

Unlock The Door

Fast-tracking accessible housing for people with MND

Action Guide

This is a guide for how to take part in Unlock the Door, our campaign on accessible housing for people with Motor Neurone Disease (MND).

Got questions? Need help? Get in touch with us on campaigns@mndassociation.org

If you need support with accessing home adaptations yourself, please contact MND Connect on 0808 802 6262 or email mndconnect@mndassociation.org.



Motor Neurone Disease Association
mndassociation.org
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What is the Unlock The Door campaign asking for?

We're calling on every council to implement a fast-track process for vital home adaptations, for people with progressive conditions like MND.

We want councils to commit to completing all approved large adaptations (such as a stairlift or wet room) within four-and-a-half months.

Because with MND, every day matters.

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 a DFG, people with MND ought to be able to spend the time they have left with their loved ones, not being made to navigate a 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, these lengthy timescales mean adaptations often arrive too late.

How you can get involved

Please ask your council to implement a formal fast-track process for home adaptations for people with progressive conditions like MND.

Step 1

Find out whether your council already has a fast-track process in place. Use our postcode lookup tool at mndassociation.org/UnlockTheDoor

Step 2

Use our simple online tool to email your council with a pre-written message. You'll be taken there from our postcode lookup tool, or you can go to www.mndassociation.org/UnlockTheDoor

In the box labelled 'Why is this issue important to you?', you can write about how you have been affected by MND issues, or even your own experiences of trying to get vital home adaptations.

Step 3

If your councillors reply, ask them for a meeting so you can discuss why the fast track is needed.

Step 4

Meet your councillors! We'll support you fully and provide all the information you need. Depending on staff availability we may be able to accompany you to the meeting (or join the meeting if it is held online), if you think that would be helpful.

Speaking to your councillors

- Please ask your councillors to bring a motion at the next council meeting to implement a fast track. We've drafted different versions of the motion for councils that have no fast-track at all, and for those that already have one that needs strengthening. You'll find both versions in English and in Welsh at the end of this Action Guide.
- At the end of this guide you'll also find the full list of our recommendations, which you can take to the meeting.
- If you feel comfortable sharing how you have been affected by MND, or your experience of trying to get adaptations for your home, that can be very compelling.

Can my MP do anything?

- While the Unlock the Door campaign is primarily focused on local councils, as they are the ones who administer the Disabled Facilities Grants (DFGs), local MPs are important stakeholders and their intervention can be very important.
- You can find your MP's name and send them a message at [WriteToThem.com](https://www.writetothem.com).
- Please ask your MP – especially if you have an existing relationship with them – to write to local councillors asking them to pass our motion about fast-tracking home adaptations.

Our recommendations

to local authorities in England and Wales, and to the Northern Ireland Housing Executive

- Implement formal fast-track processes for people with progressive conditions such as motor neurone disease.
- Provide training and education for staff so that fast-tracking is applied consistently and appropriately.
- Adhere to the following target timeframes:

Simple adaptations: 55 days

Complex adaptations: 130 days

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.

- Waive the means test for adaptations of all sizes for 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.

- Keep a register of accessible social homes.

Draft motion for councils with no fast-track system

Unlock The Door: Fast-tracking accessible housing for people with MND

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.

Draft motion for councils with some fast-track system

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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.

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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.

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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.

I gyngorau heb system llwybr cyflym

Mae clefyd motor niwron (MND) yn gyflwr sy'n datblygu'n gyflym – mae traean o bobl yn marw o fewn blwyddyn i gael diagnosis a hanner o fewn dwy flynedd. Wrth i'r clefyd fynd rhagddo, mae symptomau'n gwaethygu ac anghenion yn cynyddu, yn aml yn anrhagweladwy.

Mae pobl sy'n byw gyda chyflyrau cynyddol neu derfynol fel MND yn haeddu byw mewn cartrefi diogel a hygyrch. Mae ganddyn nhw'r hawl i annibyniaeth ac ansawdd bywyd yn yr amser sydd ganddyn nhw ar ôl.

Rôl ein cyngor yw sicrhau bod pobl leol sy'n byw gydag MND yn cael eu cefnogi i gael mynediad at yr addasiadau cartref sydd eu hangen arnyn nhw mewn modd amserol. Mae'r system bresennol yn rhy araf i ymateb i anghenion pobl ag MND sy'n newid yn gyflym. Heb gefnogaeth amserol, mae pobl yn wynebu cael eu dal mewn cartrefi anaddas ac anniogel. Mae hyn yn peryglu effeithiau negyddol sylweddol ar eu hiechyd a'u lles, gan gynnwys risg uwch o dderbyniadau i'r ysbyty y gellir eu hosgoi a mynediad cynnar i ofal.

Mae Cymdeithas MND wedi cynnig set o argymhellion ac wedi tynnu sylw at enghreifftiau o arfer da yn eu hadroddiad diweddar, Rhaff Achub, nid Moethusrwydd ('A Lifeline Not a Luxury').

Un argymhelliad o'r fath yw cyflymu ceisiadau am gyllid a gosod addasiadau cartref. Byddai hyn o fudd mawr i bobl sy'n byw gydag MND, a allai fyw'n ddiogel gartref am gyfnod hirach, cynnal eu hiechyd a'u lles cyhyd â phosibl, a pharhau i ymgysylltu â'u cymunedau, teulu a ffrindiau. Nid oes gan bobl sy'n byw ag MND amser i aros - mae pob dydd yn hanfodol.

Mae'r cyngor hwn yn cydnabod y dylai pobl â chyflyrau sy'n gwaethygu allu gwneud cais am addasiadau cyn gynted â phosibl ar ôl diagnosis, fel y gellir rhagweld eu hanghenion yn y dyfodol yn hytrach nag ymateb iddynt mewn argyfwng. Mae'r cyngor hwn hefyd yn cydnabod y gall ymyriadau cynnar arbed arian i drethdalwyr drwy alluogi pobl i reoli eu cyflwr yn fwy effeithiol a lleihau'r angen am ymyriadau critigol yn ddiweddarach.

Felly mae'r cyngor hwn yn ymrwmo i gyflwyno proses gyflym ar gyfer cyflawni addasiadau cartref i bobl â chyflyrau cynyddol neu derfynol fel MND, gan sicrhau bod amserlenni targed o 55 diwrnod ar gyfer addasiadau syml a 130 diwrnod ar gyfer addasiadau cymhleth yn cael eu dilyn. Mae'r amserlenni hyn yn seiliedig ar y canllawiau cenedlaethol a nodir gan safonau cyflawni'r Sefydliad ar gyfer Grantiau Cyfleusterau i'r Anabl (DFG). Gyda hynny mewn golwg, mae'r cyngor yn cydnabod y dylid ystyried 55 diwrnod (bron i ddau fis) fel uchafswm, ac nad yw'r amserlen hon yn briodol ar gyfer addasiadau llai fel rampiau neu lifftiau grisiau. Y nod yw sicrhau bod yr addasiadau llai hyn yn cael eu cwblhau'n llawer cyflymach. Gyda'n gilydd, byddwn yn sicrhau urddas i bobl sy'n byw gydag MND.

I gynghorau sydd â rhywfaint o broses gyflymu

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