



**ACT TO
ADAPT**

Access to home adaptations for
people with motor neurone disease

mnda

motor neurone disease
association

Act to Adapt campaign bite-sized briefs:

Challenges and solutions for people with MND requiring housing adaptations

What is motor neurone disease?

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.

Why do people with MND need accessible housing?

An accessible home helps a person with MND live independently for as long as possible, preventing isolation and injury. Many people with MND need to adapt their homes to meet their changing needs. Adaptations range from smaller aids such as grab rails or ramps, to more complex changes such as wet rooms, stairlifts or through-floor lifts.

Challenges for people with MND

If people with MND are unable to access and install housing adaptations swiftly, this can have significant negative effects including:

- preventing them from living independently
- risks to their physical safety and that of their carers
- social isolation
- emotional strain
- financial pressure

These impacts are in addition to the already serious challenges of living with MND.

What are the solutions?

Everyone with MND must be able to continue to live in a safe and accessible home. At a national level, we want to improve policy on Disabled Facilities Grants (DFGs). At a local level, we want to improve the process of applying for funding, requesting and installing adaptations. Below is a short summary of the solutions from the *Act to Adapt* report we think would make a real difference – not only for people with MND, but for other people who may need housing adaptations too.

What do we want?

We want Westminster government to:

- commit to ongoing central funding for DFGs when current allocations end, rising to reflect demand and demographic change
- improve the suitability and effectiveness of DFGs, by raising the financial cap on grant payments
- improving the financial assessment process for applicants
- monitoring and evaluating target waiting times for adaptations

We want local government in England to:

Improve the process of delivering adaptations and all councils with responsibility for DFGs in England to

- put in place a transparent, fast-track process for adaptations under £5k without the need for a financial assessment
- make greater use of discretionary financial support
- improve target timescales for adaptations
- better identify and share good practice

We want to work with people with MND, councillors, as well as housing, health and social care professionals to make this happen

You can find our full list of solutions in our *Act to Adapt* report here:
www.mndassociation.org/acttoadapt.

What is the MND Association doing to implement these solutions?

To respond to these challenges, the MND Association launched the *Act to Adapt* campaign in September 2020. Overall, the campaign aims to improve the cost and speed of housing adaptations across England, so people with MND can live safely, independently, and with dignity in the time that remains to them. We will be working with national and local supporters in partnership to help implement the solutions we've outlined above.

Where can I find out more?

- Go to our *Act to Adapt* campaign webpage: www.mndassociation.org/acttoadapt to read our *Act to Adapt* report and access the wide range of campaign resources.
- Contact the MND Association Campaign team on: campaigns@mndassociation.org or call 020 7250 8447.