



**ACT TO
ADAPT**

Access to home adaptations for
people with motor neurone disease

mnda

motor neurone disease
association

What can I do? For councillors

Key aims of the *Act to Adapt* campaign in England

1. Get councils to introduce a fast-track process for people with MND
2. Remove the financial assessment for Disabled Facilities Grants for adaptations up to £5,000.

What is the *Act to Adapt* campaign?

The *Act to Adapt* campaign aims to push for accessible homes and a fairer and faster system for delivering housing adaptations. We want people with MND to be able to live safely, independently, and with dignity in the time that remains to them.

Motor neurone disease (MND) is a fatal, often rapidly progressing disease that affects the brain and spinal cord. It kills a third of people within a year of diagnosis and more than half of people within two years. MND can leave people locked in a failing body, unable to move, talk, swallow and eventually breathe. Many people with MND face significant challenges in adapting their home. These can include the high cost of adaptations, length of time the process takes, and a lack of information about how to go about adapting your home.

Councils are responsible for supporting people with MND to find accessible housing or adapt their homes. But there is significant variation in the quality of support they provide. Serious delays in the system make it difficult for people to access financial support for adaptations, particularly via Disabled Facilities Grants (DFGs). These issues have only been exacerbated by the impact of Covid-19 on people's health, our economy and public services.

The current picture

To respond to these challenges, the MND Association launched the *Act to Adapt* campaign in September 2020. In September 2019, the *Act to Adapt* report was released which detailed the problems faced by people with MND around accessible housing and recommendations for how councils can improve the support they currently provide. In May 2021, the MND Association gathered further data to discover how councils are supporting people to deliver home adaptations since the *Act to Adapt* report was published. This showed a high degree of variation across the country in how councils provide support for home adaptations and accessible housing. We will now begin influencing councils in England¹. Our key aims are to get councils to fast track DFG applications from people with MND and to remove financial assessment for adaptations under £5,000. We hope this will make a significant difference for people with MND.

¹ In Wales we are running a separate campaign on home adaptations called *Welsh Homes for MND*.
Find out more here: <https://www.mndassociation.org/adapt-now-welsh-homes-for-mnd/>

How I can help?

6 steps to support the *Act to Adapt* campaign

We're asking local councillors, particularly Cabinet Members/Portfolio Holders for Housing across England to:

1

If you hold the housing brief, please:

- **Meet with your local MND Association branch or group to discuss their housing needs.**

2

If you do not hold the housing brief, please contact the lead councillor with responsibility for housing at your local authority about this campaign, and:

- **Meet with the lead councillor and discuss potential actions.** This would likely include engaging local people affected by MND; the council reviewing how the housing adaptations process works; and/or evaluating how availability of accessible accommodation is managed currently, to identify what specific improvements need to be made. You can use the A2A housing map to find out in a bit more detail how your council is currently delivering DFGs.

3

Attend Councillor events hosted by the MND Association

4

Agree and implement the actions agreed

5

Keep in touch with us – let us know or the local campaign group in your areas how you get on, and any progress you see!

6

Ask us if you have questions. You can speak to our Campaigns Team on campaigns@mndassociation.org or call 020 7250 8447. Join our Campaign network so you can keep updated with all the news on the *Act to Adapt* campaign at www.mndassociation.org/campaign-network/

Where can I find out more?

- Go to our *Act to Adapt* campaign webpage at www.mndassociation.org/acttoadapt. You can read our *Act to Adapt* report, and access the wide range of campaign resources.
- Finally, if you are living with MND or know someone with MND who needs help to adapt their home, please contact MND Connect on 0808 802 6262 or email us at mndconnect@mndassociation.org

Thank you so much for your help. Your efforts will help people with MND to live safely, independently, and with dignity in the time that remains to them.