



Access to home adaptations for
people with motor neurone disease

FAQs: Act to Adapt campaign

1. What's the aim of the campaign?

To achieve long-lasting change and improvements in support services for securing accessible housing and housing adaptations for people with MND.

2. What will happen in Phase 1 and Phase 2 of the campaign?

Phase 1: Raising awareness and increasing support for the campaign

Many people, including decision makers, aren't aware of the problems that people with MND face when having to find an accessible home or access home adaptations.

During Phase 1, we aim to raise awareness of the challenges people with MND face and highlight the solutions. We will encourage people with MND, their carers and families to share their experiences and call on decision makers and other key stakeholders to show their support for the campaign.

Awareness is a crucial part of the campaign and the first step. Without it, we cannot achieve our ultimate aim which is to achieve real, long lasting change and improvements in services for people with MND.

Phase 2: Ensure decision makers adapt their services so that people with MND can live in safe and accessible homes

Decision making at the local level in England and Wales leads to a wide variation in services across the country, referred to as a 'postcode' lottery'. Therefore, to achieve real change for people with MND, it is crucial we focus our campaigning at the local level.

Together with staff and volunteers, we'll create local campaigns to calling on councils to review their current systems, identify gaps and areas of improvement and urge them to take action to improve their services for local people with MND.

3. How can I get involved if I live in England or Wales?

As part of Phase 1, if you are affected by MND and have experience of accessing home adaptations, please [share your story or simply share a message of support on our jigsaw.](#)

In England and Wales, delivering home adaptations is the responsibility of local councils. [Email your local councillor](#) and ask them to show their support for the campaign.

4. How can I get involved if I live in Northern Ireland?

As part of Phase 1, if you are affected by MND and have experience of accessing home adaptations, please [share your story or simply share a message of support on our jigsaw](#).

In Northern Ireland, the Housing Executive has sole responsibility for delivering housing adaptations. Therefore, the 'email your councillor' action is not relevant for people living in Northern Ireland.

We have shared the Act to Adapt report with the Northern Ireland Housing Executive and will be working closely with staff and volunteers to campaign to improve services in Northern Ireland during Phase 2 of the campaign.

5. What are Disabled Facilities Grants?

Disabled Facilities Grants (DFGs) are grants available to help pay for essential adaptations to give disabled people better freedom of movement into and around their homes, and to give access to essential facilities within the home.

You can apply for a DFG whether you rent your property or own your home. If you live in a local authority or social housing and you apply for help with adaptations, the local authority/housing association will decide whether to carry out the work itself or may refer you for a DFG. DFGs are administered by local authorities in England and Wales, and by the Northern Ireland Housing Executive.

There is a legal requirement to provide funding for DFG applications that meet certain national criteria. These "mandatory" DFGs are means-tested grants, restricted to the individual and their spouse or partner's, if they have one, income and assets below a certain level. The maximum mandatory DFG grant is £30,000 in England, £36,000 in Wales, and £25,000 in Northern Ireland.

Authorities also have discretionary powers to provide funding using more flexible criteria. This allows authorities to provide discretionary grants over the maximum limit or to waive the means test in some circumstances.

6. I am struggling to access home adaptations at the moment, what should I do?

As the Policy and Campaigns Team, we are unable to give direct support for individual cases should you be experiencing difficulty in accessing home adaptations. However, you can contact the Association's helpline MND Connect by telephone on 0808 802 6262 or by email on <mailto:mndconnect@mndassociation.org>

We are always looking for people's experiences to help push our campaigning work. If you wish to share your experiences of getting home adaptations with us, good or bad, then please email us using the address below.

7. How can I approach my council about making changes?

The first step is to email your councillor(s) and make them aware of the Act to Adapt report, highlighting the challenges people with MND face and the solutions to improve the situation. [You can use our simple e-action to do this.](#)

The Act to Adapt report includes several examples of good practice and recommendations that the council can follow to improve the system for people with MND. You should also encourage your councillor to share the report with other key local authority decision makers, including the housing director/lead and the adult social care director/lead.

Some of the ways councils can improve services for people with MND are:

1. Put in place a transparent, fast-track, non-means tested process for adaptations under £5,000 by 2021
2. Provide a single point of contact for disabled people
3. Review their compliance with target timescales ensure these are met in 100% of cases
4. Promote good practice in discretionary policies, eg:
 - Passporting for people with a terminal illness
 - Removing the means test for stairlifts
 - 'Lean' or no means tests for low-cost high impact adaptations
 - Increasing the cap on maximum grant
 - Mandatory national accessibility standards for new developments.

If you would like to get more involved in the campaign and work with local campaigners on this issue, [please get in touch with Senior Campaigns Adviser Fran Monticelli](#) who can chat to you about Phase 2 of the campaign.

Please note that housing is a responsibility of unitary and districts/lower tier authorities. However, in two tier areas, shire counties/upper tier authorities deliver adult social care so they are responsible for the OT assessments, and the districts/lower tier have housing responsibility so they are responsible for administering the DFG directly and providing adaptations. Unitary councils carry out both housing and adult social care responsibilities.

8. My council is saying it is busy responding to the Covid pandemic at the moment. What should I do?

While councils have been incredibly busy responding to the pandemic, they still have an obligation to process and deliver home adaptations. The COVID-19 pandemic, the national lockdown, and ongoing localised lockdowns have likely had, and will continue to have, an impact on the ability of councils to deliver this service.

However, the needs of people living with MND who require home adaptations have not gone away and having to shield and remain indoors will have made life incredibly difficult for those who were already living in homes that do not meet their needs. It's essential that councils are made aware of the campaign to improve the system for people living with MND alongside their efforts to respond to the pandemic.

9. My council has adopted the MND Charter so does that mean the council should be providing better accessible housing services to people with MND in my area already?

Adopting the MND Charter is a positive, symbolic gesture of support and the primary aim is to help raise awareness and increase understanding of MND within the council. In the process of getting the Charter adopted, our campaigners have forged relationships with councillors, and this has opened doors to closer working with the council to improve services, provide training to staff and organise fundraising initiatives.

However, we are aware more needs to be done in some areas to plug the gaps in services led by councils. We hope that the Act to Adapt campaign will provide a clear framework to help councils, MND Association staff and volunteers to work together to improve local home adaptations services.

10. It looks like my council is supposed to be an area of good practice. Does that mean I don't need to take part in the campaign?

We would still encourage supporters to be active in the campaign, even if your council has good practices in place. It is still important to make them aware of the unique challenges faced by people living with MND who require home adaptations and consider how services could be improved further to support people more effectively. We would hope that all councils are open to suggestions that might further improve their home adaptations policies.

11. You have shown my council as an area of good practice, but we've had a negative experience. What does this mean?

Sometimes whilst a home adaptations policy may have the best intentions and look good on paper, it may still not meet the needs of people living with MND. We would encourage supporters to be a part of the campaign as being able to show that good practice hasn't applied in your case could be a good starting point that could lead to meaningful engagement and change.

This campaign is a good opportunity to show how a council's home adaptations policy hasn't worked in practice. Also, with the ongoing Covid pandemic, many councils will have likely experienced difficulties in running their services as normal.

12. Will you be approaching building contractors as part of the campaign?

Builders and developers have historically been resistant to higher accessibility standards. To address this, we are calling for a mandatory national requirement for a proportion of all new developments to be accessible in order to be approved.

13. How will MPs be involved in the campaign?

In Phase 1, we'll be encouraging members of the APPG on Motor Neurone Disease and other supportive MPs to join the campaign and to raise awareness in their local area. Several MPs who are APPG members have already shared messages of support for the campaign.

14. Are we collaborating with other charities on the campaign?

We work with other organisations including the Housing Adaptations Consortium on a number of issues related to accessible housing. The messaging of this campaign focuses more closely on the needs of people living with MND so we are conducting it as a standalone campaign. We will continue to collaborate with patient groups and other key stakeholders with an interest in accessible housing.

15. Why aren't we calling for the Disabled Facilities Grants (DFG) means test to be less rigorous?

Councils have a lot of discretion to do things differently when it comes to the DFG means test. Our research showed that there are some good practice examples where councils provide funding using more flexible criteria, for example waiving the means test for certain types of adaptations or for certain groups of people or carrying out work below a certain cost level. Our campaign will focus on promoting good practice as set out in our Act to Adapt report and encouraging councils to follow these examples of good practice.

16. Councils received funding allocation for DFGs via the Government's Better Care Fund but this has now come to an end. What does that mean for councils?

The Government allocates annual funding to local authorities to pay for DFGs. Previously this was bundled into the Better Care Fund, which came to an end in 2019-20, but the funding was rolled over for 2020-21 at the same level as the final year of the Better Care Fund.

It is very likely that central DFG funding will continue, but we will be calling on the Government to ensure that annual funding is increased year-on-year to keep up with growing levels of need. We made this point strongly in our submission to the Treasury's Comprehensive Spending Review, which allocates Government department budgets for the coming years.

17. How long will the campaign last?

We envisage this to be a long-term campaign for the Association. Tackling this issue is a priority and we are determined to make sure that we step up our local campaigning to create positive change for people with MND when it comes to getting the home adaptations they need.

We recognise that the duration of local campaigns depends on the local situation and capacity of local volunteers and staff. But we will work together with stakeholders to ensure we develop the right approach and resources to deliver effective local campaigns on this issue.

We anticipate that part of the local area pilot work in Phase 2 will be completed in 2021 before we roll out resources to local volunteers to support them to set up their own local Act to Adapt campaigns.

18. Why have there been delays to launching the campaign?

We had to postpone this campaign due to a snap General Election taking place and then again during the COVID-19 pandemic. We also had a major restructure internally, both in the Policy and Campaigns team and our regional Care directorate.

This is a very important and new area of work and we wanted to ensure that we were able to devote enough time and capacity to it and that key stakeholders were also able to engage with the campaign.

For further information or support, please email campaigns@mndassociation.org