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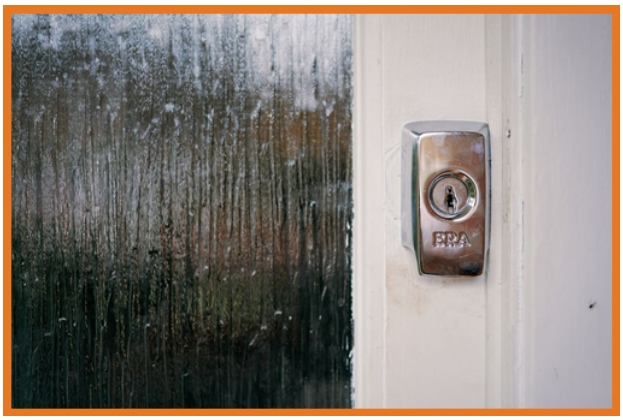
Welcome

This is a short guide for campaigners to take part in the first stage of Unlock the Door, our campaign on housing adaptations for people living with MND.

This guide takes you through how to contact councillors, MPs and other stakeholders in your area to discuss the issues people living with MND have in accessing adaptations. This could be the starting point for building ongoing relationships with your local politicians.



If you'd like any help with taking action or if you have any questions, get in touch with us on campaigns@mndassociation.org or reach out to your staff point of contact:

Midlands, South West, South East and London: Amaani Khan (amaani.khan@mndassociation.org)

North East, North West, Yorkshire, East Anglia and Wales: Alex Charilaou (alex.charilaou@mndassociation.org)

For queries about Northern Ireland please contact Patrick Malone on patrick.malone@mndassociation.org.

If you need support with the issues raised by this campaign, please contact MND Connect on 0808 802 6262 or by emailing mndconnect@mndassociation.org.

Motor Neurone Disease Association
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www.mndassociation.org

Contact the campaigns team
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Unlock the Door: what are we asking for?

As MND progresses, timely home adaptations are critical to maintaining good health and wellbeing for as long as possible. Without them, people already trapped in failing bodies can find themselves trapped again in inaccessible homes, leading to isolation, injury, illness and emotional distress.

However, many people with MND struggle to get the support they need to adapt their home before it is too late. Our research found that 52% of people living with MND said they were dissatisfied with the key source of support available for home adaptations: the Disabled Facilities Grant (DFG).

When applying for an essential DFG, people with MND ought to be able to spend the time they have left with their loved ones, not being made to navigate an overly-long and complex process. The average time from submission of a DFG application for a large adaptation to completion of the works is 289 days in Wales, 357 days in Northern Ireland and 375 days in England.

For people living with MND, a rapidly progressive condition, these lengthy timescales mean adaptations often arrive too late to make a difference.

Our recommendations

Local authorities in England and Wales, and the Northern Ireland Housing Executive, should implement formal fast-track processes for people with progressive conditions such as motor neurone disease. These processes should ensure rapid decision-making and delivery of adaptations, supported by training and education for staff so that fast-tracking is applied consistently and appropriately. Based on national guidance from Foundations, we're recommending that target timeframes of a maximum of 55 days for simple adaptations and 130 days for complex adaptations be adhered to. We also recommend a 21-day timeframe for installing equipment such as ramps and stairlifts, as these adaptations are typically straightforward to fit, readily available, and essential for enabling individuals to move safely and independently around their homes.

Local authorities in England and Wales, and the Northern Ireland Housing Executive, should waive the means test for adaptations of all sizes for all people with progressive, life-limiting conditions such as MND. Currently, the Disabled Facilities Grant (DFG) means test does not reflect the substantial and unavoidable extra costs of living with MND, which average over £14,500 a year. These non-discretionary expenses can quickly erode household finances, meaning that an income which appears sufficient on paper may in practice be inadequate. As a result, people with MND may be deemed ineligible for support and unfairly penalised for remaining in work, creating a perverse incentive for both them and their carers to stop working.

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Our recommendations (continued)

Local authorities in England and Wales, and the Northern Ireland Housing Executive, should be required to keep a register of accessible social homes. This would be a vital step toward understanding the availability of accessible housing stock and ensuring that it is allocated to those who genuinely need it. Once a comprehensive UK-wide register is established, it could be used to safeguard these homes specifically for people with accessibility requirements.

How you can get involved

The most useful thing our campaigners can do is to meet with your councillors asking them to submit our recommended motion to their next council meeting. Our motion, if passed by a council, would commit them to introducing a fast-track process to access the DFG.

We have one draft motion for councils that have some sort of fast-track process that needs strengthening, and another for councils with no fast-track process whatsoever. If you're not sure which to send to your councillors, please ask campaigns@mndassociation.org.

You can find both recommended motions to send to your local councillors across the next two pages of this action guide.

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Council motion for councils with no fast-track system

Motor neurone disease (MND) is a rapidly progressing condition – a third of people die within a year of diagnosis and half within two years. As the disease progresses, symptoms worsen and needs increase, often unpredictably. People living with progressive or terminal conditions like MND deserve to live in safe, accessible homes. They have the right to independence and quality of life in the time they have left.

It is our council's role to ensure that local people living with MND are supported to access the home adaptations they need in a timely manner. The current system is too slow to respond to the rapidly changing needs of people with MND. Without timely support, people face becoming trapped in unsuitable and unsafe homes. This risks significant negative impacts on their health and well-being, including increased risk of avoidable hospital admissions and early entry into care.

The MND Association has proposed a set of recommendations and highlighted examples of good practice in their recent report, A Lifeline Not a Luxury.

One such recommendation is to speed up applications for the funding and installation of home adaptations. This would be hugely beneficial for people living with MND, who could live safely at home for longer, maintain their health and wellbeing for as long as possible, and remain engaged with their communities, family and friends. People living with MND do not have time to wait – every day is critical.

This council recognises that people with progressive conditions should be able to apply for adaptations as early as possible following diagnosis, so that their future needs can be anticipated rather than responded to in crisis. This council also recognises that early interventions can save taxpayer money by enabling people to manage their condition more effectively and reducing the need for critical interventions at a later stage.

This council therefore commits to introducing a fast-track process for delivering home adaptations for people with progressive or terminal conditions such as MND, ensuring target timeframes of 55 days for simple adaptations and 130 days for complex adaptations are adhered to. These timelines are based on the national guidance set out by Foundations on Disabled Facilities Grant (DFG) delivery standards.

With that in mind, the council recognises that 55 days (almost two months) should be seen as a maximum, and that this timeframe is not appropriate for smaller adaptations such as ramps or stairlifts. The goal is to ensure these smaller adaptations are completed much faster.

Together, we'll ensure dignity for people living with MND.

Call to action

Ask your local councillors to put forward this motion calling for your Local Authority to introduce a fast-track process for the DFG, or asking them to formalise and improve their fast-track options.

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Council motion for councils with some fast-track system

Motor neurone disease (MND) is a rapidly progressing condition – a third of people die within a year of diagnosis and half within two years. As the disease progresses, symptoms worsen and needs increase, often unpredictably. People living with progressive or terminal conditions like MND deserve to live in safe, accessible homes. They have the right to independence and quality of life in the time they have left.

It is our council's role to ensure that local people living with MND are supported to access the home adaptations they need in a timely manner. The current system is too slow to respond to the rapidly changing needs of people with MND. Without timely support, people face becoming trapped in unsuitable and unsafe homes. This risks significant negative impacts on their health and well-being, including increased risk of avoidable hospital admissions and early entry into care.

The MND Association has proposed a set of recommendations and highlighted examples of good practice in their recent report, A Lifeline Not a Luxury.

One such recommendation is to speed up applications for the funding and installation of home adaptations. This would be hugely beneficial for people living with MND, who could live safely at home for longer, maintain their health and wellbeing for as long as possible, and remain engaged with their communities, family and friends. People living with MND do not have time to wait – every day is critical.

This council recognises that people with progressive conditions should be able to apply for adaptations as early as possible following diagnosis, so that their future needs can be anticipated rather than responded to in crisis. This council also recognises that early interventions can save taxpayer money by enabling people to manage their condition more effectively and reducing the need for critical interventions at a later stage.

This council therefore commits to reviewing its fast-track process for delivering home adaptations for people with progressive or terminal conditions such as MND, and taking all necessary steps to ensure that target timeframes of 55 days for simple adaptations and 130 days for complex adaptations are adhered to. These timelines are based on the national guidance set out by Foundations on Disabled Facilities Grant (DFG) delivery standards.

With that in mind, the council recognises that 55 days (almost two months) should be seen as a maximum, and that this timeframe is not appropriate for smaller adaptations such as ramps or stairlifts. The goal is to ensure these smaller adaptations are completed much faster.

Together, we'll ensure dignity for people living with MND.

Call to action

Ask your local councillors to put forward this motion calling for your Local Authority to introduce a fast-track process for the DFG, or asking them to formalise and improve their fast-track options.

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Speaking to your councillors

You'll be able to find your local councillors' details here: WriteToThem - Email your Councillor, MP, MSP, MS, MLA or London Assembly Member for free.

Write to them asking if they'd would be open to meeting you to discuss housing adaptations in your area. In asking for a meeting, make sure to tell your own story about how you've been affected by MND, and if you've got experience of trying to navigate the DFG system this would be good to include too.

When you meet with your councillor, let them know that we are asking them to bring our recommended motion to their next council meeting, to ensure dignity in the adaptations process for people living with MND.

We recommend using our Meeting with Councillors Factsheet for best practise on how to get the most out of the relationship with your councillor!

Many areas in England (and all in Wales) now have only one council responsible for all services in an area, including the Disabled Facilities Grant. However, some counties still have (for now) a county council and district/borough councils underneath. It is usually the district or borough councils you need to contact, but if you are not sure which one please ask campaigns@mndassociation.org.

Speaking to your MPs

While Unlock the Door is primarily a council-focussed campaign, local MPs are important stakeholders and their intervention can be very important. We're advising that you ask your local MP – especially if you have an existing relationship with them – to write to local councillors asking them to pass our motion.

You'll be able to find your local MP's details here: WriteToThem - Email your Councillor, MP, MSP, MS, MLA or London Assembly Member for free.

We recommend using our Meeting with MPs Factsheet for best practise on how to get the most out of the relationship with your MP.

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