.uk), or 0141 332 3903.

# Housing needs and MND

Article 25 of the Universal Declaration of Human Rights states that everyone has the right to adequate housing. Having suitable and safe housing is important to every aspect of life. While people with MND are diverse in their disease presentation and their household circumstances and preferences, they are connected by a need for an immediate response.

Some frequent challenges facing people with MND include being unable to manoeuvre safely in housing with steps and stairs, having insufficient turning space behind doors, or having doorways which are too narrow for wheelchairs and mobility aids. Symptoms such as drop-foot in early presentations of the disease, and more widespread mobility issues as the disease progresses mean that it often becomes impossible for people to use and access bathrooms, particularly if they are upstairs. The consequences of this are significant with regard to dignity and care. Likewise, being able to access and leave houses and flats is critical to safety, welfare and quality of life.

In the context of MND, there is a requirement to act quickly because the average prognosis of the condition from diagnosis is estimated at 18 months (Scottish MND Register 2019). The time element of housing is critical, but it does not fit well with many current practices across Scotland. As a result, some people are left trapped in a single room or unable to leave their home.

Accessible housing and adaptations are necessary to ensure that people can live their lives with support, safety and dignity. Most people diagnosed with MND will require aids and adaptations to their home, such as the fitting of a ramp, hand rails or a wetroom to enable them to continue to live independently. Health and Social care services in Scotland are responsible for providing people with adaptations via Integrated Joint Boards (EHRC 2018). However, what this looks like in practice, and the delivery, is determined by local authority processes.

This means that the kind of support a person receives, and when they receive it, is a postcode lottery. In addition, there is a diversity across tenure types. Despite several calls for tenure-neutral approaches, this is not yet the case in practice (Adaptations Working Group 2012; Scottish Government 2017a; EHRC 2018).

We found across our research that a lack of consistency across tenure types and how adaptations processes worked was not only confusing, but there was often not clear and accessible information about what support was available. For owner occupiers (homeowners) and private rental tenants living in Scotland, financial support for adaptations comes from the Scheme of Assistance (2006). For those living in council-owned properties and housing associations, adaptations are provided free of charge, as outlined on page 7. However, navigating these application processes in order to access support is complex. They often fail to take into account differences in communication needs that face people who cannot speak on the phone, or easily navigate forms.

## THE AVERAGE PROGNOSIS AFTER DIAGNOSIS OF MND IS JUST 18 MONTHS.

Not everyone with MND will live somewhere where it is possible to have adaptations fitted to make their home accessible. In these cases, people require an alternative accessible home. Housing policy is part of a Scottish approach to public policy, giving local authorities powers of delivery (Gibb 2015). This means that each of Scotland's 32 local authorities set their own local assessments of housing needs and processes which they see to be fitting.

Each local authority is required to prepare a Strategic Housing Investment Plan (SHIP), outlining the area's investment priorities for affordable housing. This plan sets out the local authority's responsibility, outcomes and targets, and formalises the grant provision for housing investment decisions. Local authorities are also required to have a Housing Needs Demand Assessment. This document acts as the authority's evidence base when it comes to housing planning, by providing an estimate on how many additional housing units will be required to meet existing and future housing needs in the local area.

Population changes and projections will place additional and significant pressure on the requirements facing local authorities. The National Records of Scotland (2015) predict that between 2014 and 2039, there will be an 85% increase in the number of people in Scotland who are aged over 75. The need for adaptations and accessible housing is therefore ever more important across wider sections of society.

It is widely recognised that better adaptation and accessible housing processes are needed to cope with current and future needs. The Scottish Government has committed to reviewing the Housing for Varying Needs (1998) Standards, which sets out requirements for all public housing to meet barrier free standards, based on principles of inclusion and definitions of accessibility. Several other organisations have illustrated the current challenges around housing for disabled people (EHRC 2018; Horizon Housing 2018; McCall et al 2020). Our findings show that the picture has not changed. For those affected by MND, there are additional challenges, particularly around timing, which require urgent change and attention<sup>3</sup>.

These reports do not paint a complimentary picture of current housing and adaptations processes in Scotland. They highlight widespread issues around the number of accessible homes, inconsistency across tenure types, and the complexities of adaptations to housing. Gibb (2012; 2015) outlines how housing policy and practice is running behind the market in terms of disconnect between what is available, and what is needed. Whilst affordability is a key issue in terms of the number of available homes, this disconnect also refers to accessible housing, where needs are not matching up with the speed, the quantity or the quality of stock available.

These issues are also more geographically widespread – the OECD’s (2021) report ‘A Crisis on the Horizon’ notes that across OECD and EU countries, people with disabilities are struggling to access affordable, accessible housing. Their findings suggest that these struggles are compounded by insufficient attention to the specific design features making housing accessible, and informational barriers.

The specificities of terminal and progressive illnesses make these challenges more apparent because there is no time to wait. This report now builds on our ongoing campaign work that highlights the importance of time in the context of MND. In Parts 1 and 2 next, we set out the current picture and experiences that people affected by MND have with regard to adaptations and then, accessible housing. This is followed in Part 3 by recommendations which were developed with those affected by the disease.

# Part 1: MND and Housing Adaptations

Adaptations are put in place to enable people to live as well, and for as long, as possible in their own homes. They are grouped into 'minor' and 'major' adaptations. Minor adaptations can be installed quickly and are usually equipment-based, such as having handrails fitted. Major adaptations usually involve making structural or other permanent changes to a property (Scottish Government 2009b; Wane 2016). Different local authorities may have different ways of differentiating between major and minor adaptations – most use the Scottish Government's definition, but a handful use cost as a way of determining which category the adaptations are.

Adaptations can be an important way of supporting people to live safely and independently at home, and of reducing pressure on the health service. Bield, Hanover (Scotland) and Trust Housing Associations (2011) commissioned a Social Return on Investment study, finding that on average, adaptations cost £2,800 and each saved the Scottish Health and Care System an average of over £10,000 – a return on investment of around £6 for every £1 spent on adaptations. We suspect that this saving will be even greater 10 years on.

**Most people with MND need adaptations. They help with the nature and progression of the disease. These include:**

- Ramps, in and out of homes, to make stepped entrances accessible
- Grabrails and handrails to manoeuvre around homes safely
- Wetroom bathrooms which have an open shower with floor flush to the rest of the room, enabling access in wheelchairs

**People may also require:**

- Widened doors to accommodate wheelchairs and mobility aids
- Stairlifts to move between floors
- Through floor lifts, which are sometimes preferred to stairlifts as they do not require being able to transfer in and out of a wheelchair.

There is no consistent process across all local authorities, nor across tenure types, in terms of what is involved in applying for and getting these sorts of adaptations. The consequence of this diversity is a postcode lottery – where you live, rather than your needs, determines the care that you receive.

The type of tenure a person has determines the process of adaptations. For homeowners, local authorities are required to provide grant funding through the Scheme of Assistance (2006). The Scheme of Assistance covers adaptations which are deemed necessary by an assessment from a relevant professional (usually an occupational therapist). It means that funding is given for a minimum of 80% of the cost of adaptations (not means tested), and up to 100% of the cost if an applicant receives certain benefits (universal credit, income support, income-based jobseeker's allowance, guarantee credit part of pension credit and income related employment and support allowance).

Across the 30 local authorities who responded to us, an average of 68% of applications were awarded at 80% grant funded, and 29% at 100% grant funded in 2019–2020. Despite the impact of the Covid-19 pandemic, for those local authorities who said they held this information, the average number receiving 80% funding stayed relatively consistent, at 64% in 2020–2021. The average number of applicants receiving 100% also stayed at a similar level, again falling only slightly, to 28% in 2020–2021. This suggests that local authorities were able to maintain consistent funding for adaptations for those who needed it.

Private tenants can receive the same grant support through the Scheme of Assistance, with permission from their landlord. Under Section 20 of the Equality Act (2010), landlords (and other service providers) are required to make reasonable adjustments for disabled people, however there is no specification of what might be deemed as 'reasonable'. What it does outline is that a landlord cannot say no without giving an explanation, but they can set certain clauses like needing to return a property to its original state.

Local authorities have the discretion to decide whether or not to accept an application from a homeowner or private tenant. A person requiring adaptations will usually be assessed by a local authority Occupational Therapist (OT). Some local authorities also use 'Care and Repair' services, which are responsible for overseeing adaptations in some areas (Care and Repair Scotland 2018; Care and Repair Scotland, undated). In East Ayrshire, for example, Care and Repair take over the management of major adaptations, and in Renfrewshire, the OT will liaise with Care and Repair who will then arrange to obtain two quotes from contractors (awarding the grant based on the lowest quote). This can also help to reduce the onus on the individual applicant to get quotes for adaptation work from VAT registered businesses.

Adaptations for those living in council properties and housing associations should be provided without charge – in these cases, a person's need will be assessed, and the local authority (council properties) or housing association/registered social landlord will pay for and organise work that needs to be done. However, this is subject to Stage 3 funding from the Scottish Government (Scottish Government 2011a; Bield Housing & Care 2017). Several of the Housing Associations across Scotland outline on their websites that funding can run out quickly. In these instances, people who apply for adaptations are added to a waiting list until the next year of funding. The consequence of this is that people who may urgently need adaptations in these properties may be required to wait for the following round of funding, or longer if there is already a waiting list.

Our research found that information about applying for grants and who was suitable for them was limited and not easily accessible. Some local authorities were not forthcoming on publicly facing documents and websites that mandatory grant funding (non means tested) is available. One authority for example states that “there may be grants available to help (subject to assessment)”. We found evidence from people affected by MND which emphasised the lack of opaque information – some simply did not know that they could get financial support.

Respondents told us that one consequence of not being aware of their eligibility for support was that they used their own money, loans and savings to fund adaptations:

“ We spent our savings paying for adaptations, thousands and thousands of pounds which I could have saved and left my wife had I known that I qualified for funding earlier ”  
**person with MND**

“ No one told me that I could get support to pay for adaptations ” **person with MND**

“ We hadn’t known we could get a grant until after we’d paid, and then it was too late because the local council would only fund work that hadn’t been started yet. But they never informed us of any funding when we applied and just led us through the process blindly. It felt like we were had on ” **bereaved family member**



One respondent from our research also told us that in order to find out information about a housing adaptations policy, the council informed them that they would be required to put in a freedom of information (FOI) request. This particular instance occurred in the time period where local authorities had an extended timeframe of 60 working days in which to respond to FOI requests due to the Coronavirus pandemic, potentially adding over three months in waiting time for what should be clearly available information.


We would strongly support a requirement for local authorities to set out clear and up to date summaries about the Scheme of Assistance, the stages of adaptations for different tenure types in their local area, and who is responsible for each stage of application. Some local authorities have this information online, but we often found it difficult to locate and more clearly accessible information on websites would help to ensure that people are receiving the support that they are entitled to. A lack of transparency also means that there can be additional delays in getting support at the right time, all of which impact upon health and safety – such as staying out of hospital.

## Waiting times for adaptations

A key issue with current adaptations processes relates to the time-sensitive nature of MND. From the local authorities who responded to our questions, waiting times vary by adaptation type. Handrails and grabrails tend to be classed as urgent, and many local authorities recorded supplying handrails, or arranging with applicants for them to be fitted within 48 hours and 7 days of an application. One local authority however shared that their waiting time was 126 days. This was more closely matched with the findings from our survey which showed that 40% of respondents who needed to have handrails fitted reported that they waited 4–6 months for these.

Ramps are another commonly required adaptation for people with MND, providing a way for people to leave their homes. Of the 30 local authorities who responded to us, there is an average waiting time of 149 days. However, there was a range of 452 days – one local authority said that they had an average waiting time of 23 days, while another local authority had an average waiting time of 475 days. 28% of people affected by MND who responded to our survey waited between 7 months and 1 year for a ramp; 10% waited more than a year.

Entering and leaving homes becomes a challenge which can lead to health and safety issues, such as risks of falling, for the person diagnosed and anyone supporting them. It can also mean that people are simply unable to leave their homes.

 We cannot access the stairs to get into our house” [person with MND](#)



“ We lifted my wife in and out the house ” **bereaved family member**

Not having adaptations fitted in a timely manner also impacts significantly upon the dignity and care with which people are able to live their lives. Adaptations processes can keep people out of hospitals and care homes and enable them to live their lives in the places that they want to. The need for greater dignity is particularly apparent in relation to personal care, and to wetrooms and toilet facilities.

Of the local authorities who responded to us, the average waiting time for wetrooms to be fitted in 2020–2021 was 158 days. As with ramps, waiting times for wetrooms varies across authorities with a range of 175.3 days – one local authority shared an 80.7 day average waiting time, while another recorded an average of 256 days. However, for the people affected by MND who responded to our survey, 29% said that they had waited between 7 months and a year. A further 11% had waited more than a year for a wetroom.

Several local authorities noted that this length of time was due to Covid-19 restrictions and associated delays. However, evidence from our research, and from our Advocacy service, suggests that challenges with wetroom fitting also preceded the Coronavirus pandemic. Several people recounted stories of being unable to access bathrooms and relying upon commode chairs in kitchens and living rooms and make-shift washing facilities.

“ They needed to do the bathroom but I didn’t have enough time. For about a month the carers came in and gave me a clean with a wet towel and bucket sitting on the commode in the living room ” **person with MND**

“ I have not had a bath or shower since late 2020 ” **person with MND**

While some respondents eventually got wetrooms fitted, either through waiting or through paying for them using savings, for some this continued to take too long, and people reported being left living without dignity.

“ My husband lived in the living room with no shower facilities at all. We were washing him out on the decking with buckets of water. No dignity in that whatsoever ” **bereaved family member**

This waiting time and a lack of forward planning resulted in substantial emotional impacts and several respondents reported feeling that delays were personal and disheartening:

“ They are delaying everything they can. I think they are holding out until I pass away so that they don’t need to do anything ” **person with MND**

## THERE IS NO KNOWN CURE OR EFFECTIVE TREATMENT FOR MND.

These waiting times are particularly concerning considering that the Scottish Government's (2009a)<sup>4</sup> 'Guidance on the provision of equipment and adaptations' states that "once an individual is deemed to have an eligible need, failing to meet that need within a timescale cannot be excused by a lack of resources" (Wane 2016, p.12). It also states that "applications should not be put in a queue or on a waiting list" (ibid). Our findings suggest that despite these intentions, there are failures in processes across the board to meet these statements.

“What is unique with MND is with respect to time and to how quickly people can go down and how you need these things now. So the local authorities need to have something in place that recognises the need to do things quickly. By the time they've had 3 or 4 council meetings to get things passed through, for some people that we're talking about, it's too late”  
**bereaved family member**

Some people with MND, who were aware of the Scheme of Assistance, still chose to use savings to get adaptations done quickly. They felt this was important to gain a sense of control over what could happen and when. For others, bearing this financial burden was not possible.

This means that people reported getting into debt, withdrawing pensions early to cover the costs, or using savings that they had wanted to leave for their family. For others, it also meant relying upon temporary measures that were not always safe or increased the risk of having a fall.

“Instead of making my quality of life better it has made it worse over the last year. I have ended up in A&E with a split head because I fell down the steps at my front door due to the ramp not being started back in December” **person with MND**

“My brother-in-law fitted a step lift as an emergency measure because I could not walk and could not wait. It works for us for now but it's homemade” **person with MND**

Across local authorities there were no formal fast-track procedures in place to assist with waiting times for people living with terminal illnesses. 30% of the local authorities who responded to us outlined how the power to prioritise applications lay with OT's who were able to assess and categorise the need as urgent. While there is not a formal process in place, a further 23% of local authorities who responded say that they assess applicants with a terminal or progressive illness first.

“ It is not easy for the terminally ill to get a fast tracked decision ” **family member**

The issues around time were not just in terms of waiting. Having to navigate complex systems, and what many respondents described as 'fighting' for services, took time away from other things that people wanted to do. Instead, people had to spend time trying to get support and adaptations applied for and fitted.

“ Applying and fighting to get the wetroom took up so much time that we should have spent doing nice things together ” **bereaved family member**

## Reactive adaptations processes

The Scottish Government's independent Adaptations Working Group (2012) previously highlighted that the majority of adaptations are focused on current problems, which they deemed an inappropriate approach for conditions which have a foreseeable progression. Our findings suggest that this move away from being reactive to being proactive has still not happened.

In the case of MND, recognising that a wetroom, ramp or handrails/grabrails would be needed should enable forward planning to ensure that these adaptations are fitted by, or at the time, people start to need them. This ensures that people are not then left waiting unnecessarily for adaptations which it was always clear that they would need. There was evidence of good practice in some local authorities, where respondents described OT's and specialist nurses getting adaptations in place at, or before, the point of needing them.

“ What helped most was having things there for when we needed them ” **family member**

However, this was not common practice across local authorities. The consequence of adaptations processes being reactive means that in some places, people are unable to join the waiting list until their point of need, or until they tick prescriptive boxes such as the inability to walk being required in order to qualify for a ramp.

“ We got in touch to apply for a ramp and we were asked by the local council if he could still walk. He said yes, and so they said, we'll not look into it until you can't walk. But then he can't get out the house. He asked how long the waiting list was and it was 9 months. So, they wanted us to wait 9 months from the point that he couldn't get out ” **carer and family member**

“ We have also widened interior doors and en-suite but again the council were not interested as we adapted straight after diagnosis and this was 'too soon'. However, this was peace of mind for MND sufferer and the transition has been so much better for them. Adaptations were there when needed them ” **person with MND**

The consequence of not being able to join the waiting list for a ramp until a person could no longer walk, and the length of the waiting list, meant that our research also sadly showed evidence of adaptations not being fitted in time.

“ My husband passed away nine and a half months from diagnosis and the ramp wasn't even begun ” **bereaved family member**

It is disheartening that our research continues to show that many local authorities are not recognising the needs of rapidly progressive conditions in their adaptations processes. Future needs in the context of these conditions must be anticipated to avoid people being admitted to hospital, becoming trapped, having a poorer quality of life, and sometimes dying before adaptations are fitted.

## Understanding and awareness of MND by local authorities

The Adaptations Working Group's 'Adapting for Change' report (2012) also identified several changes needed to adaptations processes, including a move toward more person-centred and enabling approaches. Our research did find some instances where adaptations processes were forward thinking and accommodating of needs, usually where one key worker facilitates change and understands MND. In the examples that respondents shared with us, this person is typically a physiotherapist, or an OT, and is equipped to push for, and prioritise adaptations – often before they are needed.

“The biggest help to us was having an excellent OT who could come and look at the house and tell us what we'd need based on the progression of the disease. She sorted it all”  
carer and family member

There were cases where a lack of an excellent OT had significant impacts upon the application for and delivery of services, emphasising a need for increased understanding, trained and supported front line council workers who can deal with MND appropriately. Our findings here support the EHRC's recommendation that “where there are good links with occupational therapists and other health and social care professionals, the outcomes for disabled people are more positive” (2018, p.24).

However, there were many more instances across the research where the local authority staff did not demonstrate an awareness of MND and its impact. People missed out on opportunities for help when they received insufficient information about eligibility for support. A lack of awareness around the disease also meant that people had to spend energy and time explaining their situation to each worker they encountered. Our research suggests that a person-centred approach is still not happening for many people.

“The system is too generic. Even when explaining that time is something MND does not allow this is not taken into account and precious time that we should have been making memories and enjoying was lost in fighting battles to get help and support to just allow basic human needs to be met” bereaved family member

“It requires a great deal of resilience and strength, and the council workers who we dealt with seemed to have no understanding of our situation” family member

“We have been made to feel as if my life was not really worth the bother, that the house we live in means nothing and that our right to a decent quality of life was not important because the local authority didn't listen to us and didn't care” person with MND

## Complex processes

For homeowners and those in private rented accommodation, it is typically the responsibility of the household to apply for, and negotiate, adaptations processes. Our findings showed that often these are multi-part, complicated and more can be done to ensure that each stage is enabling and empowering.

Some adaptations require planning permissions if they will develop the property in any way. Often this refers to extending or altering a house or flat but planning permission can also be required for adaptations such as handrails and grabrails if it is a listed property, or occasionally, for external ramps. While many parts of planning permission processes such as opportunities for comments from neighbours and other stakeholders are necessary, this adds further waiting time. We found evidence that the ways in which councils had described work to parties with potential interest did not match up with what was actually being done. There were also cases of contractors and architects not understanding the speed of the disease and making similar errors.

“ They [council] had made a mistake meaning that [an interested conservation party] came back and questioned the application. It was fine in the end but it added on further weeks and weeks while they looked into it which we just didn't have ” **family member**

“ They [council] were saying we needed planning permission for this ramp but we actually didn't because it wasn't as long, so it went on and on and on ” **bereaved family member**

Ramps sometimes require planning permission, but this is not always necessary. Our findings showed that what is more commonly an issue with ramps are the strict regulations around length and angle. These strict regulations are not always in keeping with the needs of some people affected by MND. As well as adding to waiting times, the prescriptive nature of current adaptations processes does not empower people to share their needs and wants.

“ The City council refused to fit a ramp as the ramp dimensions would overlap a communal path by a few millimetres. The most annoying part is they made this decision after looking online at our property. I had a few ideas to offer by taking away part of my garden if they could come and look and discuss but they said no. They were okay with me being imprisoned in my own home ” **person with MND**

“ Access to our property is by two front doorsteps. The council stipulated wheelchair access to the property would be by a 30-foot ramp ” **family member**

Aside from planning permission, many local authorities require homeowners and private renting applicants to put work for adaptations out to tender, typically to 2 or 3 VAT registered companies, or from a list of contractors used by that local authority. However, there is little consistency in this across the country. One authority states that for work that is projected to cost up to the value of £1500, one quote is required (though two may be needed if the quote is deemed by the local authority as being significantly higher than previous work), three quotes are required for work costing between £1500 and £3000, and for work over £3,000, applicants are required to refer to the local authorities 'tendering procedures'. Other local authorities categorise anything under £1500 as a minor adaptation (requiring no quotes), and then 2–3 quotes for costs between £1500 and £20,000.

Needing to source multiple quotes with a terminal and quickly progressive disease extends the waiting time. It also requires the additional navigation of processes that are difficult for those with conditions such as MND that cause communication challenges and symptoms like fatigue.

“ The length of the forms were quite overwhelming. If someone was on their own or didn't have the energy, I've no idea how you could do this ” **family member**

“ If my wife had been by herself, I don't think she'd physically be able to complete all the forms. And second, even if she struggled through, I think the number of things the council ask for is so overwhelming when you're already coming to terms with this devastating diagnosis ” **family member**

In some instances, the Covid-19 pandemic alleviated challenges regarding putting work out to tender because several local authorities temporarily changed their processes to request only one quote before funding work. Respondents who experienced this told us that this had made the process easier for them as they did not need to spend as much time getting competitive quotes and could start adaptation work faster.

This indicates a need for a simplified tender process of fewer quotes which places less onus on the individual and reduces waiting times. A simplified process does not, however, mean there should be a greater financial cost. One local authority currently works with a single contractor which holds a monopoly on providing adaptations in this area. The local authority or contractor manages the process from start to finish. However, excessive amounts for the work are charged:


“ In this local authority area, we've had cases where people are quoted as much as £40,000 for a wetroom ” **MND Scotland advocacy worker**

Local authorities restricting the number of contractors to a single, or a small list of approved contractors, and charging more for streamlined services reduces the impetus on that company or selection of companies to provide competitive pricing. Several respondents in our research identified instances where they had found cheaper options, including adaptations that, for the whole item, cost less than they would be asked to make through their 20% contribution to the Scheme of Assistance. In addition, people told us that they had established relationships with registered tradespeople who had done work previously, who were familiar with the house, and who they trusted to do work quickly and carefully. However, as these tradespeople were not on the lists of contractors held by local authorities, they were not able to get the funding to do this work. Instead, they had to use significantly more expensive companies that sometimes lacked an understanding of MND and the individual's preferences.

While our findings show the value of only needing one quote, there also needs to be an evaluation in local authorities of current contractors, and greater freedom of choice around where Scheme of Assistance funding can be spent. This not only offers people using the service more choice, it also enables opportunities for better cost-effectiveness and efficiency of service.

Alongside costing practices, the process through which information is gathered for application, tender and planning permission needs to be reviewed. Many councils and associated adaptations processes rely on phone calls or post rather than email and text. As MND often affects dexterity and speech, people may not be able to complete forms or speak on the phone, or require someone else to do so on their behalf.

Our research provided strong evidence that prescribed methods of communication do not fit well with the needs of people with MND.

 **Because of MND, I am unable to talk normally or on the phone. I rely on using emails, messenger or messages. My voice is just garbled on the phone and I have to keep repeating myself. Despite this, sometimes local authorities still try to do things on the phone”**  
**person with MND**

Our evidence once again strongly supports the findings of the Adaptations Working Group (2012) which asked for more accessible information, and processes which are enabling. These issues continue to be overlooked to the detriment of those affected by MND and other disabled people.



## Independence and internal adaptations

The United Nations Human Rights Commission (2006) sets out that disabled people have a right to autonomy and independence. This is relevant to adaptations, not only in being able to access them, but also in terms of having a choice about what adaptations a person wanted to have done.

There was evidence in our research that showed that councils were not fitting adaptations inside properties if the property itself was deemed as inaccessible (for instance, not suitable for a ramp). Instead, people are added to accessible housing registers. However, the current waiting times, and the reality that people affected by MND may not be rehoused within good time, means that homes are not being made accessible inside either. This results in a further restriction on lives, when being able to move around one's home would be an improvement on current situations.

“ I'm in an upper floor tenement flat. Because it's classed as inaccessible, the authority won't do anything to the inside of the property ” **person with MND**

“ It wasn't great that we couldn't get out, but life would have been better for us if we'd just been able to get him round the house into different rooms because you could see how frustrated he was stuck in one room ” **bereaved carer and family member**

“ What would make a difference to me is moving round my own home even if I can't ever actually leave the house again ” **person with MND**



## A PERSON'S LIFETIME RISK OF DEVELOPING MND IS 1 IN 300.

### Other concerns raised

#### 1. The overwhelming nature of adaptations

In cases where adaptations are fitted quickly, they can still be overwhelming and require humane approaches. Even for those for whom adaptations were installed in timely ways, having them fitted represented a significant change to life – some people had only just been diagnosed, while others had shielded often without visitors for the past two years due to the Covid-19 pandemic. Having people come in to fit adaptations was daunting. Similarly, it caused disruption and help was needed afterwards to clean up from fitting the adaptations.

“ They left so much mess and debris in the house that I had to get someone in to help to clean it up and redecorate after ” **person with MND**

MND means that a person has less control over what they are able to do, compared with what they could do prior to diagnosis. This can be particularly difficult to cope with. Several respondents commented on the importance of choice – whether in choosing what kind of adaptations they needed, in not wanting the house to resemble a hospital, and in not having to wait. This requires recognising that the places that adaptations are being fitted are first and foremost, people's homes. There is resistance to homes looking like hospitals, and for adaptations to be a permanent reminder of the disease. Several people shared a desire for adaptations to work *with* applicants to fit these in a way that listens to their needs.

“ We don't want the house to look like a hospital ” **person with MND**

“ Adaptations are a constant reminder of our situation and so I need them to work for us, and not take over the place when something else would work just as well ” **family member**

“ When they fitted out wetroom, they took off all the bathroom tiles which we'd recently decorated and just left the debris all over the place. There was no care towards the fact that this was our house ” **family member**

“ Other people live here too– it's a family house not a hospital facility ” **person with MND**

## 2. Need for better communication between health service and the council

Having more connected services, which had an understanding of MND and the speed of progression, helped. In some cases, a specialist MND nurse, OT, physiotherapist or the MND Scotland Advocacy Team communicated directly with local authorities to reduce the onus on an individual applicant.

The need for connection and communication also extended to those within and outside of the council (i.e. contractors) who were delivering adaptations work, particularly when there were multiple adaptations happening at the same time. It was not always the case that adaptations were fitted in joined up ways, and it meant that many people were doing things at the same time:

“one person was fitting the shower and sink and toilet. They did not relate to the tilers or flooring fitters so we didn't know when they were coming in or in what order. We were outside the conversation of what was going to happen ” **person with MND**



## Part 2: MND and accessible housing

The majority of people affected by MND will require adaptations to their homes. However, some people affected by MND will require an alternative accessible home instead. This is often because a home is deemed unsuitable for a ramp or alternative adaptation to be fitted for access, because the flat is not on the ground floor, or because the property's internal structure cannot accommodate adaptations. In these instances, people are deemed as requiring an alternative accessible home. Usually this is social housing – either because the person is already living in social housing, or because of other housing issues, such as the difficulties of getting a mortgage with a terminal illness. Across our research, people with MND experienced a wide range of problems with securing an accessible home, due to a scarcity of housing stock, waiting times, and different local authority understandings around accessibility.

It is well understood that Scotland faces a scarcity of accessible housing across all tenure types (EHRC 2018; Horizon Housing 2018). The current wheelchair accessible housing stock across local authorities is low. Of the 30 local authorities who responded to our questions, the wheelchair accessible housing stock varied from 10.3% to 0.28%.

In practice these statistics are unlikely to provide an accurate picture – some local authorities did not hold information from registered social landlords and several identified issues with recording of information. One local authority did not have a consistent way of reporting on housing stock. One noted that what they categorise as accessible and wheelchair accessible may not meet the full definition used in their policies. Another could not provide information on accessible and wheelchair accessible properties because their current housing information system does not identify features in this way.

Each part of the assessment, application and allocation processes for accessible housing is impeded by a scarcity of suitable properties.

**“** It's not for the lack of will on the part of housing officers. Everyone wants to do their job, but they're fighting in a completely under-resourced system. Housing officers want to give a house to our clients, but they just don't have that house. **”** [MND Scotland advocacy worker](#)

## Allocating accessible homes

The Housing (Scotland) 2014 Act specifies categories of 'reasonable preference' as applying to people who are homeless or threatened with homelessness; people who are living in unsatisfactory housing conditions; existing tenants who are under-occupying their current property. In most instances, people with MND fall under the second category. Each local authority has their own process of allocating housing, and for assessing applications<sup>5</sup>.

There are two primary methods through which landlords and local authorities allocate properties: needs based approaches, or choice based approaches. Needs based approaches to allocating accessible housing is the main method used by local authorities in Scotland. Under this system, applicants are awarded a certain number of points – in the context of MND, these typically are 'medical points'. Some local authorities also have social care points. Applicants who are eligible for both may have their points added together in some cases, the need which is awarded the highest number of points will be recorded for them – whether that is medical points, or social care. The higher the number of points, the greater the priority a person has for a property.

Anderson et al (2019) set out that points allocations systems may work through a points only; group plus points (where applicants are awarded points and placed in different queues); date order only (where applicants are in a single queue based on date of application); and group plus date (where applicants are placed in groups in order of the date). When a suitable property becomes available, the applicant with the highest number of points, or who are positioned first in the queue, will be allocated that home.


The number of points within allocations systems vary across local authorities. For example, Clackmannanshire's 'severe health/care' award is 12 points, whereas Argyll and Bute have a system of giving 200 points to 'urgent health issues'. In each local area these allocated points (whether 12 or 200) would award a person the same top priority, however it can make it complicated for potential applicants to understand points systems in different areas. There are also circumstances in some local authorities where priority passes are awarded (for example, The Highlands Council and Glasgow City). Gold priority (urgent) points are awarded to people to prevent long term hospital and care home admissions, and gold priority points, the level below this, may be awarded to people with MND.

In many of the cases which MND Scotland's advocacy workers deal with, this means that despite the prognosis and urgency of the condition, people with MND are not top priority for medical rehousing. However, having an unsafe home increases the risk that a person with MND is admitted to hospital following a fall or similar.

Other councils use choice based letting systems. Under choice based systems, applicants fill in a registration form to join the housing register. Applicants are usually awarded a priority pass. When a property becomes available, applicants will make a bid based upon their priority pass or on how much a property meets their needs. An offer should then be made to the applicant who has the highest level of priority. While choice based allocations are justified by local authorities on the grounds of enabling people to choose where they live, it requires a person to actively bid for available housing (typically online), rather than the local authority offering them the property (Anderson et al 2019; Shelter 2005). Local authorities have a duty to monitor choice based letting systems: this should include monitoring under the Equality Act (2010), that support is available, and the outcomes of allocations.

The Scottish Government's Allocations policy Review Advisory Group (2009b) found that disabled people had difficulty accessing information about the different allocation systems. They also concluded that there was a limited amount of monitoring of equality information (EHRC 2018; Scottish Government 2009b).

Bidding systems are ill-equipped for people with MND and exacerbate problems caused by a lack of accessible properties.

 **For every house that's bid on, there can be up to 700 people bidding on that property ”**  
**MND Scotland advocacy worker**

Not only does this make the possibility of getting a home less likely, it is also demotivating and means either bidding on properties that may not meet all of a person's needs, or spending time bidding with no positive outcome. For people diagnosed with MND, this is particularly concerning given the issues with dexterity and fatigue. It also takes up time at what is already an immensely difficult point in a person's life.

Placing the onus on the individual rather than on the local authority to review their priority applications means that there is a risk that people affected by urgent health conditions miss out on properties which they would otherwise be the first priority for. The EHRC (2018) also found that medical assessments for choice based lettings are complex – the bar is set so high that people are not always given reasonable preference.

Some local authorities also use direct matching in certain circumstances. This means that applications submitted by those needing accessible housing are directly matched with properties that the local authority or social landlord assesses as meeting certain criterion. If there is a person who urgently needs a property with these features, then they will be awarded it. Direct allocations work directly with, or are informed by, health and social care professionals.

Horizon Housing's 'Match Me' report by Anderson et al (2019, p.4) identified a need for more effective matching and connectedness through using OTs' and Housing Officers' knowledge of the needs of applicants and of property types "to generate creative responses and appropriate housing offers". Through a series of pilots with local authorities, they outlined several key features and examples of good practice, including the value of having a local Disabled Persons Housing Service, a key person to provide tailored advice for disabled applicants, and a shift towards a social model of Housing Needs Assessment. What they reported as working well within one of their pilots was having a needs database, which held the needs of applicants from the Housing Needs Assessment form. When an adapted property became available, the local authority were then able to filter applicants to only show those who have a need for this kind of property. In addition, applicants' details of needs are also shared with strategy colleagues when new build developments are planned.

Similar to this practice of grouping, direct matching and using local knowledge, MND Scotland's advocacy team reflected that what worked well in their current practice was working closely with housing referral teams to enable direct matching. One local authority housing referral team, for example, have established an exceptional circumstances group for applicants who do not have time to wait. When the referral team see a property come up for letting, they look first at this group and check if there are suitable applicants and if so, are able to allocate them this property.

## ALMOST 200 PEOPLE ARE DIAGNOSED EACH YEAR WITH MND.

“ Having a system across local authorities where people who cannot wait are placed in exceptional circumstances grouping, and this group is checked first when relevant properties come up would help a lot of people ” **MND Scotland advocacy worker**

Directly matching people with properties through formally establishing this kind of exceptional circumstance group for those who have received a diagnosis of a terminal illness, would help to ensure that processes work most effectively for those who do not have time to wait. Whatever letting system a local authority uses must be sensitive to the disease prognosis and associated needs.

### A lack of definition

A lack of a consistent definition about what might be classed as an accessible home enhances several of the issues with allocations processes. A lack of definition particularly means that local authorities and landlords may not have accurate information about the liveable accessibility of housing stock.

The Scottish Government's (2019a) 'More Homes Division Guidance Note' identifies that "there is currently no universally agreed housing standard to define housing for wheelchair users to live in. Often terms such as wheelchair accessibility or wheelchair liveability are used to refer to properties that are suitable for wheelchair users to live in" (p.2). Accessible housing by comparison refers to housing that "can be accessed easily from the outside and supports good freedom and safety of movement inside" (Scottish Government 2019b, p.42). Our research found similar inconsistencies in how local authorities defined accessible.

The consequence of no common definition means that even when people are allocated or seeking wheelchair accessible or accessible housing, they may not be getting the homes that they need.



“ Even though it’s an accessible home, I still have three steps at the back door. On the first day of arrival, I fell down the steps and smashed into the fencing ” **person with MND**

“ We see properties advertised or being offered as accessible, but they might just have a wetroom. In reality, the doors aren’t wide enough for a wheelchair, or there are a couple of steps to get in. The person with MND might be penalised for not bidding on a property which is listed as accessible, when it doesn’t actually meet their needs ”

**MND Scotland advocacy worker**

Of the local authorities who responded to us, 77% have a definition for accessible housing. The majority of these definitions of accessible come from a variety of housing documentation. 13% of these local authorities referred to the Scottish Housing Register which uses the terms ‘sheltered housing’, ‘very sheltered housing’ and ‘sheltered wheelchair housing’ rather than accessible. Wheelchair housing is described as “dwellings for people confined to wheelchairs. It is built or adapted to give extra floor area, whole house heating, and a special bathroom, kitchen and other features”. A further 6% referred to the Housing Need and Demand Assessment, using terms ‘accessible and adapted’, ‘wheelchair’ and ‘supported’. These include general aspects such as a design that is step-free and that has space for a wheelchair to circulate and access all rooms. 30% referred to Housing for Varying Needs, which shares the previous definition. 3% used the Scottish Government Guidance on Local Housing Strategy and 3% use the resource ‘Homes Fit for the 21st Century’. The remainder of definitions are established by the individual local authority.

23% of the local authorities who responded did not have any agreed upon and council wide definition of accessible or stated that they did not hold this information as they were a stock transfer authority. Without an agreed upon definition, it is difficult to ensure that the same standards are in place across tenure types, in new build requirements, and in matching people to the right houses. One local authority for instance responded with a series of features for accessible homes which includes “access to front door level or with a maximum for 4 steps”. Other local authorities reported seeking to make their homes more suitable. Glasgow City Council (2017) produced a document outlining a specific set of key considerations that need to be considered in designing what they term ‘adaptable housing’. This goes beyond turning circles to ensure that it also considers parking, approaching the home, entering and leaving the dwelling, moving around inside, using living space, using kitchen, using bathroom, using bedrooms, windows and internal doors, technology, power and communication and external facilities.

The current variation means that although a property might be deemed accessible, it is not clear as to whether it will suit needs, or if additional adaptations will be later required. This is particularly the case in the context of MND, as its progression means that being allocated a house based on present needs will not necessarily be suitable in the future. It also leads to issues and potential miscalculations when it comes to defining housing stock. One local authority stated that 100% of their properties are potentially accessible.

Without a commonly agreed definition of accessible and the requirements to deem it such, there is a risk that these statistics are misleading, particularly when the need for accessible housing is increasing (EHRC 2018). Our research highlighted several instances where what was deemed as 'accessible' housing failed to meet needs.

“ This supposedly accessible new build wasn't actually wide enough for the wheelchair. You could get through the front door, but you couldn't get through the cloakroom or get into the toilet ” **carer and family member**

“ They had put a bath into the accessible new build and there was a lip to get up into the bathroom ” **person with MND**

“ The local council doesn't understand what is needed for people with MND. Just because there's a ramp outside doesn't mean that it's fit for people with MND ” **carer and family member**

The impact of this is more than an inconvenience for people affected by MND. It causes risks to health and safety, meaning that someone might end up being admitted to hospital or a care facility, and become unable to leave because they do not have a suitable home to be discharged to. An accessible home which does not meet requirements causes additional waiting which is time that people with MND do not have.

“ It became very apparent quickly that even though we were in a house that was [deemed] accessible, the adaptations within it were not suitable for him. So we started the long process of trying to get a suitable toilet. It was thousands of pounds and by the time it arrived his illness had progressed and he was never able to use it ” **bereaved family member**

The consequences of this are that people are left spending time and energy fighting for homes that meet their accessibility needs and requirements. For many bereaved family members and carers, this meant there was less time spent with the person diagnosed. Instead, navigating forms and arguing for needs took up time that they did not have and took time away from doing things together and making memories.

Even after a person is allocated to an alternative accessible home, respondents shared that they still required additional adaptations and equipment in order to make them liveable and suitable for need. This means that even after an accessible home has been sought and awarded, people are still waiting for adaptations to be fitted and are required to negotiate the grant, tender and approval processes (depending upon tenure type) for adaptations, set out in Part 1.

A lack of understanding around what is needed from an accessible home means that people are continuing to wait when, for many, there is not enough time to do so.

## Waiting times for accessible housing

Waiting lists are particularly devastating for those with MND and similar terminal conditions as the nature of their disease means they do not have time to wait. Of the local authorities who responded to us, some have processes in place to support people with terminal illnesses. East Lothian for instance have a formal practice of prioritising housing applications for those with terminal illnesses. They have a distinct category of prioritisation for 'life limiting illness' which concerns applicants with a life-limiting condition who have been issued with a DS1500 form. This Department for Work and Pensions (DWP) form is currently used to fast track terminally ill people for certain benefits, if their death can be reasonably expected within 6 months. In Scotland, the DS1500 will soon be replaced with a (Social Security Scotland) BASRiS form. Whether or not someone is assessed as being terminally ill will be based on clinical judgement rather than life expectancy. It is assumed East Lothian will start to use this form once it comes into use<sup>6</sup>.

Perth and Kinross and Angus also stated that they take terminal illnesses into account, but that this is dealt with on a case-by-case basis. Angus for instance have an 'exceptional circumstances' section within their allocations policy which recognises that their allocations policy will not cover all circumstances or situations, and that in such instances, the service manager, director or housing manager, or equivalent can use discretion when there is an urgent need for rehousing.



Across other local authorities, there was a widespread lack of formal processes prioritising applicants with terminal illnesses. In several cases this is because many local authorities determine housing needs by a points based system. Medical conditions, including terminal illnesses, are assessed under Housing Needs Assessments, but there is not separate or formal guidance regarding terminal illness. East Renfrewshire, Midlothian and South Ayrshire, for instance, stated that applicants with terminal illnesses will be awarded highest priority medical points or passes within their current allocations systems.

In other local authorities, the responsibility for prioritisation is passed to occupational therapists who may prioritise terminal and progressive conditions through pathways. One local authority stated that they do not differentiate between debilitating and terminal illnesses. The complexity of these different ways of allocating and determining needs, and a scarcity of formal practices, means that people affected by MND risk not being dealt with quickly enough and face a lack of understanding of MND and its impacts.

An insufficient number of accessible properties, and a lack of prioritisation processes means that the current waiting times for accessible housing are extensive. The EHRC (2018) notes that someone has been on a waiting list for 18 years. With an average prognosis of 18 months from diagnosis, this is inconceivable in the context of MND.

However, several people who took part in our research felt that their short prognosis was not valued compassionately by their local authority:

“ It feels like they [the local council] are just waiting for you to die ” **person with MND**

“ There is no value given to my life. It feels like it doesn't matter if I spend the last year of my life stuck in one room, unable to go out ” **person with MND**

Less than half of the local authorities shared their average waiting times for a disabled person being allocated or assessed. Local authorities who were unable provide this information said that they did not hold it as a stock transfer authority, could not easily extract it from their databases, or did not record whether an applicant was disabled. For those that did share their waiting times, these varied from 272 days (7 months) to 1511 days (4.1 years) with an average across these local authorities of 635 days. 75% of our respondents who had required accessible housing waited longer than this minimum waiting time (7 months) recorded by local authorities.

Due to the nature of MND, this waiting time translated into restricting life that was already significantly shortened. There was strong evidence across all parts of our research of people becoming trapped in one room or within their flat or house.

“ Being trapped in a flat was mentally challenging and the thought of not having much time left and not being able to do the things together that we planned to have taken its toll. To go out and make memories would have meant everything ” **bereaved family member**

“ The family had to lift him in and out of the house and upstairs because the bedroom and bathroom are upstairs ” **bereaved family member**

“ I struggle knowing that we could not give him the last six months of his life filled with family and adventure that he planned and deserved ” **bereaved family member**

The impacts of this were more than an inconvenience – waiting restricted people’s lives in every way. This impact was not only physical, but it irrevocably altered people’s quality of life. It limited how people were able to choose to spend their remaining time. This meant not being able to do things that they wanted to, and making memories with loved ones. This is carried heavily by family members too, beyond the duration of the disease.

For some, the lengthy waiting times meant taking other action at an already stressful time. Several respondents moved to more accessible ground floor flats when they were diagnosed as they recognised that they would need to live somewhere else and delays and waiting times for housing was incompatible with their prognosis. This had a significant financial cost, and adds additional complexities because it can be difficult to get a new mortgage following the diagnosis of a terminal illness.

For others without this financial resource or mortgage, it can mean moving in with families, into nursing care and into spaces that are unsuitable and unsafe. In one instance, one person was left with no option but to move into an unheated caravan over winter while waiting on the accessible housing list.

## Target setting

Local authorities recognise the need for more accessible housing. In response to this, 70% of the local authorities that responded to us stated that they have set targets for the percentage of housing that is to be wheelchair accessible or accessible. However, what this target looks like varies significantly.

Some local authorities organise this by number of homes built. For instance, the Scottish Borders sets an annual target of 20 wheelchair accessible units for new build estates. West Lothian have a similar annual target of 30 wheelchair accessible homes. Others base it upon a percentage of total stock built. Building on the EHRC's (2018) calls for 10% accessible housing targets, 8 local authorities outlined having set a target of 10%. For Glasgow City Council this applies to all tenure and property types, but in other local authorities this target varies – for some it refers only to new affordable homes, to new build council homes, or to private housing.

13% of local authorities who responded to us stated that they were in conversations about extending or applying targets to private housing too. This is necessary in order to ensure that accessible housing can meet growing needs. It offers people more choice in where they live and is fundamental to recognising that young people and young families may be affected by disabilities and health conditions (including MND), as well as being important for future accommodations for an ageing population.

## IN SCOTLAND AT ANY ONE TIME, AROUND 400 PEOPLE ARE LIVING WITH MND.

Within their most recent Housing Need and Demand Assessment (HNDA) in 2017, Moray identified that as a local authority area, they would need approximately 179 units of extra care housing between 2018 and 2033. Others have similarly set targets based upon predicted or current local needs. Highland Council aims for 100% of ground floor properties to be wheelchair accessible, and 10% of these to be wheelchair liveable. South Ayrshire Council stated that they are currently developing their HNDA for 2021–2026 and as part of this process intend to provide an estimate of current unmet need among wheelchair users and an estimate of projected need to inform the setting of a target for wheelchair accessible housing across tenures. This projected need must identify features of accessible housing and also account for changing and progressive conditions that might not currently meet the need for wheelchair accessible housing, but which will in the future.

Minimum percentage targets for accessible housing need to be enshrined into legislation to ensure that local authorities are consistent in their practices, and that current and future needs are being met for those who desperately need somewhere safe and accessible to live. We support calls made by the EHRC (2018) for a 10% minimum target, and for local authorities to individually assess whether a greater percentage commitment is needed in accordance with their HNDA.

“ I spoke to multiple councillors to try and push for ground floor accommodation with a wetroom shower, but I was informed by a councillor that at the last meeting, it was voted against raising wheelchair accommodation to 10% and so I believe for future developments in this local authority it’s only 4% of properties, despite the ageing population in this council district ” **bereaved family member**

“ More homes built as accessible from the start. I would like to see big developers forced to build disability adapted homes that is not just ‘accessible’ but useable ” **person with MND**

An additional challenge with accessible housing due to the limited stock is that there are instances where the person with accessibility needs is no longer living in the accessible home. Some local authorities have practices in place for supporting family members to move out of the property to enable it to open up for others on the waiting list for an accessible home. This involves awarding them priority points to get a property of similar sizing, but it is difficult to find information on these policies.

## Accessible housing and connections to care

**Accessible housing is not separate from other provisions of support and care. In the context of MND and other disabilities and progressive conditions, where people live also determines their care packages, and often the communities and informal care opportunities.**

A number of respondents discussed feeling like they had to accept offers of accessible housing up to hundreds of miles away from where they were living. This removed them from the communities that they had been part of, and who were often instrumental in providing support and care in dealing with a challenging disease and diagnosis.

“ I had to move back for family support. I need my family’s help to get to appointments to do shopping, cooking and personal care ” **person with MND**

For others moving would have altered their care packages.

“ Losing our care package was the biggest thing that put us off moving ” **person with MND**

“ We felt like we couldn’t accept the offer of accessible housing because it would have meant moving to a different area and we’d have lost our enhanced [care] package ” **family member**

For several people this meant that they did not feel able to accept their offer of accessible housing because it would have meant losing their care package which currently suited their needs well, remaining in an inaccessible home. Or it meant feeling like they had to accept their housing offer and leaving their care packages and the relationships that they had developed, for an area that did not meet their needs.

This then had knock on impacts on the sort of care they were able to get in a new location, as well as needing to renegotiate processes of re-applying for care based on their new postcode rather than their pre-established needs. East Renfrewshire and Angus, for example, state that they will provide housing for people currently outwith areas who need to move to these locations for reasons such as to receive care from family.

“ We often deal with situations where people have built up good relationships with care workers and have care packages in place that work for them, but then they are offered properties miles away. This is often to areas which aren’t serviced by the same care companies, or where people have to reapply for different care packages ”  
**MND Scotland advocacy worker**

The proposals made in the Scottish Government’s National Care Service (2021b) consultation have committed to introduce the portability of care, meaning that the amount of care and support that a person receives will not be determined by their postcode. Our findings suggest that this needs to happen now for people living with terminal and progressive conditions like MND.



# Part 3: Conclusion and Recommendations

MND is a rapidly progressing, degenerative, terminal illness. Average life expectancy is just 18 months from diagnosis. For people with MND, having an accessible home is central to being able to live safely and with dignity. However, this report reveals widespread practice across housing in Scotland which fails to meet basic needs and take account of the speed at which MND progresses. Tragically, this means that some of those who took part in our research reported loved ones with MND dying before they had an accessible home.

## Adaptations

Most people with MND will require adaptations to their home – including wetrooms, ramps and hand rails. Across the 30 local authorities who responded to us, waiting times for adaptations are consistently high. For example, one local authority reported an average waiting time of 475 days for fitting a ramp – over 15 months.

These figures represent a devastating reality for those living with a disease with such short life expectancy. People reported being washed using buckets on garden decking or over a commode while waiting for a wetroom. Reactive adaptations processes, such as requiring people to be unable to walk before joining a waiting list for a ramp, lengthened waiting times further. Family members reported that their loved one could no longer use the adaptation, or had died, by the time it was fitted.

Evidence also shows that adaptations application processes are inconsistent across local authorities, complicated to navigate, and critically, not fast enough. Adaptations processes can be improved. Accessible and consistent information, services based on need rather than postcode, and a fast-tracked and proactive provision of adaptations are urgently required. Crucially, those living with terminal conditions like MND should be fast-tracked for adaptations at the point of diagnosis. Doing this will enable people to spend the time they have left at home making memories, rather than fighting to get adaptations which may never arrive within their lifetimes.

## Accessible housing

Not all homes can be made accessible through adaptations, meaning some people with MND require an alternative accessible home. However, despite the urgency of MND many waiting lists are longer than the average life expectancy with the illness with one local authority reporting a waiting time of 4 years. Not all local authorities even record waiting times.

Additionally, there is no national definition of what an accessible home is. There is great variation across local authorities and people with MND reported being allocated properties deemed as accessible, despite having steps to reach the front door.

A scarcity of truly accessible housing, inadequate target setting, and a lack of formal prioritisation processes for those living with terminal illness, means that waiting times for accessible housing are too long for people with MND. This restricts lives that are already significantly shortened by the illness, and across our research, people shared stories of being trapped in unsafe homes – sometimes, in a single room.

A nationally consistent definition of accessible housing should be developed so that sufficient accessible house building commitments can be made and delivered. Fast-tracking those with rapidly degenerative terminal illnesses like MND is critical. Similarly, replacing waiting lists, as well as inappropriate and inaccessible bidding systems, with direct matching for those living with a terminal illness like MND is key.

It is promising to see the Scottish Government's commitments through Housing to 2040. The identification of a need to streamline and accelerate adaptations systems, to commit to consistent practices, and for more accessible housing and supportive moving processes intersect with several of the themes we have discussed through our report.

However, short-term 'Housing to 2040' commitments, such as the review of the adaptations system, should not be delayed. In addition, the rapid progression of MND, and the need to act now shines light on further issues needing urgent action and attention, as described above. It is concerning that previous working groups and consultations around adaptations (Adaptations Working Group 2012) and accessible housing (Scottish Government 2009b) have already identified many of the key issues we present in this report a decade later.

There is a significant risk that if the 20-year commitments set out through Housing to 2040 are not responsive to what is urgently needed, then we face 20 more years of people with MND struggling to access support, and sadly dying before adaptations are fitted, or alternative accessible housing is found. The recommendations in this report are critical to ensuring people with MND live with the dignity and care which everyone is entitled to. There is no time to wait.

# Recommendations

People affected by MND are best placed to know what would improve systems for them. The recommendations in this section have been developed from conversations around accessible housing and adaptations processes with people affected by MND.

## Adaptations

### 1. Fast-tracking applications for adaptations

- **Local authorities to fast-track all people with MND for adaptations.** Social security BASRiS or DS1500 forms could be accepted as evidence of having a terminal illness, like MND.
- **Local authorities to work with health and social care at all points of adaptations processes.** This includes working with OTs and specialist nurses who are well-placed to advise on the speed of the disease and likely adaptation needs – typically ramps, grab/hand rails and wetrooms. Input should be sought at the first point of application.
- **Scottish Government to require local authorities to formally fast-track applications for adaptations for people with MND.** Implementing fast tracking should be included in the government's current commitment to reviewing adaptation practices and processes. However, interim guidance is needed more urgently to ensure that fast-tracking takes place now, to ensure that people with terminal conditions such as MND are not stuck on waiting lists.

### 2. Anticipatory care planning for adaptations

- **Local authorities to adopt proactive, rather than reactive, approaches to awarding adaptations.** This should include reviewing policies which prevent people from joining waiting lists before they meet set requirements for particular adaptations. By the time a person with MND can no longer walk (the point at which some local authorities require an applicant to reach before assessment for a ramp), it is too late to be added to a waiting list and they risk never reaching the top.
- **Scottish Government to increase investment and resources available for adaptations across local authorities.** The government should also review current practices of Stage 3 funding for housing associations, to ensure that where a person is living with a terminal illness, they are given funding immediately, and are not required to wait for the following year, or to be added to a waiting list.

### 3. Clear and publicly available information about the Scheme of Assistance

- **Local authorities to ensure that information about the Scheme of Assistance for owner-occupiers and private renting tenants is clearly displayed on websites and information forms.** This includes stating that a non-means tested grant of 80% of funding is available to applicants with particular health conditions and disabilities, and that 100% is available if a person receives certain benefits (outlined on page 7). This is necessary to ensure that everyone in the local authority has access to the same information.
- **Local authorities to provide more integrated training for housing, health and social care professionals to ensure that everyone has the same information about eligibility and expected processes regarding funding.** This will help to ensure that information can be passed on more consistently to applicants.
- **Scottish Government to require local authorities to actively promote the Scheme of Assistance to those living in their communities.** There is also an opportunity for the Scottish Government to review how they present this information, ensuring that it is shared more clearly and advertised proactively at a national level.

### 4. Making internal adaptations to a property

- **Local authorities to fund adaptations to the inside of a property for people with MND, even if the property is deemed externally inaccessible.** Current waiting lists for accessible properties are longer than the average life expectancy with MND. This means that without internal adaptations, people are left trapped in a single room, or in an unsafe home which could be made better within their lifetime.
- **Scottish Government to enable and ensure local authorities fund internal adaptations for people with MND even if the property is deemed externally inaccessible.** This will help ensure consistency across Scotland.

### 5. Simplifying contractor and tender processes, but not at any cost

- **In circumstances where work needs to be done quickly and sensitively because a person has MND or another terminal illness, local authorities to:**
  - Require 1 quote for major adaptations
  - Single form for completion
  - Offer greater freedom where, and with whom, grant money is spent

There should be no contractor and tendering monopolies. Applicants should be able to use funds to seek adaptations from tradespeople they trust to deliver on time and at a fair price.

- **Local authorities to actively seek feedback from, and consult with, people who have been provided with adaptations.** This should include asking about what worked well, and what could have been improved about the process. This needs to be reviewed at regular intervals to improve future practices and the awarding of work to contractors (instilling a need for good practice)
- **Local authorities to review current contractor and tender practices to ensure quality and cost effectiveness for adaptations.** This is important because sometimes the 20% share paid for by a person with MND can be more than the total cost of another contractor.
- **Scottish Government to ensure that consistent, simplified and consulted upon processes are put in place for people with MND across the country.** This is needed to avoid a postcode lottery.

## Accessible Housing

### 1. A national definition of accessible housing

- **Scottish Government to establish a common and consistent definition of accessible housing.** This needs to include the key features of a wheelchair liveable property, informed by consultation with disabled people.
- **Scottish Government to develop a system for establishing and sharing a consistent definition of accessible housing.** The government has committed to reviewing Housing for Varying Needs, however it is important to note that only 9 of the 30 local authorities who responded to us stated that they use this for their definition of accessible housing.
- **Scottish Government and local authorities to ensure that these key features are reflected consistently across building standards.** While we support the commitments to a new Scottish Accessible Homes Standard, people with MND need immediate change, and cannot wait until 2025-2030 for a new housing standard to be introduced.

### 2. 10% minimum accessible housing target

- **Local authorities to review current housing stock to ensure that properties deemed to be appropriate for wheelchair users are meeting wheelchair liveable standards.** This includes reviewing information about properties held by local authorities, registered social landlords, and stock transfer authorities. Publicly listing features such as the width of door frames, turning spaces, steps and the gradient of an entrance or exit, in the interim of a national definition, will help disabled people to determine in a house is truly accessible for their needs.

- **Local authorities to ensure that a minimum of 10% of new build homes are built to a wheelchair accessible standard.** This should be across all tenure types, and each authority should consider whether a higher percentage is necessary.
- **Scottish Government to require all local authorities to ensure that a minimum of 10% of new build homes are built to a wheelchair accessible standard.** This should be consistent across all tenure types. Our findings suggest that a lead from national government is needed to encourage some local authorities.

### 3. Fast tracking for accessible housing

- **Local authorities to fast-track all people with MND for accessible housing.** Social security BASRiS or DS1500 forms could be accepted as evidence of having a terminal illness, like MND.
- **Local authorities to formally remove penalisation practices for people with MND and other progressive illnesses on the grounds of refusing a property.** The reasons for refusal are often due to the care and support needs a person has. Even if medical and care reasons overwrite current practices of suspension, the risk of being suspended can still be a concern for people and means they may feel that they need to accept unsuitable properties.
- **Scottish Government to require local authorities to formally fast-track applications for accessible housing for people with MND.** This is needed to ensure consistency and avoid a postcode lottery.

### 4. Portable care packages

- **Local authorities to implement like-for-like care packages now for people with MND when accessible housing is offered outside of the current local area.** This care package should be carried over without reassessment, unless asked for by the cared for person. We support the National Care Service's proposals around the portability of care packages but suggest that local authorities need to act on this now for people with MND.
- **Scottish Government to allow for, and support local authorities, to provide like-for-like care packages now for people with MND, when accessible housing is offered outside of the current local area.** In the interim of the National Care Service, local authorities should be supported at a national level to introduce like-for-like care packages when a person with MND is required to move to a different local authority area for housing needs.

## 5. Direct matching – rather than waiting lists and choice based lettings

- **Local authorities to develop and formalise practices such as having a priority or exceptional circumstances group for applicants who cannot wait to be directly matched to suitable properties, bypassing need for bidding and points systems.** This includes working closely with OT's and other health and social care professionals to enable applicants with terminal illnesses to be referred to this group of exceptional circumstances for direct matching to properties.
- **Local authorities to recognise the inaccessibility of bidding practices for people with MND, and other health conditions.** Similarly, a waiting list is of no use to someone with a rapidly progressing terminal illness like MND.
- **Scottish Government to formally support the implementation of direct matching of properties across local authorities for people with MND, and other similar health conditions.** This should include opportunities for local authorities to come together at a national level to discuss learning and develop best practice solutions which can be learnt from, and then developed into formal guidance.

## Other recommendations

### 1. Increasing understanding and awareness of MND

- **Local authorities and those involved in local authority housing and adaptation processes (including those involved in assessing applications, social landlords and contractors) to commit to working with MND Scotland to obtain better awareness and understanding of MND.** This includes working together to develop best practices in housing and adaptations for people with MND in the local area.

### 2. Alternative methods of communication

- **Local authorities to adopt a consistent, disability positive approach to adaptations and accessible housing processes which enables people to communicate in ways that best suit them.** People with MND face various challenges to speech, movement and dexterity. Local authorities must be flexible with how forms are filled out and consider if there are more inclusive methods of communicating and sharing information.
- **Local authorities to ensure that communication preferences are shared with all who are involved in delivering adaptations or accessible housing services.** This will ensure that a person's preference is upheld in every encounter of support.
- **Local authorities to reduce the number of forms which require completion for adaptations in the case of MND.** This will help to reduce the burden on the applicant.

# Endnotes

- 1 Data from the Scottish MND Register
- 2 The statistics that we use throughout this report are drawn from these responses, however it is important to note that they cannot offer a complete picture. They are limited by the varying ways that local authorities record and report on information about housing. Not all local authorities were able to provide information for each question in the format requested.
- 3 Our findings are Scotland specific. The MND Association have produced excellent resources and research in their 'Act to Adapt' work for areas in which housing and adaptations are governed by Westminster policies and grants. Housing in Scotland has been devolved to the Scottish Government since 1999, meaning policies and grant systems are different.
- 4 This is currently being reviewed by the Health Directorate
- 5 The introduction of a Common Housing Register in many local authorities means that people needing to apply for social housing are required to complete a single form.
- 6 While it does not apply to all terminal illness (including MND), Fife Council shared that they, and other local authorities, have a specialised pathway for applicants with housing needs who have cancer. Through a partnership with Macmillan they use a housing advice pathway called 'Improving Cancer Journey Service'. This allows customers affected by cancer and who are experiencing any housing related difficulties to be provided with high level advice, exploring all housing options available. This process includes a fast-tracking of the Housing Functional Needs Assessment, or a review of medical needs, if appropriate (see Macmillan Cancer Support 2017 for further information).



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# Time is running out for people with MND

## Who we are

Our vision is a world without motor neuron disease (MND). Until that day comes, our mission is to make time count for everyone affected by MND in Scotland.

Scottish Charity No. SC002662  
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