



This resource aims to aid you in setting up a local campaign in your area for the *Act to Adapt* campaign, by the MND Association. If you have any further questions that are not answered in the resource, we are always happy to help. Contact the MND Association Campaigns Team on [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) or call 020 7250 8447

Other accompanying resources can be found and downloaded at [www.mndassociation.org/ActToAdapt](http://www.mndassociation.org/ActToAdapt)

### 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.

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.

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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 England. 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.

### To organise a campaign, consider following these suggested steps:



## Pathway to success



## A2A local campaign check-list

- Start**
  - Set up your campaign group (3 – 4 people is enough to get going). Let the P&C team know by emailing [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org)
  - Book in a meeting with your campaign group. We suggest you use Doodle Poll, a free website that helps group members share their availability. There are two development session agendas, book them in within two weeks of one another to keep momentum
  - Use our *Act to Adapt* housing map to find out more information about your council to discuss with your local councillors
  - Set up regular monthly check-in meetings (these can be hosted online or in-person- please check the latest COVID-19 guidance)
  - Recruit people who are living with MND or have been affected by it to your campaign group as their direct experience is important
  - Identify volunteers to facilitate the sessions (this can rotate between members to give everyone a chance to have a go)
  - Check-in between meetings and catch-ups and follow-up on action points to keep things moving
- Once you begin your first session**
  - Establish how support for home adaptations is currently provided by the council in your area as a crucial step to start the local campaign
  - Create and monitor actions
- After the second session**
  - Set goals and reminders for the next month
  - Try to secure media interest for your local campaign. The staff team can support you to liaise with journalists and can provide you with template press releases
- Monitoring & evaluation of campaign outcomes**
  - Campaign wins may look different depending on which council you are working with.

## How to WIN? A process...

The process map below shows how your local campaign may run. However this is likely to be different in every area. Actions and movements within the council may happen at a different time-scale than the below, so do not worry.

Wins can also be different in different councils, as illustrated in the examples in the Wirral and West Dorset. The crucial thing is to keep going. Campaigning can take a long time and there is no one approach that is the winning approach. We suggest you try a variety of the tactics, that have been identified here. It can take a long time to achieve success, so celebrate all the small wins along the way too!

### In the first month you should...



Start by setting up your local campaign group



If you already hold a relationship with a councillor in your area (no matter what their responsibility is within the council) make contact with them to tell them about the campaign and what you are trying to do



If you do not have a relationship with a local councillor, find the contact details of the councillors responsible for housing and/or social care and reach out to them informing them of the campaign. You'll find these on your council's website



Identify the key power holders in the council (most likely those in the housing department)

### After the first month...



Set up a meeting with the relevant councillor

a. N.B this can take a while so don't be afraid to follow up.



At the meeting bring someone with you that is directly affected by MND, if that isn't you.



At the meeting discuss what challenges there are with the DFG process for people living with MND. Ask the councillor what they can do to help implement improvements to the process and how you can support them



We recommend both a councillor engagement approach as well as getting in contact with council staff, for example the OT department within social services



Use case studies of people living with MND who are struggling to access home adaptations when speaking to both council staff and/or councillors

## Examples of how it's worked so far

The examples below are from this last year where we have trialled the campaign in various areas. As you can see the progress is different in both areas.

### Wirral Metropolitan Borough Council

#### April 2020

Lead councillor launches case review into MND case, of a young mother who died before adaptations were put in place.

#### July 2020

Outcome of review within the council signals the current home adaptations process for people with an end of life diagnosis isn't adequate

#### November 2020

Local campaign is launched, volunteers carry out local analysis

#### December 2020

Local group volunteers reach out to lead councillor to understand outcome of the case review

#### February 2021

Wirral volunteer attends annual Labour Councillor Conference to discuss the case study mentioned above

#### March 2021

Wirral Borough Council announces the introduction of the Time-Critical Adaptation Grant. That means people living with MND can now get access to home adaptations more quickly than via the normal DFG route

#### Ongoing

Monitoring of how the council will implement the Grant and evaluating how it works in practice for people living with MND

### West Dorset Borough Council

#### October 2020

Local campaign launched (regular group catch-ups from then on happened once every 6 weeks)

#### January 2021

Social Services OT joins local campaign group meetings giving insight into council procedures

#### February 2021

Specialist Community OT attends Labour Councillor Conference and Conservative Councillor Conference to discuss the issues she supports with when dealing with people living with MND

#### April 2021

Housing provider staff attends local campaign meeting to give insight into how they work with the Council to provide housing

#### May 2021

Local volunteer meets Head of Housing to discuss the campaign and what can be done. At the meeting the Head of Housing agrees to set up a meeting with the Councillor responsible for Adult Social Care

#### September 2021

Meeting with councillor responsible for Adult Social Care will happen...

## Troubleshooting

### *What if my councillor doesn't respond?*

Sometimes councillors do not respond to constituency emails. Try and use Twitter to chase the email. If your councillor hasn't responded to you in 3 to 4 weeks then do send a follow up email.

### *What if I can't find local volunteers to support the local campaign?*

Try and promote the local campaign on your social media channels. Or you can contact your local MND Association Branch or Group. Failing that, email [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) and we can help you try and link up with other volunteers.

### *What if I can't find someone living with MND to join me?*

Use social media or other local connections to look for people living with MND in your area who might be interested in joining your local campaign. If you are working with local healthcare professionals, they might know of someone.

## Organising the sessions

Check the resources online. Here you will find agendas for the sessions, accompanying slides and a local action plan to fill in and keep you on track.

We recommend running two 1.5 hour long sessions online. Two sessions were carried out in each of the pilot areas, ideally no more than one month will pass between the first and second session. These will be attended by people living in the area with an interest in the campaign (potentially a Campaigns Volunteer, branch/group volunteers, an Occupational Therapist or/and an Association Visitor). We would recommend letting your local Service Development Manager know you are starting a local campaign.

## First session

In the first session, a member of the Group should give a brief presentation on what campaigning is and a briefing on the *Act to Adapt* campaign. You can access the slides on the resources section of the *Act to Adapt* page of the website here: [www.mndassociation.org/acttoadapt](http://www.mndassociation.org/acttoadapt)

Next you should facilitate a discussion about what the current situation is in your area and begin to produce a local action plan. The discussion will cover:

- **SWOT analysis** - what does the council do well/not so well in terms of adaptations? What strengths do we have to influence them? What positive signs do we have that they may be open to improving the adaptations process?
- **Our links in the council** - who do we know in the council that could help drive the campaign forward? Who else should we be contacting to support?

## Second session

The second session is all about building on the information gathered from the first session. Therefore, expanding on the links you have already within councils, exploring the opportunities, so you can begin making changes and encouraging councils to adopt the recommendations. The strategy for Phase 2 is to move councils to a place where they have scrapped the financial assessment for DFG funded adaptations under £5,000 and introduced a fast-track process.

After the campaign development sessions have happened, a local action plan will begin to be populated and the campaign begins. We recommend that you organise monthly check-ins with those that attended the two initial sessions so that you can monitor progress and action points. We suggest you record progress and updates in a tracker that we have provided.

## Learnings from other local campaigns

- Local knowledge is invaluable for the campaign to work so having local volunteers is important
  - Particularly volunteers with associated professions, such as occupational therapists. Community OTs are with the person living with MND throughout the journey to get access to home adaptations
- Having health professionals (such as council OTs) in the group can be beneficial as they've been able to offer insight into the pathway and some contacts at the council

## Additional resources available

You can find the resources mentioned below on our website:

[www.mndassociation.org/a2alocalcampaign](http://www.mndassociation.org/a2alocalcampaign)

- Campaign Development Session 1
  - Slides
  - Agenda
- Campaign Development Session 2
  - Agenda
- Local action plan template
- [Doodle Poll](#) – to schedule meetings and catch-ups
- [Zoom](#) – to host meetings online

## How can I find out more?

- Go to our *Act to Adapt* campaign webpage at [www.mndassociation.org/acttoadapt](http://www.mndassociation.org/acttoadapt)
- Contact the MND Association campaign team on [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) or call 020 7250 8447

**Thanks for joining us to help people with MND  
live safely and independently.**