Challenging benefits changes: local campaigning toolkit

Campaigners in Parliament to brief MPs ahead of World Parkinson's Day 2025

Introduction

In March 2025, the UK government announced its latest plans to reform disability support. This includes making changes to Universal Credit (UC) and Personal Independence Payment (PIP).

We know from research conducted by Sheffield Hallam University that living with Parkinson's costs more, and many people rely on PIP and UC. The proposed changes will impact people living with Parkinson's and other disabled people across the UK.

Some of the changes won't even be consulted on, so the government won't hear how they will impact the Parkinson's community. This is why we need you!

We're asking campaign volunteers across the UK to speak to their MP, local councillors, and local press to share how the government proposals will impact people with Parkinson's. And urge them to think again.

We're working with the MS Society and Motor Neurone Disease (MND) Association to show the strength of feeling about these changes and how they will impact people with other neurological conditions too.

If you would be happy to invite local campaigners from the MS Society or MND Association to join your meeting with your MP, we can help to coordinate that for you. Involving campaigners from the other charities in any meetings with MPs is a great way to show how many people will be affected in their area.

This toolkit should have all the resources you need to contact your local decision makers and the media. Together, we can stop the cuts.

Checklist of activities

The UK government is due to debate the changes to PIP and UC in June, so we need campaigners to contact their MP, local councils and the media in May and June. We want the government to hear our point of view loud and clear.

Here are the actions we'd like you to take, in order of importance:

1. **Email and meet your MP**: if you're new to campaigning, this is the most important first step.
2. **Email your councillors**: this is a great way to make an impact locally.
3. **Contact your local media:** this will take more time and effort.
4. **Share your activities on social media**: this is quick and easy to do, ideal if you're short on time.
5. **Feedback any progress to us**: this helps us understand which MPs support us and will take action to encourage the government to rethink its plans.

Key proposals and our messages

The key proposals we are campaigning against are in the table below, along with our responses.

Proposal	Our response
A claimant must score at least 4 points for at least 1 daily living activity and score	Making it harder to access PIP in the earlier stages of Parkinson's, by increasing the number of points needed,

at least 8 points overall to be eligible for the daily living part of PIP.	will mean people with the condition will find it more difficult to stay in work. PIP contributes to much-needed support, such as critical aids and adaptations, assistance to maintain a clean home, and continence products. A recent Freedom of Information request found that 48% of people with MS and neuropathic conditions and 36% of people with neurological conditions will lose out on PIP.
The government wants to return to face-to-face assessments and record them as a matter of routine.	Paper-based medical assessments work much better for people with Parkinson's. We think the UK government should look to the Scottish paper-based Adult Disability Payment to learn lessons on what works best.
The government will scrap the Work Capability Assessment and use the PIP assessment process from 2028 onwards.	We think that basing the Universal Credit health element on an assessment process that has been failing people with Parkinson's for well over 10 years is deeply worrying. According to figures from the Department for Work and Pensions, initial decisions on PIP are overturned about 10% more often for people with Parkinson's than for people with other conditions.
People with the 'severest life-long conditions' will be supported and will not be regularly reassessed for PIP**.**	The government has not clearly defined what they mean by this and how they will determine who is in this group. As Parkinson's affects everyone differently, we fear that people with the condition could miss out.

MPs will have to vote on some of the proposals before the Office for Budget Responsibility has published its impact assessment of the reforms. We're concerned about this and want MPs to call for the government to delay any votes on these changes until the assessment is published.

Data and evidence

In the UK, around 153,000 people are already living with Parkinson's.

Broken down within the UK, estimated figures for 2023 are:

- England: 128,000
- Scotland: 12,900
- Wales: 8,300

With population growth and ageing, this is likely to increase to around 172,000 people in the UK by 2030.

Every hour, 2 more people are diagnosed. That's the same as 18,000 people every year.

The number of people with Parkinson's under the age of 50 is estimated at 1,800. 1% of people with Parkinson's diagnosis are under 50.

- 50 to 59 years old: 9,000
- 60 to 69 years old: 28,300

To find more stats and facts about Parkinson's, visit our website.

For more local data and any questions, please contact the Campaigns team on campaigns@parkinsons.org.uk or 020 7963 9349.

Share your story

It's important to have personal stories to give decision makers something they can relate to. We'd encourage you to share your experience of claiming PIP with decision makers, if you feel comfortable, to show what works, and doesn't work, with the system.

What makes a good story?

Your story should:

- be easy to understand and show the problems with the government's plans
- make you sympathetic to the situation by showing how the problem will affect someone.

Get in touch with your local campaigns officer (you can find their details on page 11) if you want any help with sharing your story.

Email or meet your MP

We want to make sure as many MPs as possible hear why the planned changes by the UK government will harm people with Parkinson's and other neurological conditions.

We're working together with the MS Society and MND Association to highlight the impact these changes will have on people with Parkinson's and other brain conditions. This might mean there are opportunities to hold joint meetings with MPs to show how we're stronger together.

Finding your MP's details

- Enter your postcode on the UK Parliament website to find your MPs name, party and contact details.
- If you can, use their local constituency contact details (rather than their London parliamentary ones).
- An MP's personal website will usually tell you what issues they're interested in and whether they're a member of any All-Party Parliamentary Groups (APPGs). APPGs are cross-party groups of MPs and members of the Lords who are interested in a particular issue.

Emailing your MP

You can use this template to email your MP.

Dear [add name of MP],

We are writing from [name of group or branch] of Parkinson's UK and Motor Neurone Disease (MND) Association to ask if you will meet with us to hear how the UK government's disability support reforms will impact hundreds of people living with these progressive incurable neurological conditions in your constituency.

Around 1 in 6 people in the UK live with a neurological condition and organisations estimate around 308,000 people live with 1 of these 3 conditions in the UK.

The government plans will make it harder for people living with these neurological conditions to access financial support to maintain their independence and, where they're able to, remain in employment.

The plans will also see the Personal Independence Payment (PIP) eligibility criteria become stricter, meaning thousands will miss out on support. A recent Freedom of Information request found that 48% of people with MS and neuropathic conditions and 36% of people with neurological disorders will lose out on PIP. This is a huge worry for our communities.

The PIP assessment will be the only way people will get government financial support, and the government wants to increase the number of face-to-face assessments. Each of these fluctuating conditions is poorly understood by assessors, so this will greatly disadvantage anyone living with MS, MND or Parkinson’s.

A group of people living with these conditions would be keen to meet with you to share the impact of the government's plans on accessing PIP and Universal Credit.

Please let us know when would be convenient for you, and we look forward to meeting you before legislation is voted on in Parliament.

Best wishes
[add your contact name and telephone number]

Preparing to meet with your MP

Meetings with decision makers gives you the opportunity to put your message across directly.

As decision makers are often very busy, you’ll probably only have a short time with them, so make it count!

Before the meeting

- Think carefully about what you want to say and write down the key points to take with you.
- Check how long you have with the MP, as it could impact the agenda and which issues you prioritise discussing.
- Get all your evidence together.
- Send information to everyone who will be there (the attendees). This should be a list of the attendees and an agenda or short summary of the issues you want to talk about.
- Be clear what you want your MP to do - ask them to:

    - speak out about the impact of the cuts in Parliament
    - vote against the proposals in Parliament
    - write to the Secretary of State about their concerns
    - urge the government to reform the PIP assessment through consultation with disabled people and health charities before making any other changes to disability benefit payments. This will make sure the assessment accurately captures applicants' needs.
- You can leave this briefing with them outlining the issues and what we want them to do, that's been drafted by the MS Society, MND Association, Parkinson's UK and Neurological Alliance.

At the meeting

- Make notes during or after the meeting to record what was said and who said it.
- Ask permission to take a photo. You can use it in any press or social media posts. Avoid taking photos of people who are under 18 years old.

After the meeting

- Write to the people you met afterwards. Thank them for coming to the meeting and share any photos you took. An email is fine.
- Include a summary of what was discussed and a list of actions that people agreed to take.
- If you don't hear back, get back in touch about 4 weeks later to find out what's happening.

Remember that people will need to sign our consent form for us to use their photo in other materials. You can ask them to fill out our consent form on our website.

Top tip about consent: If a person is not the focus of the image, for example, you can only see the back of their head or they're walking or standing in the background of a shot, consent is not needed.

If you're posting an image of a posed group where everyone is clearly recognisable, it's best to check that they are happy before you post it. Try to make sure there are as few people in the background as possible. For example, take photos against a wall rather than in the middle of a busy hall.

Email or meet your local councillors

Your local authority is an important body to lobby. They deliver a wide range of services (such as disabled parking) and decide which social care services are provided. Some decisions around financial support are devolved locally, you can make a real impact here.

Getting in touch with your local councillor is a good way of making contact with the council, as they have a duty to you as one of their constituents. Each local council will have cabinet members, who are responsible for specific services they provide, and a council leader.

Check your local council website to find the details of your local councillor, the cabinet member who's responsible for personal health budgets (likely to be the cabinet member for adult social care) and your council leader.

In advance of the meeting with your councillor check how long you have, as it could impact the agenda and which issues you prioritise discussing.

What we want councillors to do

- request that the council assess the impact of the cuts on adult social services and to let you and the MP know the results
- make representations within their own party
- speak out in the press.

Letter to councillor template

Dear [add name of councillor],

We are writing from [add name of group/branch] of Parkinson's UK and Motor Neurone Disease (MND) Association to ask if you will make representations to our local MP on how the UK government's disability support reforms will impact hundreds of people living with these progressive incurable neurological conditions in your council area.

Around 1 in 6 people in the UK live with a neurological condition and organisations estimate around 308,000 people live with 1 of these 3 conditions in the UK.

The government plans will make it harder for people living with these neurological conditions and many thousands more to access financial support to maintain their independence, and also where they're able to remain in employment.

The plans will also see the Personal Independence Payment (PIP) eligibility criteria become stricter. And the thousands who miss out on PIP could then be directed to your council's personal health budgets for support.

A recent Freedom of Information request found that 48% of people with MS and neuropathic conditions and 36% of people with neurological disorders will lose out on PIP. We believe that council budgets are already stretched and fear you may be inundated with requests for support that you simply can't meet.

As a group of people living with these conditions in your area, we ask you to make representations about these concerns to our local MP and urge that these issues are picked up in Parliament during the debate on the legislation that will enact these changes.

Best wishes

[add your contact name and telephone number]

Media

Getting the media to cover your campaign will give you valuable publicity, could win you new supporters, and put pressure on decision makers.

Getting coverage in the media

To contact your local media, go online to find newspapers, magazines, or radio stations in your area. You can usually find an email address or phone number for their newsdesk under the 'About us' or 'Contact us' sections of their websites.

When you work with the media, nothing is ever certain. Journalists get lots of requests from people wanting publicity for their cause.

If you don't hear back after initially reaching out to the newsdesk, send a follow up email or call them the next day to give them another chance to review the campaign and get in touch with you if they want to cover the story.

We encourage you to use this template letter to the editor to get the message out to your local media about your campaign activities.

Letter to editor template

Dear editor,

RE: Benefit reforms will push people with neuro conditions into poverty

1 in 6 people in the UK live with neurological conditions such as Parkinson's, MS, and Motor Neurone Disease, and many now face being pushed into poverty by the government's disability benefit reforms.

That's why I am joining them in urging [add local MP's name] and [add council area] councillors to hear our call and speak out on behalf of their affected constituents before it's too late.

Living with a neurological condition costs more and people rely on Personal Independence Payments (PIP) and Universal Credit. The changes, including stricter PIP eligibility criteria and more face-to-face assessments, could see between 36% and 48% of claimants with neurological conditions left without the vital financial support they need. Pushing them further into avoidable poverty.

Under the government's plans, people who lose their PIP will be directed to councils for support through personal health budgets. However, with councils already financially stretched, charities are worried that they won't be able to meet the surge in demand. The Parkinson's UK helpline has already seen a steep increase in calls.

In the coming weeks, these changes will be scrutinised in Parliament, but some changes won't be consulted on. This means that the government won't hear the devastating impact these changes will have on real people. Charities supporting thousands of people living with neurological conditions are urging people to share their concerns with MPs, so vulnerable people don't miss out on the vital financial support they rely on.

Best wishes
[add your contact name and telephone number]

Social media

Don't forget to use social media to promote your activities and build support for your campaign. If you have permission, you can also share any photos of meetings you've had on your social media channels.

Think carefully about what you're writing before you post it. You might want to run your posts by someone to make sure it's clear and says what you want it to say.

Your local campaigns team can work with you to amplify your social media on our channels. Remember to tag the @ParkinsonsUK account in your posts so we can share them.

Social media post templates for Facebook, Instagram and X

- Today I met with [add MP name or handle] to share concerns from people with Parkinson's, MS and MND about planned government benefit changes. I'll keep an eye on Parliament to check they raise them with ministers.

- Today I asked [add councillor name or handle] to take action to safeguard support for people with Parkinson's, MS and MND if they lose their PIP as part of the government benefit reforms

Share your progress with us

Please let us know about any responses or meetings you have with MPs or local councils, as it'll help us understand who supports us. To share any updates, **please complete this Google form**.

The form also gives you the opportunity to comment on the contents of this toolkit and how we could improve the support we provide in the future.

Claiming expenses

You should never be out of pocket when you volunteer with us. Before arranging an event, please speak to your local campaigns team to tell them about the event and what will be required.

You can claim expenses for travel (including mileage and parking), lunch (up to £15) and snacks (up to £10). Read our expenses policy.

Fill out our expenses form to claim your expenses (Excel).

Please send your completed expenses form with receipts to your local campaigns team contact.

If you have any questions, contact your local campaigns team. Remember to send the expenses form to any volunteers after the event and encourage them to claim.

Your local campaigns officer

If you need help or advice with any of your campaigning activities, you can get in touch with your local campaigns officer.

- **Georgina Sait (East):** gsait@parkinsons.org.uk.
- **Jack Grant (London and South East):** jgrant@parkinsons.org.uk.
- **Jenna Lowry-Hubball (Midlands):** jlowry-hubball@parkinsons.org.uk.
- **Mattie Shannon (North East and Yorkshire):** mshannon@parkinsons.org.uk.
- **Kim Snape (North West):** ksnape@parkinsons.org.uk.
- **Rob Davies (South West):** rdavies@parkinsons.org.uk.
- **Sarah Bowdidge (Wales)**: sbowdidge@parkinsons.org.uk

The local campaigns team can put you in touch with MS and MND colleagues if you don't already have contact details.