

No Time to Lose

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Abbreviated abstract: Having an accessible home is critical to being able to live safely, and with dignity. Most people with Motor Neuron Disease (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, current housing processes do not take account of the speed in which MND progresses. Our research found that systems are not acting fast enough, and, tragically, some people are dying before they can get the support they need.

Related publications:

– MND Scotland (2022) 'No Time to Lose: Addressing the housing needs of people with MND'



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Please read our full report here:



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Previous work, challenge, and approach

Article 25 of the Universal Declaration of Human Rights states that everyone has the right to adequate housing. For people with MND (which is a rapidly debilitating terminal illness), home adaptations are often needed. However, waiting times and support, across Scotland can be a postcode lottery (Adaptations Working Group 2012; Scottish Government 2017; EHRC 2018). Finding an alternative accessible home can take longer than the average life expectancy with MND, which is just 18 months from diagnosis (MND Scotland 2022). It is widely recognised that more accessible housing and better allocations and adaptations processes are needed (EHRC 2018; Horizon Housing 2018; McCall et al 2020). For people with MND, this is particularly urgent.

Techniques and methods

During summer 2021, we undertook research into the experiences of people with MND as they to secure adaptations and accessible housing. We explored housing processes and sought to identify what people with MND felt would improve their experience. We examined local authority practices and asked questions about key indicators such as average waiting times through FOI requests. 30 of 32 local authorities, and 134 people affected by MND responded.

Results

With an average life expectancy of just 18 months from diagnosis, waiting times are too long and processes are not working for people with MND.

ADAPTATIONS

8.5 months

was the average wait time for a wetroom shared by one local authority

15 months

was the average wait time for a ramp in another local authority

ACCESSIBLE HOMES

20.9 months

was the average wait time for an accessible home across 30 local authorities

49.2 months

was the longest average wait time recorded by a local authority

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

“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*

Recommendations for Scottish and local government include:

Adaptations

Recommendations

- 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 processes, but not at any cost

Accessible Housing

Recommendations

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