PIP summer of action:
A step-by-step guide to meeting your MP

Parkinson's UK is a member of the Disability Benefits Consortium (DBC) – a coalition of over 90 charities campaigning to improve the benefits system.

We will be joining the DBC summer of action to support people with Parkinson's to meet their MP to talk about Personal Independence Payment (PIP) and the urgent changes that are needed.

This comes after our petition to improve PIP for people with Parkinson's received over 33,000 signatures. Last month the government announced they would be ending regular reassessments for those on the highest rate of PIP – one of our key asks. Thanks to our campaigners we won!

This guide will help you arrange and prepare for a meeting with your MP, and also has tips on what to do afterwards.

Introduction

What is PIP?

PIP is replacing Disability Living Allowance (DLA) as a benefit that provides extra financial support for disabled people and people with long-term health conditions. It is there to help with the extra costs of their condition.

What are the problems with PIP?

From the experiences of our members and a recent DBC survey of 1,700 PIP claimants, disabled people too often find:

- **The process of claiming PIP is incredibly complex and confusing:** 70% of survey respondents found the PIP application form 'hard' or 'very hard' to complete.
- **Assessments are causing stress and making people's health worse:** over three quarters of respondents agreed that the stress and anxiety associated with their PIP assessment had made their condition worse.
- **Initial assessments are inaccurate:** 65% of PIP decisions which are appealed are overturned in the claimant's favour.
- **People are being reassessed from DLA to PIP and losing support they have been receiving for long periods of time:** 48% of those reassessed from DLA have received a reduced or no award.
- **Shorter awards are meaning people are facing regular assessments** despite no improvements in their condition.

Why should I meet my MP?

Your MP is elected to represent you and your concerns in the House of Commons and your local area. This means they want to hear your views so they can represent you properly.

You can help your MP understand the issues people with Parkinson's who apply for PIP are facing by telling them about your own experiences, or those of people you know.

MPs can then influence what the government does about PIP - so talking to your MP can change PIP, for the better, for everyone.

Liz's story

"I met with my local MP James Brokenshire and it felt positive, he was very encouraging. From the meeting he agreed to contact the Department for Work and Pensions about our concerns and shared their reply with us."

"From our meeting it helped us build a relationship with our MP, and he became more involved with our local group and supported a Parkinson's UK led debate on benefits in parliament."

What needs to change?

The DBC thinks urgent improvements are needed to PIP to ensure that disabled people and people with long-term health conditions can access the support they need. The processes and assessments in place to get this support must understand their conditions.

We call on the government to:

1. **Urgently review the PIP assessment criteria** to ensure these are fair and they reflect the extra costs that people face. Any review must involve disabled people and people with long-term health conditions.
2. **Ensure indefinite PIP awards are available for all people with severe, complex conditions** (like Parkinson's) who have no prospect of improvement or whose conditions are progressive in their nature.
3. **Simplify the PIP claim process.** This could be done by introducing forms that don't have to be returned within four weeks. Forms should be simplified and made available in Jobcentres, to download online and in accessible formats.
4. **Improve staff training and guidance for PIP assessors.** This will help them to get decisions right the first time.
5. **Explore ways to improve the evidence gathering process.** For example, there should be clear guidance given to health and social care professionals and PIP claimants on what is good evidence for PIP claims.

What your MP can do:

- Write to the Minister of State for Disabled People, Health and Work - Sarah Newton MP - highlighting the problems with PIP and urge the government to make urgent reforms to the PIP assessment process.

- If you or someone you know is having problems with PIP, ask your MP to support you with this as well.

Before your meeting

Step 1: Who is my MP and how can I arrange a meeting with them?

Find out who your MP is and how to contact them by entering your postcode on the Parliament website (https://www.parliament.uk/mps-lords-and-offices/mps/).

Write, email or call your MP to request a meeting with them. You should ask what dates they can meet with you.

For most MPs, Fridays will be the best day to meet when Parliament is sitting.

Parliament goes into summer recess on 24 July 2018, which means your MP might be available on days other than Friday after then. They might also be away on holiday over summer, so the best thing to do is contact your MPs office nice and early to find a day you both can do.

You can also invite your MP to come along to a group meeting or another event, if you would prefer. If you do this, make sure it is somewhere you will be able to have a proper conversation with them.

When you write to them, include your full address and postcode in your message. MPs only represent their own constituents (someone that lives in the area they are MP for) and so without your postcode they might not get back to you.

Top tips

- In your first message briefly explain what you want to talk about and why it matters to you. This will help make your message more memorable.
- Keep this to just a few lines, as you can say more in your meeting.
- If you're unsure what to say, have a look at the introduction here for some ideas.
- If you need any support you can contact the campaigns team on campaigns@parkinsons.org.uk or call 020 7963 9349.

What if I don't hear anything back?

MPs get lots of emails and letters every day, so it can take a while for them to reply. If you haven't heard anything after 3 weeks, you might want to try sending them a short reminder and check they received your first message.

You could also try calling their constituency office. The phone number for this office (separate to their Westminster office) will be clearly marked on their page on the Parliament website.

Step 2: How do I prepare for my meeting?

MPs try and meet as many constituents as possible so you may only have 10-15 minutes with them.

The most important thing is to share your own experiences. This is what will matter most to your MP. It can help your MP understand the issue and help them realise how it is affecting people in their area.

Your MP will want to know:

- Why this issue is important to you.
- How it's impacted you, a family member, or friend.
- What the broader problems are with PIP (see 'What are the problems with PIP?' and 'What needs to change?' above).
- What they can do about it (see 'What your MP can do' above).

Make sure you check that your MP's office (or wherever you are meeting) is accessible for you - e.g. if you are a wheelchair user, check there is a ramp.

Top tips

- Prepare a few notes on what you want to say and take them into your meeting to help you remember.
- Check your notes before the end of the meeting to make sure you've said everything you planned to. It's okay to ask your MP to give you a moment to do that.
- Be yourself and don't worry about being nervous. MPs want to hear your views and so should be thoughtful when listening to your story. All the information you provide in the meeting will be confidential.

What should I wear?

Wear whatever you feel most comfortable in. The MP will be wearing smart clothes but you don't have to.

Lastly, **please tell us when you have your meeting booked in.** Contact the campaigns team on campaigns@parkinsons.org.uk or call 020 7963 9349 to share how the meeting went with your MP.

We want to know what MP meetings are happening across the country - but don't worry, we won't share any personal information about you.

During your meeting

Step 3: What will happen on the day?

Try to arrive a little early, so you have time to get to wherever the meeting is inside the building and still have a few minutes beforehand to relax and prepare.

Your MP will meet you with a member of their staff who usually takes notes. It's an informal conversation, so if you want to you can use your notes to remind you what you want to say.

It's possible your MP will be sympathetic, but not agree with your views. Even if your MP doesn't agree with you, you can still ask them to act on the issue on your behalf. They might not agree to do what you ask them, but there might be something else they suggest they could do instead.

If your MP is happy to act, remind them what they've agreed to do at the end of your meeting.

Questions your MPs might ask and suggested answers

- Q: Government research has found that claimant satisfaction rates with PIP are generally high, are these problems only affecting a small group of people?
- A: From the research the Disability Benefits Consortium has done, a large majority of disabled people find claiming PIP stressful and confusing. The statistics around successful appeals also speak for themselves. There are clear problems with the PIP assessment process - but these are problems which can be fixed by the government.

Don't forget to **take a photo** with your MP (MPs love photos!) and share this on social media using the hashtag **#GetAGripOnPIP** to let people know that you're a PIP campaigner!

After your meeting

Step 4: What should I do afterwards?

1. Send your MP an email to thank them for meeting you, remind them what they agreed to do when you met, and ask them to update you on any progress.

2. Let the campaigns team know how it went by emailing campaigns@parkinsons.org.uk or calling 020 7963 9349. Please include:
    - Who you met
    - If they agreed to write to the Minister/what else they agreed to do

The information you share will help us know how supportive different MPs are of the changes we want to make to PIP. And, if your MP is supportive, we'll be able to ask them for help on similar issues in the future.

Even if your MP didn't seem supportive or you think there isn't much to say, letting us know about your meeting may help us to influence in other parts of the country.

3. If you receive follow-up emails from your MP, please send these to the campaigns team on campaigns@parkinsons.org.uk or call 020 7963 9349.

If you need any help or have any questions, you can contact the campaigns team on campaigns@parkinsons.org.uk or call 020 7963 9349.