



**GET IT  
ON TIME**

# Medication on time, every time, in hospitals

A volunteer guide for campaigners in England

**PARKINSON'S<sup>UK</sup>**  
CHANGE ATTITUDES.  
FIND A CURE.  
JOIN US.

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## INTRODUCTION

We want to make sure that everyone with Parkinson's who goes into hospital gets their medication on time – every time.

Too often hospitals struggle to ensure people with Parkinson's get their medication on time, with the majority of people with Parkinson's reporting major failings.

As you will probably know, if people with Parkinson's don't get their medication on time, it can seriously impact their health, and their ability to manage their symptoms may be lost. The person could end up in hospital for longer than planned and, sometimes, the damage can be irreversible.

In the 2015 Parkinson's UK audit, just over 50% of patients said they didn't get their medication on time every time.

We understand hospitals often deal with an overwhelming workload, but it is important that professionals know how vital it is for people with Parkinson's to get their medication on time. Get It On Time is Parkinson's UK's campaign to help improve the system.

Volunteers like you are an important part of making sure everyone gets their medication on time – every time.

We believe there are three key ways to help people get their medication on time:

① Ensure patients who are willing and able are given the option to manage their own medication.

Self-administration policies can empower people living with Parkinson's to take their own medication on time and make sure the routines that enable them to control their symptoms are maintained while they're in hospital.

② Allow carers to visit their loved ones outside official visiting hours. Carers can play a vital role in ensuring medication is taken regularly.

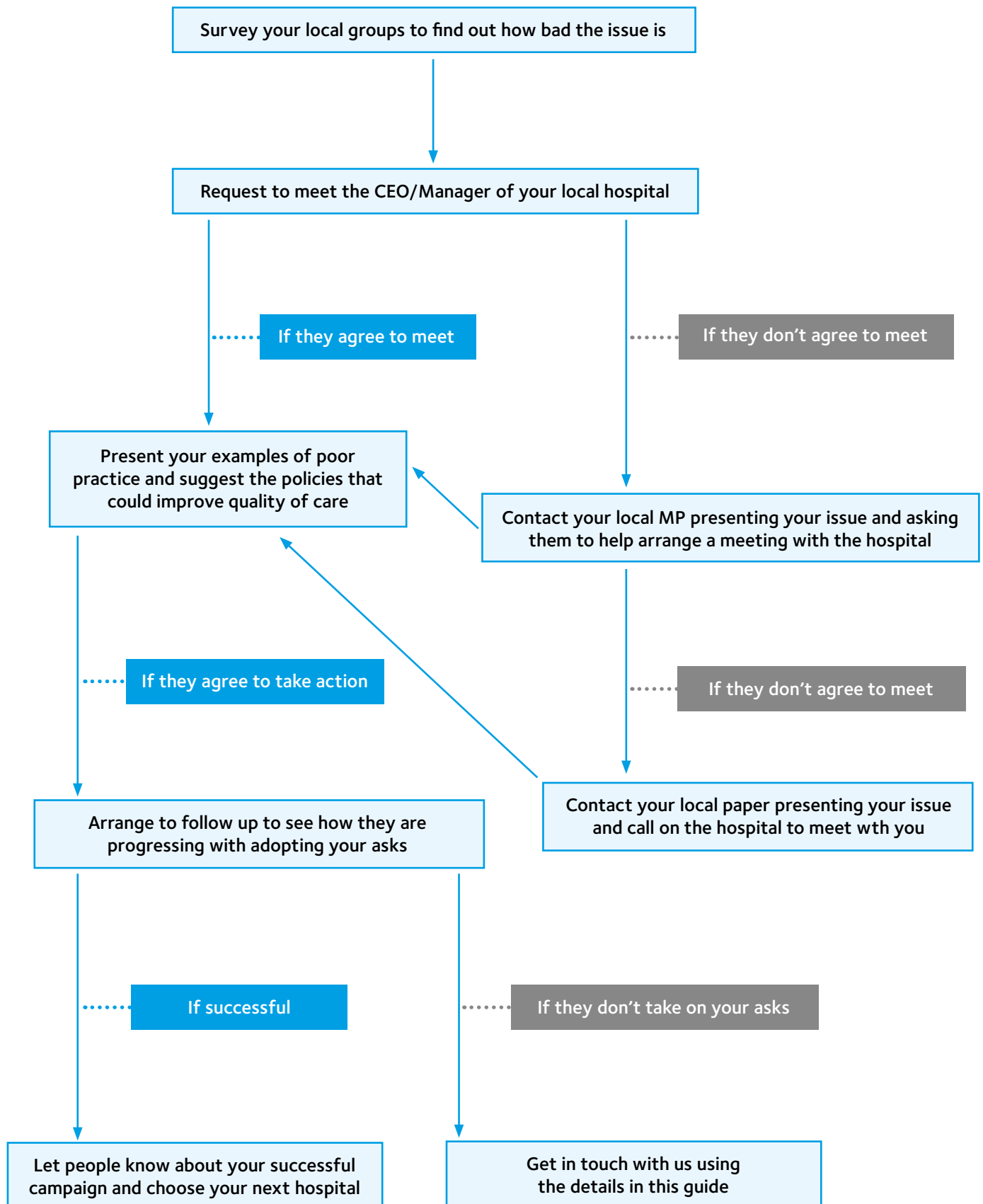
They could either help administer the medication themselves or flag to professionals when medication is needed.

③ Ensure professionals are always aware of how important timely medication is for those living with Parkinson's by encouraging them to access the specialist and free training and resources available from the UK Parkinson's Excellence Network.



## CAMPAIGN STEPS

Our campaign diagram gives you a clear idea of what a Get It On Time campaign looks like:



## CHECKLIST

Here's our checklist of steps for a successful campaign. Later in this guide we'll give you more information on each of these.

- ☐ Identify a hospital to target.
- ☐ Speak to a Parkinson's UK Area Development Manager or Local Campaign Officer about your plan.
- ☐ Gather evidence or case studies.
- ☐ Identify the chief executive of your local hospital using the tips in this toolkit.
- ☐ Write to them with your concerns and ask for a meeting.
- ☐ Follow the letter up four weeks later if you haven't heard anything.
- ☐ If your hospital trust still doesn't respond, contact your MP or write a letter to the editor of your local newspaper outlining your concerns.
- ☐ Prepare to meet with the hospital if they agree.
- ☐ Conduct a meeting with the hospital and key people who work there (the head of nursing, hospital manager and medication safety officer).
- ☐ Thank them by letter or email after your meeting, summarising the steps they agreed to take to help.
- ☐ Two weeks after your meeting, follow up any actions the hospital agreed to undertake for you by letter or email.
- ☐ Complete the feedback form to let our Policy and Campaigns team know how you got on.
- ☐ Share any news with groups and supporters locally.



## GATHERING EVIDENCE

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To get a hospital's attention you will need to prove there is an issue in your area. If you have a personal story of being in hospital and not getting your medication on time, this will be a powerful way of demonstrating the problem.

You could also talk about the experiences of friends or family.

The next challenge is helping the hospital understand that you are not an isolated case.

Here are some tips to help you:

- Connect with someone else in your area who has had similar problems and ask them to help with your campaign by coming along to meetings with the hospital.
- Collect case studies from the people you know or you meet. Their personal experiences of when care hasn't been good enough can help your campaign. Get them to write down their experience and get their permission to share it with decision makers.
- Take our questionnaire to your local Parkinson's groups (we have an example of one you could use on page 7). You can find your local group by going to **[parkinsons.org.uk/localgroups](https://parkinsons.org.uk/localgroups)** – contact them to ask for a meeting slot to speak about the campaign and your plans.
- Talking to your Parkinson's nurse or Parkinson's local adviser – they may be able to talk to people locally about your campaign and link up those who are interested.

Next, find out if your local hospital already has a policy which lets:

- patients, or their carers, administer their medication
- carers visit outside usual visiting hours.

If you can't find information on the hospital you want to visit, get in touch with us using the details below or you can write a letter and ask them to share their policies with you.

If you find that your local hospital doesn't have policies in place, then these can be your clear campaign asks when you meet with the hospital manager, head of nursing and/or medication safety officer.

If your local hospital already has these policies but you know people aren't receiving their medication on time, every time, then you could argue the policies aren't being used well.

You could focus your campaign on asking for better enforcement of these policies, as well as promoting Parkinson's training for the professionals who work in the hospital.

Free training and resources aimed specifically at professionals to support them in improving care for people affected by Parkinson's can be found via the Excellence Network.

Professionals can find out more at **[parkinsons.org.uk/excellencenetwork](https://parkinsons.org.uk/excellencenetwork)**

If you find that local groups don't have a major issue, and there are already good policies around medication, that's great news. Why not look at other hospitals in your area to see if they're doing just as well.

Use the questionnaire on page 7 to gather local information. Ask people you know who are affected by Parkinson's (including carers, family and friends) to fill it out, or you can take it to local groups and branches.

If you need any more support or advice please email us on **[campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)** or call on **020 7963 9349**.

## GET IT ON TIME QUESTIONNAIRE

We're campaigning at local hospitals to help make sure people with Parkinson's get their medication on time – every time – whenever they're in hospital. Will you to help by answering these questions?

**1 Which of the following best describes you?**

- ☐ A person with Parkinson's
- ☐ An unpaid carer, friend or family member of a person with Parkinson's
- ☐ A paid carer of a person with Parkinson's

**2 What's the name of your local hospital?**

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Please answer the following questions about the hospital you have named here.

**3 When was the last time you, or the person you care for, visited your local hospital?**

- ☐ In the past month
- ☐ Less than six months ago
- ☐ Less than a year ago
- ☐ One to two years ago
- ☐ More than two years ago

**4 Did the hospital let patients take their own medication?**

- ☐ Yes
- ☐ No
- ☐ Sometimes
- ☐ Not sure

Additional comments

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**5 Did the hospital let carers stay outside visiting hours to help with medication?**

- ☐ Yes
- ☐ No
- ☐ Sometimes
- ☐ Not sure

Additional comments

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**6 During the most recent visit, did you, or the person you care for, always get medication on time?**

- ☐ No, none of the medication was given on time
- ☐ Partly, some of the medication was given on time, but other medication was not
- ☐ Yes, the medication was given on time, because I reminded staff
- ☐ Yes, the medication was given on time without needing to remind staff
- ☐ Not sure

Additional comments

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**7 If your medication was not given on time, how did it affect you?**

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**8 Would you like to support this campaign to make sure medication is given on time – every time?**

- ☐ Yes
- ☐ No

**If you said yes, please let us have your contact details:**

Name:

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Address:

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Telephone number:

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Email address:

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## ASKING FOR A MEETING

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Once you've collected evidence for your campaign you need to ask for a meeting with the local hospital.

Ideally, a request to meet should go to the chief executive of the local hospital. You can find this out on the hospital's website. You could also try an internet search using your hospital's name with 'chief executive'.

You can use the template letter on page 9 to send in the post or via email. Please feel free to customise the letter and include the personal stories you've worked hard to gather.

The more specific you are, the more likely the hospital is to engage with you.

We suggest you also ask to see the head of nursing, hospital manager and medication safety officer.

These people will be instrumental in building policy and practice that ensures everyone gets their medication on time – every time.

Make it clear in the letter if you intend to take a friend, family member or fellow campaigner to the meeting or if it's just you.

Make sure no more than four people attend the meeting, otherwise it could be quite difficult to manage.



[Insert chief executive name]

[Insert your name and address]

[Insert hospital address]

[Insert date]

Dear [Insert name of chief executive]

**Re: Parkinson's UK – Get It On Time campaign meeting**

I am writing to ask if you could arrange a meeting with your trust's hospital manager, medication safety officer, chief nurse or director of nursing, me **[and/or]** a person affected by Parkinson's to discuss keeping people with Parkinson's safe and well.

It is vital that people with Parkinson's in hospital get their medication on time, every time. Late or missed medication can have serious consequences for a person with Parkinson's. Their symptoms can get out of control quickly, causing distress for everyone involved. Sometimes the deterioration they experience can be irreversible. They can also end up needing to stay in hospital longer if their medication is not given on time.

Yet the majority of people with Parkinson's who go into hospital do not get their medication on time. In the 2015 Parkinson's UK audit, just over 50% of Parkinson's patients reported not receiving their medication in hospital on time, every time.

**[Insert any local examples you may have here]**

It is vital that medicines administration is done efficiently and effectively to ensure people with Parkinson's remain in control of their condition, and also to minimise the financial impact on NHS trusts due to excess bed days.

There are three actions that hospitals can take to improve the safety of people with Parkinson's:

- Having a self-administration policy, so that those who can take their own medication are able and supported to do so.
- Allowing carers to stay outside visiting hours and, if they choose to do so, support the person with Parkinson's to take their medication.
- Encouraging professionals to access the UK Parkinson's Excellence Network's free training and resources on the condition to stay better informed.

I would be grateful if you would arrange a meeting as soon as possible to discuss the above and other possible solutions to ensure people with Parkinson's get their medication on time when in hospital.

I look forward to hearing from you.

Yours sincerely,

**[Insert your name]**

## If they don't get back to you

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If the trust doesn't respond to your requests for a meeting there are still steps you can take. If after two weeks they've not responded, reach out to the chief executive in another way, calling or emailing them again or their PA.

Otherwise it might be worth asking your MP for help with arranging a meeting. Your MP is there to represent you and should be able to help facilitate a discussion.

We've created a template letter you can post or email to your MP. You could also visit your MP at their regular surgery in your local area.

You can find out the details of your MP by putting in your postcode at **[www.theyworkforyou.com](http://www.theyworkforyou.com)**

Or you can call the House of Commons information office on **020 7219 4272** to get your MP's details. If you know their name already you can write to them at: House of Commons, London SW1A 0AA.

Most MPs use email and you will find their email address on their website. You can also find details of their next local surgeries on their website. If more than one MP represents the area the hospital covers it may be worth reaching out to them as well.

If your MP isn't responsive, or is unable to help facilitate your meeting, your next step is to reach out to the local papers. An example of a letter you can send to the media is on page 11.

The more you can adapt the letter for your own campaign, with experiences of local people, the more effective it will be.

You can include stories that have been anonymised.

You can find out how to send the letter to your local paper either by going onto the newspaper's website or by looking at the instructions on their letters page.



**[Insert your name and address]**

**[Insert MP name]**

**[Insert address]**

**[Insert date]**

Dear **[Insert name of MP]**

**Re: Parkinson's UK – Get It On Time campaign meeting**

I am writing to ask if you could help arrange a meeting between **[insert local hospital]**, me **[and/or]** a person affected by Parkinson's to discuss keeping people with Parkinson's safe and well in hospital. It is vital that people with Parkinson's in hospital get their medication on time, every time. Late or missed medication can have serious consequences for a person with Parkinson's, with symptoms getting out of control quickly, causing distress for everyone involved. Sometimes the deterioration they experience can be irreversible.

Yet the majority of people with Parkinson's who go into hospital do not get their medication on time. In the 2015 Parkinson's UK audit, just over 50% of Parkinson's patients reported not receiving their medication in hospital on time, every time.

**[Insert any local examples you may have here]**

It is vital that medicines administration is done efficiently and effectively to ensure people with Parkinson's remain in control of their condition, and also to minimise the financial impact on NHS trusts due to excess bed days.

There are three actions that hospitals can take to improve the safety of people with Parkinson's:

- Having a self-administration policy, so that those who can take their own medication are able and supported to do so.
- Allowing carers to stay outside visiting hours and, if they choose to do so, support the person with Parkinson's to take their medication.
- Encouraging professionals to access the UK Parkinson's Excellence Network's free training and resources on the condition to stay better informed.

We have struggled to get a response from the local hospital. There are urgent issues that need addressing, and so we would appreciate your help in pushing this issue up their agenda.

I look forward to hearing from you.

Yours sincerely,

**[Insert your name and contact details]**

## CONTACTING YOUR LOCAL NEWSPAPER

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Getting in touch with the local paper is your next step if the local hospital and your MP aren't engaging with you. Getting the issue into the local paper can help draw wider support for your campaign. We've written an example of a letter you can send out. The more you can adapt the letter for your own campaign with experiences of local people, the more effective it will be. You can find out how to send in letters to your local paper either by going onto the newspaper's website, or by looking at the instructions on the newspaper's letter page.

### How to write a letter to the editor

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Be brief – use around 100–150 words. Get to the point quickly. Make the argument for your campaign clearly and concisely and show what impact this would have locally. Say how you feel – if you're outraged, disappointed or desperately worried, you can say this. Always back up your statement with a compelling reason why and offer a solution. Make sure you include your contact details so they can come back to you.

### Template letter to editor

[Download the template letter here](#)

**[Insert your name and address]**

**[Insert editor name]**

**[Insert address]**

**[Insert date]**

Dear **[Insert name of editor]**

**Re: Our hospital must listen to people with Parkinson's**

It is vital that people with Parkinson's in hospital get their medication on time, every time. Late or missed medication can have serious consequences for a person living with Parkinson's, with symptoms getting out of control quickly, causing distress for everyone involved. Sometimes the deterioration they experience can be irreversible. Our local hospital has not always managed to ensure medication is on time every time for patients.

**[Insert any local examples you may have here]**

There are simple remedies that **[insert local hospital]** could pursue but they have so far not engaged with local campaigners. It's vital that patients are allowed to administer their own medication, if they would prefer, or have their carer visit outside the usual hours to help with this. People's long term health is at stake and we are willing to work with them to improve this situation in **[add area]**.

Yours sincerely,

**[Insert your name and contact details]**



## RUNNING A GOOD MEETING

When you get a date for your meeting with the hospital, preparation beforehand will be vital. Making it really clear what you're asking for will help make the meeting as effective as possible.

### Top tips for before the meeting

- Get all your evidence together.
- Send information to everyone who will be there (the attendees). This should be a list of the attendees' names and an agenda or short summary of the issues you want to talk about.
- Make sure you're clear about our three asks: a self-administration policy, letting carers visit outside official hours, and encouraging staff to use the UK Parkinson's Excellence Network's free training and resources.

Be clear yourself about what we're asking for. Take this summary of the campaign ask with you for reference in the meeting:

- The hospital should give people the choice about whether to self-administer their own medication, if they are willing and able to do so. Self-administration policies should be created and in regular

use. Patients should be assessed on entry as to whether they would be suitable for such a policy and their status should be communicated with all relevant staff.

- Carers should be allowed to visit outside official hours and, if appropriate, be given the freedom to help administer medication.
- The hospital should give staff access to the free Parkinson's UK training that can help professionals to understand the importance of timely treatment for people with Parkinson's.

A good self-administration policy should cover some core issues, spelling out how patients will be assessed and supported for self-administration and whether carers will be involved too.

The hospital should consider too how any changes might be managed, for instance, immediately after surgery.

### Top tips at the meeting

- Ideally, you should start the meeting by detailing the problems encountered in your local area. Talk about your own story or the other people you have spoken to.
- Make your points clearly, concisely and politely using evidence and the examples you have gathered.
- Make notes during the meeting or just afterwards to record what was said and who said it so you can hold them to account on any commitments they

make. If you can, have another attendee take notes too so you can concentrate on the conversation without worrying about missing things.

- Agree how you will follow up on their commitments. Will you organise a second meeting later on in the year? Will they keep in contact and provide updates on progress?
- Try to ensure the agreements are summarised before the end of the meeting.

### Top tips after the meeting

- Write to the people you have met, thanking them for their time. 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 in touch about four weeks later to find out what's happening.

If the hospital agrees to your requests, first of all, well done! It might be worth thinking about how to stay in touch to ensure progress is made and built on. Could the hospital amend their training, or have a working group involving people affected by Parkinson's?

Do share your success with Parkinson's UK staff so they can celebrate it and inspire others.

You could organise a second meeting, a couple of months later, to give you the opportunity to discuss what progress has been made against your agreed actions. Make sure you prepare for this meeting by reminding yourself of what was agreed. If the meeting was less positive, you may wish to go back a few steps and request another meeting.

Have a look at our guidance on engaging your MP and local newspaper and try to involve them as well. Leveraging your MP and newspaper can encourage your hospital to take your campaign more seriously.

Celebrate any success to inspire others. You can share your campaign successes with **[campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)** and we can help spread the word.



## THANK YOU

Thank you for taking the time to look through this toolkit. We hope you've found it a useful guide on how to start a Get It On Time campaign.

We'd be delighted to hear from you about how your campaign is going or if you need support.

Please use the feedback form to let us know about any meetings you've had.

If you need any more support or advice please email us on **[campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)** or call on **020 7963 9349**.

## FEEDBACK FORM

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Name

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Group or branch

---

Telephone

---

Email

---

Name of local hospital contacted

---

Name of chief executive contacted

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Who did you meet with?

---

What did you discuss?

---

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What did the hospital agree to do?

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How will you keep in touch with the hospital to track progress?

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Do you think the resources provided were adequate?

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Add any more comments

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Please return this form in the post to: Policy and Campaigns team, Freepost RLUB-RSHA-KSET,  
Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ.  
Or via email on **[campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)**



## JARGON BUSTER

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The health system has lots of jargon, here are a few terms you may come across during your campaign.

### Hospital trusts

A hospital trust is an organisation that runs a public hospital and provides services for a local area. These services include things like Accident and Emergency and specialist care.

### Self-administration policy

A self-administration policy is something hospital trusts should have in place. However, they may not have one, or they may have one that is not actively used or promoted to staff. A good self-administration policy allows patients, and their carer if appropriate, to be in charge of their own medication.

### Medication safety officer

This is the person responsible for managing medication procedures and policies in a local hospital. Getting them on board is a key part of the campaign.

### Clinical Commissioning Group (CCG)

They are in charge of organising and providing healthcare across a local area. They will be responsible for contracting services from local hospitals, GPs and other providers.



Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day  
when no one fears Parkinson's.**

Parkinson's UK  
215 Vauxhall Bridge Road  
London SW1V 1EJ

Free confidential helpline **0808 800 0303**  
(Monday to Friday 9am–7pm,  
Saturday 10am–2pm). Interpreting available.  
Text Relay **18001 0808 800 0303**  
(for textphone users only)

**hello@parkinsons.org.uk**  
**parkinsons.org.uk**