

FAQ document for Act to Adapt

If you are affected by MND and need support to access home adaptations, please contact MND Connect on 0808 802 6262 or by emailing mndconnect@mndassociation.org.

1. What has happened so far in the Act to Adapt campaign and what will happen next?

The Act to Adapt campaign is designed to not only make people aware of the problems people with MND face when accessing home adaptations and accessible housing, but also to persuade decision makers and other key stakeholders to take action and ultimately improve services for people with MND.

What has happened so far

- September 2020: We launched our Act to Adapt campaign to raise awareness of the challenges people with MND face when they have to adapt their homes. During phase 1, we raised awareness of the challenges people with MND face and highlighted the solutions. We encouraged people with MND, their carers and families to share their experiences and called 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 significant, lasting change and improvements in services for people with MND.
- November 2020: We started a small number of local campaigns across England, Wales and Northern Ireland to test how best to improve support for people with MND.
- March 2021: We presented on our Act to Adapt campaign at the annual Labour and Conservative Councillor conferences. Over 150 councillors attended.
- May 2021: We requested data from councils in England about the support they provide for home adaptations. This showed that many councils are still failing, and that there is still significant variation in support.
- September 2021: We launched a housing map and resources for setting up a local campaign to help supporters influence local councils in England to improve the support they provide

What will happen next

Phase 2: Ensure decision makers adapt their services so that people with MND can live in safe and accessible homes. During phase 2, together with staff and volunteers, we will create local campaigns targeting councils and calling on them to review their current systems, identify gaps and areas of improvement and urge them to take actions to improve their services for local people with MND.

The two aims of the campaign are to influence councils to improve local services by:

1. Introducing a fast-track process for people with MND
2. Removing financial assessment (means test) test for Disabled Facilities Grants for adaptations up to £5,000.

2. What are Disabled Facilities Grants?

Read the information fact sheet on DFGs here ->

<https://www.mndassociation.org/app/uploads/2021/07/10c-disabled-facilities-grants.pdf>

3. What's happening in Northern Ireland?

In England and Wales, delivering home adaptations is the responsibility of local councils, but in Northern Ireland the Housing Executive has sole responsibility for this. We have met with the Northern Ireland Housing Executive and will continue to be working closely with staff and volunteers to campaign to improve services in Northern Ireland.

4. What's happening in Wales?

As the situation in Wales is different, we are currently running a separate campaign on access to home adaptations for people with MND, called Adapt Now: Welsh Homes for MND. If you would like to be more involved in the campaign visit our webpage here:

<https://www.mndassociation.org/adapt-now-welsh-homes-for-mnd/>.

We are planning to launch Act to Adapt in Wales at a later date.

5. How do I get involved?

To approach your local council, we recommend first checking out our Act to Adapt Housing Map:

<https://ecampaigns.mndassociation.org/page/88773/action/1?ea.tracking.id=hub>

You can input your postcode and see how your council is doing in relation to home adaptations.

You could then set up a local campaign group and work with volunteers your area to approach the council to make changes. If you are involved with your local MND Association Branch or Group you may consider starting a group with them. Alternatively, you can use your social media channels to recruit volunteers. By visiting the local campaign groups webpage, you can find all the relevant resources to help you set up a local campaign: <https://www.mndassociation.org/launch-a-local-campaign/>. There are more general actions supporters can take in this resource here: www.mndassociation.org/act-to-adapt.

6. My council has adopted the MND Charter. Doesn't that mean the council should be providing better accessible housing services to people with MND in my area?

In theory yes – but this may not necessarily mean that action has been taken yet. 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.

7. What is the Act to Adapt Housing Map and how do I use it?

We recently requested new information on home adaptations provision from all councils with the responsibility for housing across England. We have categorised the information received from the councils that have responded, so that when you input your postcode onto the map you will be able to see how your council is performing in terms of the two aims of the campaign.

More instructions on how to use the map can be found on the link here:

<https://ecampaigns.mndassociation.org/page/88773/action/1?ea.tracking.id=hub>

8. My council hasn't provided data on your Act to Adapt Housing map. What should I do?

Get in touch with the MND Campaigns team on campaigns@mndassociation.org. We can supply you with information to approach your council to request the information if it wasn't initially provided.

9. It looks like my council has a fast-track process in place and delivers home-adaptations under £5,000 with no financial assessment. Does that mean I don't need to take part in the campaign?

It looks like you are living in an area where your council is performing well. We would still encourage supporters to be active in the campaign, even if your council has enacted the campaign aims. It is still important to make them aware of the other 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. You may want to share the news that your council has in place both a fast-track process and delivers home-adaptations under £5,000 with no financial assessment, with regional media. We can support you to do this.

10. 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 on 0808 802 6262 or by emailing mndconnect@mndassociation.org.

In the meantime, we are always on the lookout for people's experiences to help with our campaigning work. If you wish to share your experiences – good or bad - of getting home adaptations with us, then please email campaigns@mndassociation.org.

11. How are you targeting National Government?

The main campaign target is local government (councils with a responsibility for housing) because provision of home adaptations for people living with MND sits with councils. We will be working with a select number of MPs who live in the 65+ areas where data shows there is no fast-track process in place and adaptations under £5,000 are still being means tested. At a later date we will also be targeting Ministers in the Department for Levelling Up, Housing and Communities, to put forward some of the national asks from the Act to Adapt report (<https://www.mndassociation.org/app/uploads/2019/09/Act-to-Adapt-Full-report.pdf>) .

12. 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, and so we are conducting it as a standalone campaign, but will continue to collaborate with patient groups and other key stakeholders with an interest in accessible housing.

13. Councils received funding allocation for DFGs via the Government's Better Care Fund. If, however, 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., The funds are bundled into the Better Care Fund, which aims to support public services working together to provide better joined up care. For the past three years DFG funding has been set at £573 million in total. We have called 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 2020 Comprehensive Spending Review, which allocates the budgets for Government department for the coming years.

14. What is the duration of the Act to Adapt campaign?

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.