

Through The Roof: Supporter Action Guide

Autumn 2023



THROUGH
THE ROOF



TAKE
ACTION

Welcome

Welcome! This is a short guide to taking part in [Through The Roof](#) – our cost of living campaign this Autumn.

This guide takes you through how to contact the MPs in your area by letter or e-mail to introduce the campaign and highlight the impact high energy prices are having on people with MND. This could also be the starting point for building ongoing relationships with your local politicians.

If you'd like any help with taking action or if you have any questions, get in touch with us on campaigns@mndassociation.org or reach out to your staff point of contact:

Midlands, South-West, Thames Valley and Wales:
Amaani Khan (amaani.khan@mndassociation.org / [0203 8758904](tel:02038758904))

North-East, North-West and Yorkshire:
Tim Atkinson (tim.atkinson@mndassociation.org / [01604 800649](tel:01604800649))

East Anglia, London and the South-East:
Niall Murphy (niall.murphy@association.org / [0203 8758907](tel:02038758907))

For queries about Northern Ireland please contact Patrick Malone on patrick.malone@mndassociation.org / [01604 800623](tel:01604800623).

And, if you need support with the issues raised by this campaign, please contact MND Connect on 0808 802 6262 or by emailing mndconnect@mndassociation.org.

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About the campaign

This Autumn the Association has published [Through The Roof](#), a report on the experiences of people with MND and their families during the current cost of living crisis. This was based on a survey of people with MND and their families earlier in the year.

The report found people affected by MND had been disproportionately affected by the crisis. In many cases, this was forcing people to make difficult, and sometimes impossible, choices between spending money on essential living expenses or on maintaining their own health and wellbeing. The report and a summary can be found on the campaign homepage.

The report makes a range of proposals to address this but for campaigning purposes we are focussing on the issue of energy costs. While there have been significant rises in bills for all households over the past two years, again people with MND have been disproportionately affected.



Key figures: how energy prices rises penalise people with MND and their families

- The yearly cost of using and charging assistive equipment costs families, on average, £600 a year. However, families managing advanced MND can spend between £800 and £900 a month on electricity for assistive equipment, equating to an astronomical £10,000 a year.
- Many people with MND rely on assistive equipment to keep them safe, well and independent - but a quarter (28%) of families have said they have reduced their use of personal powered equipment in the last 12 months in response to rising energy costs. The crisis is forcing people to take damaging risks with their own health.



Given this problem, the aim of the Through The Roof campaign is to secure targeted support on energy bills from the UK Government for people affected by MND.

We are keeping an open mind on exactly what this targeted support looks like. There is a wider political debate with different ideas for who should be covered by such a scheme and how it should work. One way of doing this would be an Energy Social Tariff (a discount on energy prices for specific groups), which is a method we favour, but it's certainly not the only way.

The important thing for us is there is a system in place which ensures that people with MND get help, year on year.

The first stage of the campaign calls on the UK Government to come good on their promise to consult on targeted energy support proposals. The Government had promised to consult on this in 2022 and 2023. But this has not happened, and the energy crisis is not over.

By the end of the winter we would ideally want to see:

- The campaign introduced to as many MPs and politicians as possible.
- The issue being discussed at the next All-Party Parliamentary Group meeting.
- Increased awareness that people with MND are disproportionately affected by rising energy bills.
- Short-term measures in place to help during the winter
- A commitment to find a long-term solution and if possible timelines for consultation.
- Links with allies at a national and a local level – together we are stronger!

For more information, please see our campaign homepage at WWW.MNDAssociation.org/ThroughTheRoof.



What we'd like you to do

We'd like you to help us bring the report to the attention of as many MPs as possible. While we can write to MPs directly as the Association, as a campaign volunteer and local resident you are in a unique position to develop relationships with local MPs – your own MP and potentially others covered by your local MND Association volunteer branch or group.

So we'd like you to e-mail the report to local MPs with a personal message which:

- Is tailored to their interest in MND, energy cost issues, or anything else of relevance (see the next page for top tips on research)
- reflects your existing relationship with them if you have one
- invites them to the next meeting of the All-Party Parliamentary Group on MND
- asks them to show their support for people with MND on social media.
- You could also provide the MP with some information about the local branch or group and its activities.

To help with this we've produced a [template e-mail or letter](#) which you can adapt for each MP.

Which MPs should I contact?

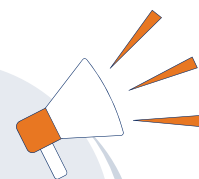
Your own MP is clearly a good starting point as you are their constituent.

But you may then be able to contact other MPs in the local area on behalf of the local volunteer branch or group. Many campaigns volunteers are part of their branch or group so - if this is you - getting permission to do this should be straightforward.

Example:

Jay is a campaigns volunteer in Bassetshire county and is going to write to their MP about the cost of living report. As they are also an active member of the local Bassetshire branch, they speak to the Branch Chair about contacting the four other MPs in the county on behalf of the branch.

The Chair agrees. They suggest that you are clear in each e-mail that the branch covers that constituency and is actively supporting people with MND there. They also ask for a link to the branch website to be included in the copy.



If you don't know your local branch or group yet, this is an opportunity to make contact and offer your help. Contact campaigns@mndassociation.org and we'll put you in touch. Similarly, if you're not sure which MPs are covered by your local branch or group, ask us and we can tell you.

Local MPs who are in Government or in the Shadow Cabinet may not give a direct answer to your e-mail, but by contacting them you are helping bring the issue to their attention, so it's still worth doing.

We also know that some MPs have declared their intention to step down at the next General Election – however as that could be over a year away they still have a job to do. So again, they are worth contacting.

Get to know your MP

Before you send your e-mails. It's important to get to know local MPs, so you can decide how best to appeal to their interests and personalise your message.

If you have a good existing relationship with your MP, you may already know this already – if not the following pointers may be helpful.

Your MP and MND

Check if your MP is an officer of the All-Party Parliamentary Group (APPG) on MND – [we've made the list available here](#). The APPG is a cross-party group of MPs and Peers with an interest in MND which aims to increase awareness of MND amongst parliamentarians and to campaign for better access to high quality services for people affected by MND.

We also held a drop-in event for MPs and Peers in Parliament this July – we've made the attendance list available on the [Campaign Volunteer Facebook group](#) and can send it to you directly on request.

Entering your MP's name and motor neurone disease into a search engine may also turn up any previous public statements on the subject (e.g. type "Rishi Sunak" and "motor neurone disease" – including quote marks).

What else are they interested in?

Every MP has their own page on Parliament's website which you can find using the [search page](#).

This will tell you:

- If they are in Government or the Shadow Cabinet (see the Parliamentary Career tab)
- What questions they have asked on which topics
- Which topics they've debated in Parliament
- Whether they are involved in any other relevant APPGs
- If they have a local website or on Twitter.

All these things can tell you to what extent this MP's interests and activities are relevant to the e-mail. Do they have an interest in health or energy issues, for example, that can be brought into your message?

How to contact your MP

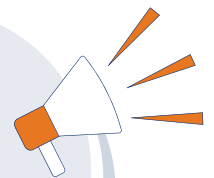
Remember that you don't need to write the letter or e-mail from scratch – you can adapt or take parts from [our template](#).

Since you are contacting MPs as a local representative the best way to contact them is via their constituency office e-mail or postal address. This will either be listed on their page on the Parliament website or on their own local website. If you have any problems finding a contact address for an MP, get in touch with us and we'll help you.

Example:

Jay is researching a local MP, William Pitt. With a bit of internet research they learn that he did not attend the recent drop-in event in Parliament but has asked questions about increases in energy costs as well as putting up a news piece on his personal website about local support available.

Jay can include references to his MP's activities in his e-mail, adapted from the template.



Be sure to include your own contact details and where appropriate your role within the local branch. If it's your constituency MP be sure to provide an address so that they know you are one of their constituents.

Responses

Please send any responses you receive to campaigns@mndassociation.org – we can advise on how to reply to any questions or arguments your MP may have.

Alternatively your MP may be offering to help or meet the Association in your area, and we'd be delighted to help with that too! This could be the next step in building a relationship and finding in them a strong ally for the local MND community.

Other actions

While our priority for Through The Roof is to make sure as many MPs as possible are aware of the report and its findings, there are always other actions that campaign volunteers can take on the campaign. Easy wins include:

- Sharing information about the campaign on social media
- Sharing information about the campaign with your branch, group or other local networks.
- Sharing information about the campaign with your local media contacts. If you need help with this, email communications@mndassociation.org.

You could also ask your local council what steps they are taking to alleviate high energy prices and the cost of living crisis this year. Are there sources of support that could be promoted to the local MND community?

We do have a list of priority MPs we'd like to discuss the campaign with – so we may be in touch with you if we think a local campaign may help.

And if you have any other creative ideas for raising awareness or reaching politicians please do get in touch for a chat!

If you are living with MND or know someone with MND who needs help or support, please contact MND Connect on 0808 802 6262 or email us at mndconnect@mndassociation.org.