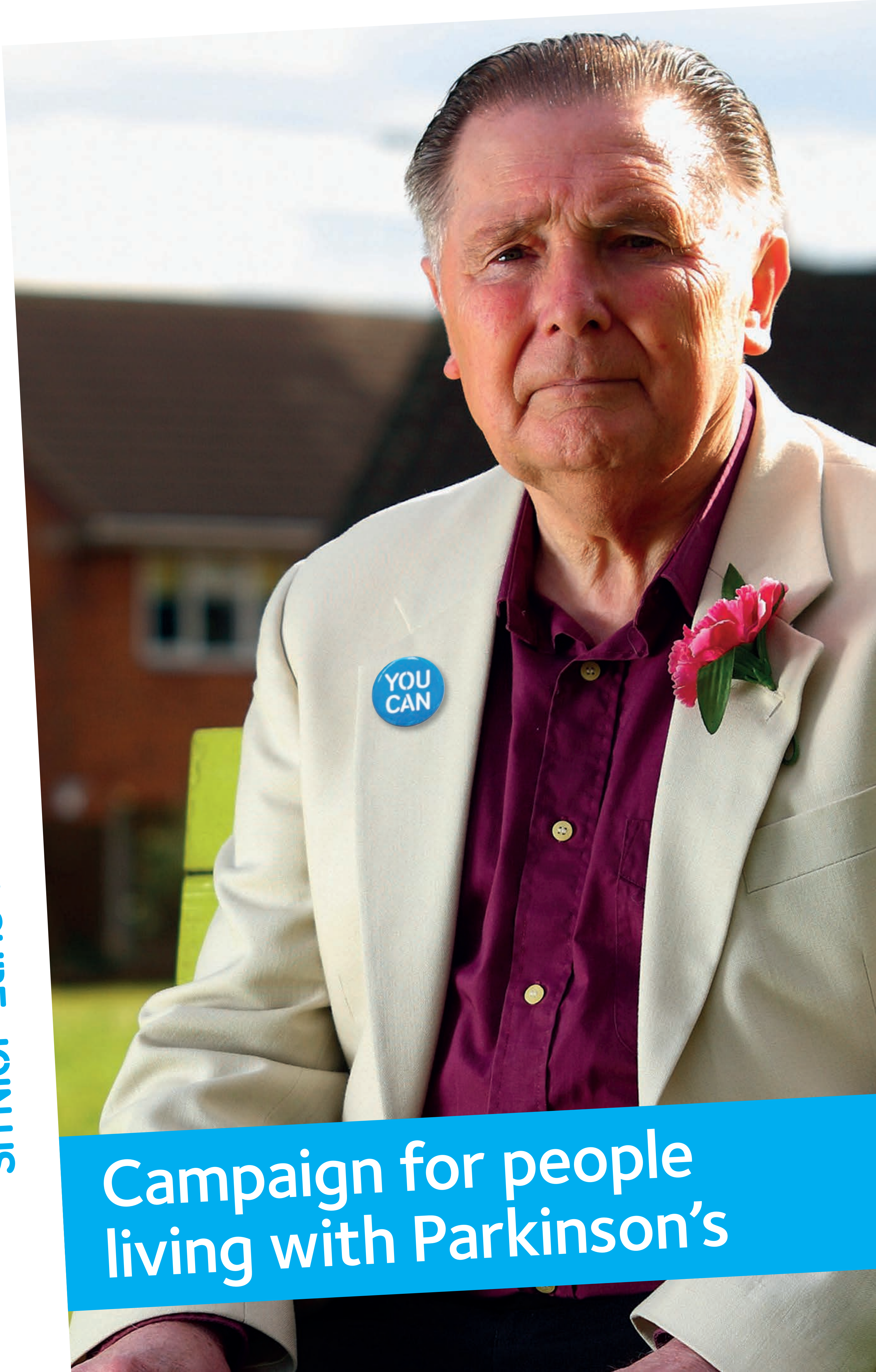
PARKINSON'S UK

CHANGE ATTITUDES. FIND A CURE. JOIN US.



Campaign for people living with Parkinson's


PEOPLE
LIVING WITH
PARKINSON'S
VOTE

CONTENTS

GETTING STARTED

PLANNING YOUR CAMPAIGN

TAKING ACTION

KEEPING MOTIVATED

RESOURCES

NB: This is the Wales version. You can get a version for Scotland, Northern Ireland and England at **parkinsons.org.uk/campaignstoolkit** or by calling **020 7963 9349**.

SO YOU WANT TO CHANGE SOMETHING...?

Do you want decision makers to understand the needs of people living with Parkinson's – and give them a fair deal?

Do you want to improve your local health and care services?

Are you already working to improve life for people affected by Parkinson's and want to do more?

You can make your voice heard

This toolkit will help you. It's designed to make you feel ready and able to campaign for better services for people living with Parkinson's.

You don't have to read it all! You can dip into it for help with something particular, such as writing to your local health body. Or you can use it as a step-by-step guide to running your own campaign.

1. YOU CAN DO IT

You have the power to create change.

2. PLAN

Decide:

What are you aiming for?
What evidence is there that change is needed?
Who should you target and who will help you?
How will you get what you want?
When are key deadlines for action?

3. BUILD SUPPORT

Create your messaging with great real-life stories and evidence. Then spread it with leaflets, posters, social media and stories in the media.

4. TAKE ACTION

Make sure your voice is heard with the actions that best fit your campaign.

- Send letters to decision makers/the media.
- Start petitions.
- Meet with decision makers.
- Organise events or stunts.

5. KEEP IT GOING

Be persistent – you might not get everything you want the first time you try. Take your campaign one step at a time and make sure to celebrate every success on the way. Remember everything you do raises awareness of Parkinson's, so it's making a difference.

> “It's fantastic what people have achieved through campaigning. If you decide to go for it, you can count on our support every step of the way.”
>
> **Steve Ford, CEO, Parkinson's UK**


YOU
CAN

GETTING STARTED

#YOUCAN

WHAT IS CAMPAIGNING?

If something affects you – or someone you care for – and you do not agree with it, you can ask for it to be changed. This is campaigning.

You can

- **Make a difference on your own.** You don't have to be part of a group to make a difference. There are lots of things you can do that fit around your commitments – such as writing letters. Small actions can lead to change.
- **Start something big.** Many successful campaigns start with one person deciding they want to change something.
- **Join an existing campaign.** We're constantly campaigning to improve life for everyone affected by Parkinson's. Find out more at **parkinsons.org.uk/campaigns**

> "We campaign for Parkinson's awareness to make sure that people feel safe and welcome in their area. We have worked to improve the bus companies, pharmacies and local shops with great results. You just need to knock on the door, explain the problem and offer the solution. Reach out and make contact. You can make a difference."

Dave Logan, Swindon Branch

WHY ARE YOU CAMPAIGNING?

Campaigns don't need to be about huge UK-wide issues. Focusing on a local problem actually gives you more chance of success.

There may be many problems with your local services, but it's best to focus on one thing at a time. Think about what would provide a better life for people with Parkinson's in your area and make this your priority.

It could be:

- better access to physiotherapy, occupational therapy or mental health services
- a Parkinson's nurse
- disabled parking for your area

Got your issue? Get to know it!

The more you know about your issue, the more likely it is your campaign will succeed.

You will need:

- **facts and figures** – how many people are affected? Will the change you want save money? Will more people end up in hospital if a service is not available?
- **real life stories** – how does your issue affect people and their families?
- **proof of public concern** – how many other people are concerned about this and how strongly do they feel about it? Remember every adult is a potential voter and everyone is a potential customer.

Looking deeper into your issue will help you ask for the right change. For example, if a service is closing there may already be plans to replace it. If so, you might want to make sure the new service meets the needs of people with Parkinson's rather than campaigning to keep the old one open.

Gerald

Want to join one of our campaigns instead?

If there isn't a specific issue affecting you locally, you can still make a difference. Parkinson's UK has lots of campaigns you could join. To find out more visit **parkinsons.org.uk/campaigns**
call **020 7963 9349** or
email **campaigns@parkinsons.org.uk**

You can find out more about how to get the information you need on **page 24**.

WHO ARE YOU GOING TO CAMPAIGN WITH?

You can campaign alone

If you have a lot of commitments, you may find it easier to concentrate on things like writing letters or starting petitions. We'll give you any help you need.

Find out more about letters and petitions on **pages 44 and 48**.

You can set up a campaign team

Chances are you're not the only person who would like a local service to improve. So it may make sense to form a campaign team.

Here's how

First you need to find people to support you. They could be:

- your local Parkinson's group – see **parkinsons.org.uk/localgroups**
- other patient groups in your area
- disability rights groups
- local health and social care service users and staff

See page 66 for contact details of groups who may support you.

Talk to Parkinson's UK – we can ask our members in your area to join you.

Don't forget friends and family – they may also want to help.

You might want to hold an open meeting to discuss your issue and see if anyone is interested in joining your campaign. We may be able to help – contact **campaigns@parkinsons.org.uk**

Tips for building a successful team

- Get people together as early as possible.
- Make sure everyone understands and agrees on the issue.
- Make decisions together so everyone feels part of the team.
- Choose a leader/co-ordinator to make sure decisions are made and things get done.

People to support your campaign

Supporters are vital to the success of your campaign. Everyone you can get on side counts, from the person who signs your petition to your local politician.

See page 20 for details of how to encourage people to support your campaign and how you can find them.

HOW TO MAKE THE MOST OF YOUR CAMPAIGN TEAM

Everyone has different skills and different amounts of time they can spare for your campaign. You need to find out what they are so you can make the best use of them.

Get everyone in your team to write down their skills and the amount of time they want to give so you know what you have to play with. It's also a good idea to ask if anyone has any connections that may be useful to you.

WORKING TOGETHER MADE A DIFFERENCE

Jenni McCabe

“Working together is crucial. You don’t need to feel like a separate volunteer. A joint campaign by staff from the Parkinson’s UK Wales office and volunteers from branches led to another Parkinson’s specialist nurse post being created. Together we were a forceful team that won through after seven years of campaigning.

This was down to our determination and the expertise of staff in the Wales office, coupled with the enthusiasm and commitment of many members of local groups. When people in power hear experiences from the heart, it makes a real difference.”

PLANNING YOUR CAMPAIGN

All successful campaigns have a good plan behind them. It will help you stay on the right track and will keep you going. Ticking off each step as you achieve it is a really great feeling.

Things to think about:

1. **Your campaign aim**
2. **Setting goals**
3. **Timing**
4. **Your audience**
5. **Your messages**
6. **The resources you'll need**

1. YOUR CAMPAIGN AIM

What (exactly) do you want to do?

Write down the change you want to see in one clear, short sentence (20 words max). This is your campaign aim. It's really important not to lose sight of this as it will keep everyone focused and motivated.

Your aim may look ambitious but don't panic! You can do it if you take one step at a time. These smaller steps are your goals.

2. SETTING GOALS

Setting (and achieving) your goals

- **Write down the things you need to do to achieve your campaign aim**.
  Think about raising awareness, getting supporters, gathering evidence and meeting the people who have the power to change things, such as politicians or NHS managers.
- **Narrow these down to specific targets**
  These could be things like numbers of supporters, signatures on a petition, collecting real-life stories and other evidence to back up your campaign.
- **Decide which goal is your top priority**
  You may want to start with raising awareness or signing up supporters.
- **Put all your goals in order**
  Which are the most important and which are the easy wins?
- **Make someone responsible for each goal**
  Make the most of your campaigns team if you have one and give people a goal to achieve.

More goals

You may find that as your campaign goes on you identify more goals. This is normal – the list should change and grow as you campaign. It's a sign that you're making progress!

See page 16 for examples of some campaign goals.


WHAT ACTIONS CAN SUPPORTERS TAKE?
TIMINGS
GOALS
ALLS TO ACTION
MESSAGES
AUDIENCES
RESOURCES

Example of a campaign goal and action plan

Keep this clear and concise

Local supermarket awareness campaign plan

Campaign aim: Raise awareness of Parkinson's so supermarket staff give people the help they need at the checkout.

Goals:

1. Find out what people with Parkinson's think about the supermarket's service using a survey.
2. Gather five personal stories of bad experiences in the supermarket.
3. Collect 150 petition signatures to show support for employee training.
4. Get a story in the local newspaper.
5. Get support from local MPs.
6. Local supermarket agrees to make staff aware of Parkinson's.

Be ambitious but stay realistic

Make them measurable so you know when you've achieved them!

Goal	Action	Key dates/ deadlines	Priority	Person Responsible	Achievements
Collect 150 signatures to show support	Run stall in high street to collect signatures	Meeting local MP– 16 November	High	Liam	200 signatures collected New volunteer signed up at stall
Meet with store manager to discuss best solutions	Contact store manager	Meet on 24 November	High	Bob	Meeting held, manager agreed to discuss things with head office

See page 68 for an action plan template you can use.

3. TIMING

Timing can make or break a campaign.

It's a lot easier to stop something happening in the first place than it is to get a decision reversed.

What are your key dates?
Identify the key dates around your campaign. Often, decision makers have to make certain decisions on set dates. They may not be able to consider changes at other times.

There may also be events you could use to publicise your campaign. For example, you could hand in your petition at a public meeting that decision makers have already organised.

Create a timeline

Timelines help you plan effectively (see below for an example).

Your timeline could work something like this.

The public meeting discussing the closure of the day centre is 28 May.

You need to make banners. This takes two weeks. So you plan to start banner making on 14 May.

You also need to give people three weeks' notice to attend the meeting. So you send out an email alert on 7 May.

HOW TO DO THINGS AT THE RIGHT TIME

- Find out when key meetings will take place.
- Identify any other good opportunities coming up.
- Make sure you get information to your target audiences, your partners and the media in plenty of time so that they can read it and consider their response.
- Count back from key activities and opportunities to plan in your work.
- Try to avoid campaigning at downtimes like the summer holidays when people will be away.

Timeline

Frank, David and Nadra

THE RIGHT TIMING HELPED TO GET MY POINT ACROSS

“When I became a carer for my husband, I felt that there was no support or information for me. I was angry that no one was looking after carers. I wanted to share my experiences to try and raise awareness and make it better for others.

Particular events made it much easier for me to let people know about the need for better communication for carers. For instance, during Carers Week I went to an event and talked to MPs. When I asked them what they knew about Parkinson’s, most of them talked about shaking! They really listened to me though and said it was so good to have someone tell you how it really is.

There were lots of other carers there too and they were all talking about the same problems. This was good because it showed the MPs what was important. I took up all the opportunities I could to get the message across. I’ve been to an event in the House of Lords and to a conference on dementia as that is an aspect of Parkinson’s I am interested in too.”

Barbara Lee

4. YOUR AUDIENCE

You know what you want and when you need to ask for it. Now you need to work out who to talk to. This is your audience.

There are different groups of people you need to reach. They are:

A. Your target(s)
The people with the power to make decisions and change things.

B. Your campaign champions
The people who can help you reach and influence the decision makers.

C. Your partners
The people who can add validity and weight to your campaign.

D. Your supporters
The people who can help you make your voice heard.

A. Your target(s)

Your targets are the people who make decisions about the campaign issue you've chosen. They can make the change you're campaigning for.

HOW TO FIND YOUR TARGET

You need to identify the person who has the ultimate responsibility for your campaign issue and the power to make the change you want.

It might be

- politicians
- a health body – an NHS health board
- senior staff at your hospital

For example, if your campaign is part of Get It On Time (our work to make sure people with Parkinson's get their medication on time in hospital and care homes), your target could be the chief executive of the hospital trust or health board. That's because they'll be able to make decisions to improve the experiences of people with Parkinson's in hospital.

Getting your target on side

You need to provide compelling evidence for them to agree to your proposed change. This means facts and figures, real-life stories and proof of public feeling about your campaign.

Be polite and very clear about what you want people to do for you – ask for something specific rather than just a general request to improve things.

B. Your campaign champions

You need campaign champions when it's hard to reach your target straight away.

Campaign champions are people your target will listen to. They will help you to meet your target or talk to them for you.

HOW TO FIND CAMPAIGN CHAMPIONS

Look for the people who are connected to your target or who have influence locally.

They might be:

- the patient experience or involvement team/service in your hospital
- your GP, consultant or nurse
- politicians
- the media – eg your local paper or radio station

Things that might help

Write down everyone you know with a connection to your campaign issue. You might be surprised to find who you already know in your area that can help you. For instance, do you know a local councillor, people in local patient groups or people in your local newspaper or radio station?

Think who could be a stepping stone.There may be people who can help you get to your target. For example, your local GP may have contacts on the local health trust or board.

If your target is the chief executive of a hospital trust or health board, see who else sits on the board. Could you talk to them too?

David and Hazel

Think who would be sympathetic to your cause. Are there people you know, such as the head nurse or someone in charge of patient experience, who can champion your cause for you?

(Please note – NHS employees may not be able to support your campaign formally if it is against the trust/board but they may point you in the right direction.)

Getting your campaign champions on side

Ask to meet them. At your meeting you should:

- discuss your concerns
- outline your solutions
- show them your evidence
- ask their opinion

If they agree with you, ask them if they can help raise awareness of your campaign. Keep in touch and then you can ask for help if you can't reach the decision maker.

C. Your partners

These are people you can join forces with to make your voice heard.

HOW TO FIND YOUR PARTNERS

- Think who else would benefit from the change you want to make. Would it help people with other neurological conditions? If so there may be other charities and support groups who will help you, such as the MS Society.
- See if there are campaigning groups, such as disability rights organisations, who will help.
- Get in contact with Parkinson's UK as we can tell you which charities and alliances we have links with in your area.

You can find details of groups and charities that might support you on **page 67**.

Getting your partners on side

When you have identified people who you think could help, get in touch and give them a short summary of the issue. Tell them why you think it affects them and ask them to join your campaign.

How much can they help?

It's a good idea to offer people a choice of how to get involved. For example, you can ask them to sign a simple statement of support. At the other end of the scale you could see if they want to help shape and run your campaign.

D. Your supporters

Sometimes it may be possible to get the change you want just by meeting decision makers. However, in many cases you will need to show the decision maker that your issue has a lot of public support. The more people you can get involved the better.

HOW TO FIND YOUR SUPPORTERS

Look for people who are likely to be sympathetic. Anybody can be a supporter, though people are more likely to support your cause if it affects them now or could do in the future.

For example, local people will be concerned about a hospital closing, and those who have a connection with Parkinson's are obviously more likely to help. You can find them through your local group or Parkinson's UK staff.

See **parkinsons.org.uk/localgroups** or email **campaigns@parkinsons.org.uk**

People who can add weight

You may also want specific supporters that give your campaign extra weight, such as hospital consultants. This is the time to use any connections you may have!

Getting your supporters on side

Let everybody and anybody know what you're doing.

Tell them:

- the problem
- the aims of your campaign
- how your solutions will fix the problem
- what you want them to do, eg sign a petition or join our mailing list

If it is a local issue you could:

- go out to your town centre or somewhere with lots of people from the area and ask them to sign a petition. Always have space for people to write their contact details so you can contact them later (email is easiest)
- hold a public meeting about the issue and collect names and contact details of those who would like to get further involved

Be sure to stay in touch!

It's really important to keep people informed about your campaign so they continue to support you. A regular email updating people is a good way to do this.

Don't forget to thank people for supporting you and to tell them how they are helping to make a difference. This makes it easier to ask for more help when you need it.

5. YOUR MESSAGES

The next step is to work out what messages will hit home with people, from decision makers to supporters. You need to think about the number of people who are affected by your issue and what it means for their quality of life.

First you need evidence

To persuade people to support your campaign or convince decision makers that something needs to change, you need to:

- prove your issue is a problem (not a one-off difficulty)
- show how it can be fixed

To do this you need evidence. Evidence can be facts and figures. It must be 100% accurate and true.

We can help

Contact **campaigns@parkinsons.org.uk**

Real-life stories

Now you have your facts and figures, you need stories to bring them to life and give people something they can relate to. The media – newpapers, radio, TV – always want a good story.

What you need to know about choosing a story

- You must have permission from the person to use their story.
- Their story needs to be easy to understand and connected to your campaign.
- The story should make you sympathetic to the situation by showing how badly the problem has affected someone.

HOW TO GET YOUR EVIDENCE

Facts and figures

See what already exists. There may be legal or good practice guidelines that will help your cause. For example, the NICE guidelines (in England, Wales and Northern Ireland) and the NHS Healthcare Improvement Scotland guidelines lay down certain standards of care people should expect. Searching the internet may turn up all sorts of useful information.

Evidence about how cost-effective your solutions are is also a powerful case for change.

You could also ask other people connected to your issue such as your Parkinson's nurse or consultant.

If you can't find the evidence you need, you could get it by:

- writing a letter to the local paper asking for people affected to come forward
- starting a petition and asking people who sign to share their experiences
- carrying out a questionnaire in patient or support groups
- carrying out a survey – either on paper or using an online survey tool
- asking a government body
- asking people via social media such as your campaign Facebook page
- asking your local patient forum – Community Health Councils

HOW TO GET YOUR REAL LIFE STORY

You may already know people who are affected. But don't be afraid to ask other people for their personal experiences – chances are they'll be glad to help if you explain how it will boost your campaign. You'll need at least two real-life stories.

You could get these when you're out on the street campaigning. Or you could ask people on social media.

Getting the most from real-life stories

- Use them in your campaign materials and online to show people why something needs to change.
- Give them to your local press and radio station.
- Ask people if they are happy to talk to the press themselves.
- Ask people if they are happy to tell their story to decision makers when you meet them.

For information on using real life stories in the press **see page 38**, email **pr@parkinsons.org.uk** or call **020 7963 9370**.

The call to action

It may seem obvious, but you need to make sure you ask supporters and the public to do something in support of your campaign. This could be anything from signing a petition to attending a meeting.

These asks are called a call to action. They need to be very specific and simple.

How a call to action works

Here's an example:

The message of your campaign is: **We want a Parkinson's nurse.**

A call to action could be: **Sign the petition to ask the Local Health Board to put a Parkinson's nurse in place.**

Each time you tell people about your campaign, ask yourself what the call to action should be, and make it as clear and simple as possible. Do you want people to sign your petition? Or write to a politician? Or come along to a meeting? It will also help if you can explain why you need people to do something. For example, getting people to come to a meeting will show the strength of local feeling about your campaign.

Getting your messages right

Got your hard facts? Got stories to illustrate why this matters?

Now you need to turn these into messages that hit home with your audience and make them want to help you change things.

Different messages for different audiences

In everyday life, we all use a different tone of voice when we talk to different types of people. You may be chatty with your neighbour, but use more formal language when you talk to your doctor. It's the same with your campaign messages.

So, if you're writing directly to decision makers, you need to be polite and professional. If you're writing flyers to recruit supporters, it's best to be friendly and informal.

See page 30 for tips on writing campaign materials.

See pages 40–43 for tips on writing press releases and letters to the editor.

See pages 44–47 for tips on writing to decision makers.

If you are sending campaign materials or information to particular people:

- include a personal letter
- get it to them in good time so they can read it and get back to you for further information or to ask questions
- keep copies of all the information you send
- keep details of who you sent it to, what the response was and how you are going to follow it up

HOW TO GET YOUR MESSAGE ACROSS

When you're writing your messages try to:

- keep everything short and simple. Don't swamp people with information – stick to your key points
- be bold so you stand out from the crowd. This is no time to be shy!
- be positive if you can. How will your campaign improve people's lives?
- be human – when you write, use the same words as you would if you were talking to someone over a cup of coffee

Remember – Parkinson's isn't easy to understand

Many people don't have a lot of knowledge about Parkinson's. You may find it helps to give people examples of how the symptoms can affect lives. You can also direct them to our website to find out more at **parkinsons.org.uk**

EXAMPLE

HELP US GET A LOCAL PARKINSON'S NURSE

Simple outline of the problem

There are around 750 people living with Parkinson's in East Lancashire. Most of these people don't have access to the specialist Parkinson's nurses they urgently need.

Easy to follow argument of the need for change

National guidelines recommend that people with Parkinson's see a Parkinson's nurse.

As experts in the condition, Parkinson's nurses help people manage complex medication and help people live independently for longer.

As well as bringing benefits to people living with Parkinson's, this helps the NHS save money.

Parkinson's UK is committed to making sure that everyone with Parkinson's can access a Parkinson's nurse, so we will fund the initial two years of their post.

Yet, East Lancashire Clinical Commissioning Group (the organisation that decides what is available on the NHS in East Lancashire) refuses to put a nurse in place.

Clear call to action of what you want people to do

Can you help us change this?

Get involved on our website **parkinsons.org.uk/eastlancsnurse**, by calling us on **020 7932 1325**, or emailing **campaigns@parkinsons.org.uk**

We'd love to hear from you.

Real-life story to bring the need for change to life

Why is a Parkinson's nurse important for Richard?

"I have been living with Parkinson's for eight years and during this time I have never seen a Parkinson's nurse. I see a consultant once a year, sometimes less, and this is just a brief visit. I get no ongoing support – I have no one that can answer questions, no one to discuss my Parkinson's symptoms with.

"My Parkinson's has got worse. The tremors have got worse and my symptoms flare up. I can be in a very rough way and feel terrible for days. It's hard to describe – especially to people who don't know about Parkinson's.

No one wants to go to hospital if it can be avoided. And with a Parkinson's nurse in place, it often can be.

"I don't know why the people who decide what's available on the NHS won't put a nurse in post. It would

GATHERING EVIDENCE LED TO ACTION

Kathleen McKeown

"I ran a questionnaire in Northern Ireland about people's experiences in hospital for the Get It On Time campaign. I went to local groups and talked to members about the importance of receiving Parkinson's medicine on time. We gave the questionnaires out and asked for all experiences. We wanted to hear the good and bad experiences. It was important we didn't look like we were just picking fault but getting actual evidence.

People were really interested and everyone took part. Talking to the local groups was important as it raised awareness of receiving medicine on time in hospital – I think this was new information to them. I also really enjoyed going around the local groups. It was good to meet people first-hand, hear their experiences and see they were engaged with Get It On Time.

This lead to a full-scale review of policy and procedure around Parkinson's medicines in hospital in Northern Ireland."

6. RESOURCES
(what you need to deliver your campaign)

You will need resources to make your campaign happen. You will need campaign materials like leaflets, posters and banners, and people to help get the message out.

People

People are your most important resource! You need them to get things done and build the momentum of your campaign.

Your supporters

Your supporters demonstrate the importance of your campaign. You need them to make a big impact, whether it's signatures on a petition, letters to decision makers or going along to an event.

It's vital to keep your supporters interested and motivated. Keep them up to date with the progress of your campaign so they feel they are making a difference.

You can do this by:

- regular emails
- newsletters
- social media, websites or blogs
- regular meetings

See page 22 on how to find supporters.

Campaign materials

You'll probably need to produce materials to gain support for your campaign. These are usually things like leaflets and posters. You may need or want to produce bilingual materials if Welsh is the preferred language of the people you are trying to reach. This applies to both printed and online materials.

It's easy to make your own

We have standard leaflet and poster designs (templates) that you can adapt for your campaign. They will then be printed for you so they look professional.

HOW TO CREATE YOUR CAMPAIGN MATERIALS

First of all, you need to get a log in so you can access the page – details below. Once you have access, the rest is easy!

1. Go to the template page on our website at **parkinsons.org.uk/templates**
2. Click 'Access the online template system'.
3. Log in to the system (see below if you do not have a log in).
4. Follow the simple instructions to add your own details, such as event dates.
5. Order the amount you want printed through our printer City Digital Ltd.

There's a small charge for this service to cover costs.

Getting a log in

If you are part of a Parkinson's local group, the secretary can get one for you. They just need to send your name, the email address you want to use, and which group you are from, to:

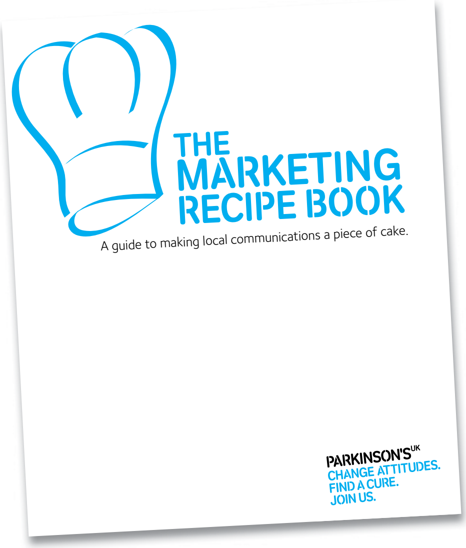
Local networks team
020 7963 3929
localnetworks@parkinsons.org.uk
(9am to 5pm, Monday to Friday)

If you are not part of a local group:

Contact
City Digital Limited
01732 466 978
citydigital.net/client-login
(9am to 5pm, Monday to Friday)

Need some help?

We have a guide to using the templates and a Marketing Recipe Book to help you decide which resources are best for you. To find out more email **marketing@parkinsons.org.uk**



THE MARKETING RECIPE BOOK

A guide to making local communications a piece of cake.

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Top tips for creating campaign materials

- ✓ Use an eye-catching title.
- ✓ Use plain English and keep in mind who your audience is.
- ✓ Clearly outline the problem and the solution.
- ✓ Have a clear ask (call to action) for the audience.
- ✓ Include evidence and a real-life story to make it persuasive.
- ✓ Use our template system for eye-catching design.
- ✓ Include details of someone to contact if they would like more information.

GETTING STARTED

How much time do we need to commit?

What about candidates in Scotland, Wales and Northern Ireland?

WHAT YOU CAN DO

What are we trying to achieve?

What can our group do?

Tips for writing letters

Invite your candidates to your Parkinson's Awareness Week events

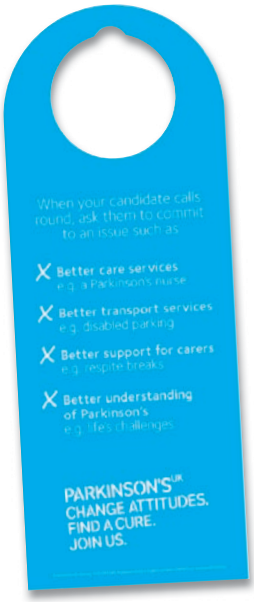
THE MEDIA

Working with the media

Tips for the media

THE LAW

Important legal things you need to know



When your candidate calls round, ask them to commit to an issue such as

☒ Better care services
e.g. a Parkinson's nurse

☒ Better transport services
e.g. disabled parking

☒ Better support for carers
e.g. respite breaks

☒ Better understanding of Parkinson's
e.g. life's challenges

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

DON'T FORGET

Make your vote count for people living with Parkinson's

#YouCan

PEOPLE LIVING WITH PARKINSON'S VOTE

☒ for ....

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

TAKING
ACTION

#YOUCAN

This section covers the things you can do to influence decision makers so they are aware of your campaign and will (hopefully) make the change you want.

Make your voice heard
There are many things you can try. You'll probably find that a combination works best.

1. Publicity

Most people use:

- social media, websites or blogs
- mainstream media, like newspapers

2. Written campaigning

This includes:

- letter-writing
- petitions

3. In person campaigning

This can be very effective and can really rally a team. It involves:

- meetings
- events/stunts

4. Lobbying

This is when you ask people with influence to help you. This could be:

- politicians
- health bodies

1. PUBLICITY

Social media

Social media can be an effective way to let people know about your campaign. It could also help get you noticed by decision makers as many keep track of what people say about them on social media.

What you need to know

Social media is a conversation, so you will need to reply to people's comments and this can take a lot of time.

Remember social media can be seen by everyone. Think carefully about what you're writing before you post it – you don't want to offend or upset people. Don't write anything you wouldn't say to someone's face. You might want to run your posts by someone to make sure it's clear and that it says what you want it to say.

If you are going to use social media, it's also a good idea to have someone in your team who knows a bit about the web.

Types of social media

The main ones are:

Facebook

Facebook is very popular – more than a billion people across the world use it. You could use your own profile or set up a page just for your campaign.

Twitter

Twitter will help you build support for your campaign. People ‘tweet’ their thoughts. Tweets must be short – 140 characters or less – and other people can then share this (retweet) or comment on it.

Using the hashtag symbol ‘**#**’ in front of your campaign name links people together and shows you who is supporting you.

YouTube

YouTube is where people share videos. It’s good for videos of publicity stunts or short films about your campaign.

Flickr and Instagram

Use these websites to share photos of your campaign.

Tips for using social media

- ✓ **Reply to people who post comments on your pages so they feel part of your campaign.**
- ✓ **Keep it up to date so people don’t lose interest.**
- ✓ **Use pictures wherever you can – people are more likely to share them.**
- ✓ **Include links to Facebook and Twitter on your website and blog – you can make the link short at bitly.com**
- ✓ **Get someone to check your posts couldn’t cause offence and that they say what you want them to.**
- ✓ **Use it as part of your campaign together with leaflets and posters so you reach as many people as possible.**

Blogging

Blogging is perfect when you want to write about your campaign in more detail. Be aware it can take a long time to build a following, so don’t expect people to go direct to this. Post links on other social media channels.

Free blogging sites include **www.wordpress.com** and **www.weebly.com**

Top tip:

✓ Make sure you link to any petition or action you've set up.

Parkinson's UK
5 January

Parliament opens again today! Welcome your MP into 2015 by asking them to ensure people with Parkinson's get the drugs they need.

NHS England won't fund Duodopa, a drug for the advanced stages of Parkinson's, despite people having had the drug prescribed.

Ask your MP to help us change this: http://bit.ly/duodopacampaign

Top tip:

✓ Use a picture to grab people's attention.

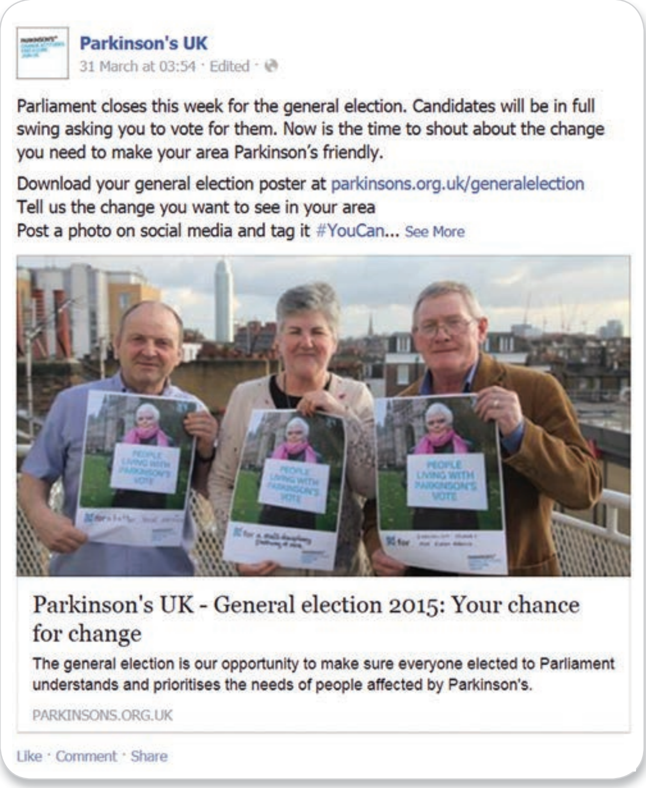
Parkinson's UK
18 March

Tell the politicians an NHS that understands Parkinson's is your priority this general election.

#Youcan get the change you need. Ask for it: bit.ly/1FptlJ4

Top tip:

✓ Link to a website or blog with more information.



Parkinson's UK
31 March at 03:54 · Edited

Parliament closes this week for the general election. Candidates will be in full swing asking you to vote for them. Now is the time to shout about the change you need to make your area Parkinson's friendly.

Download your general election poster at parkinsons.org.uk/generalelection
Tell us the change you want to see in your area
Post a photo on social media and tag it #YouCan... See More

Parkinson's UK - General election 2015: Your chance for change

The general election is our opportunity to make sure everyone elected to Parliament understands and prioritises the needs of people affected by Parkinson's.

PARKINSONS.ORG.UK

Top tip:

✓ Use facts and figures to show why people need to support you.

Parkinson's UK
5 November 2014

Stop hospital admission being a scary prospect for people with Parkinson's. Urge the chief inspector of hospitals to hold an investigation now http://bit.ly/1x8cczw

People with Parkinson's reported 617 medication MISTAKES made by hospital staff between March and July of this year

Top tip:

✓ Clearly explain what you want people to support and what action they should take.

Parkinson's UK @ParkinsonsUK · Apr 1

Sign the petition to make prescription charges fairer for people with Parkinson's and long-term conditions in England bit.ly/1F2epgm

Top tip:

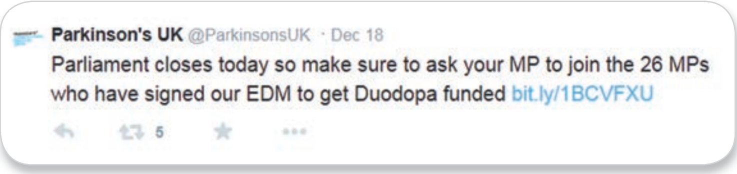
✓ Use photos to show that other people are taking part and draw in support.

Parkinson's UK
@ParkinsonsUK

What would you vote for this #generalelection? Share a photo & tell us! Download posters here bit.ly/1aryEvu

Top tip:

✓ Tell people why it's urgent that they do something NOW!



Parkinson's UK @ParkinsonsUK · Dec 18

Parliament closes today so make sure to ask your MP to join the 26 MPs who have signed our EDM to get Duodopa funded bit.ly/1BCVFXU

Top tip:

✓ Use a clear call to action to encourage people to get involved.

Parkinson's UK @ParkinsonsUK · Mar 25

Tell the politicians that you want welfare & social care that works for you #YouCan get change bit.ly/1CPpncw

Top tip:

✓ Update everyone on how your campaign is going.

Parkinson's UK
@ParkinsonsUK

1,623 voices, 98 MPs, 9 political parties, 1 call: Fund Parkinson's drug Duodopa now @NHSEngland

MPs received **1,623 EMAILS** from **Parkinson's UK supporters** asking them to back the NHS funding Duodopa

98 MPs have backed us on Duodopa

23RD **most supported motion** out of nearly **1,000** this parliamentary session

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

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

We can help. We have a dedicated Parkinson's UK media team who will give you the expert help you need to stand out from the crowd and get the media interested in your campaign.

You can also count on support from your Parkinson's UK local staff.

If you want to mention Parkinson's UK, please contact our media team at **pr@parkinsons.org.uk** or call **020 7963 9370**.

The media 'hook' and why you need one

The media always want something new to report. So dramatic facts and figures will hugely increase the chances of your story getting in the papers or on the radio or TV. This is the media 'hook'.

A media hook could be:

- 80% of people with Parkinson's in your area are scared to go into hospital because they don't get medicines on time.
- A Parkinson's nurse could save your local NHS trust/board £270,000 a year.

HOW TO FIND YOUR MEDIA HOOK

- If you don't have dramatic figures, you can get them yourself by carrying out a survey.
- Other groups who support your cause may have figures you can use.
- We may be able to help – contact **pr@parkinsons.org.uk**

Using your media hook

Always use facts and figures that will be of interest to the publication. Local papers will be more interested in a local story than statistics about the UK – again, our media team can help.

Real-life stories and the media

Real-life stories are vital when it comes to getting media and the public interested in an issue, as they give a human face to your campaign.

The people who provide your stories need to know what they will be asked to do.

Although it may sound daunting, giving a story is very simple. It will usually involve talking to journalists directly about an experience of Parkinson's, and how the campaign issue affects them. They're not expected to be a spokesperson for the charity or an expert on Parkinson's. The media is interested in their personal experience.

It generally involves:

- a 10–15 minute phone conversation with a member of the Parkinson's UK media team
- providing a quote to go in media materials, such as press releases (written by the Parkinson's UK media team)
- interviews with journalists over the phone or face-to-face
- being photographed by Parkinson's UK and/or local journalists

See page 24 for more information on real-life stories.


Is this

Press releases

Press releases are how journalists expect to receive information. Yours needs to tell a journalist what's 'new', otherwise it won't be classified as news. You will need to grab their attention. This is where your media hook comes in – the powerful facts, figures or personal stories about your campaign.

HOW TO WRITE A PRESS RELEASE

We do have templates available for you to use, but here are our tips (**see page 43** for a sample press release).

- Make your headline short and snappy – sum up your story in 10 words or less.
- Break your story into who, what, when, where and why – this is everything a journalist needs to know.
- The first paragraph is the most important part as the rest may not get read – so put your strongest key message there.
- Put the rest of your messages in order of importance and use a paragraph for each.
- Always include a quote from a spokesperson at Parkinson's UK about the campaigning issue – contact **cpo.wales@parkinsons.org.uk** for help with this.
- If possible include a quote from someone willing to be interviewed by journalists.
- Use straightforward language and replace long words with short ones where you can.

Need some help?

We're happy to check yours or write it for you. Contact **cpo.wales@parkinsons.org.uk**

Letters to the editor

You can get great exposure by writing letters to the editors of newspapers. Local decision makers often read the letters pages to see what issues really matter to the public.

Letters to the editor are written from one person's perspective – it could be an influential person within the community or a person with Parkinson's. If you can, get a local person to support your letter or provide a quote. This could be someone like a consultant at the hospital.

HOW TO WRITE A LETTER TO THE EDITOR

- Be brief – use around 100–150 words.
- Get to the point quickly and make the argument for your campaigning issue clearly and concisely.
- Say how you feel – if you're outraged, disappointed or desperately worried you can say this, but always back up your statement with a compelling reason why, and offer a solution.

Don't forget the photo opportunity!

The media love a good photo opportunity. Think how you could get great pictures, maybe with a publicity stunt or a group of supporters at a meeting.

Top media tips

- ✓ **Make sure you contact the right journalist – for example, the health correspondent or news desk.**
- ✓ **Provide all the information they will need in the first email or call.**
- ✓ **Know the key deadlines – do they need all stories on Tuesday before printing?**
- ✓ **Tell them about any photo opportunities they can attend.**
- ✓ **Offer interesting and new statistics.**
- ✓ **Make sure there's someone affected by your issue who will speak to a journalist.**
- ✓ **Have quotes ready from important supporters like a local neurologist.**
- ✓ **Answer journalist queries as quickly as possible.**

BEING A CASE STUDY GOT MY POINT ACCROSS

Bob Adams has been caring for his wife Pauline since she was diagnosed with Parkinson's 24 years ago, and was struggling to cope. Bob agreed to use his story for Carers Week 2013. He was interviewed on one of his local radio stations, Heart FM in Birmingham, and his story featured on the Parkinson's UK Facebook page.

When she heard his interview, Bob's local councillor contacted him to talk about his concerns and to help improve services for carers in the area. She also agreed to support Bob's case for NHS funded care so the couple would no longer have to contribute to care costs out of their own savings.

Bob Adams

> “I thought it was really important to speak up and let people know how hard it is for carers to get the right services. I was so pleased when our councillor contacted us and said she was coming over for a cup of tea. We are now getting some of the financial help we need, and our case is being used by the council to highlight the suffering caused by social care and health not working together.”

A campaigner visits their MP on carer issues

Parliament visit to highlight carers

A Sidcup carer visited Parliament to call on MPs to ensure the UK's 6.5m carers get the support they need.

Elizabeth Taylor, 58, supports her 59-year-old husband Bob, who was diagnosed with Parkinson's 16 years ago when he was 44.

Mrs Taylor was invited to talk to MPs at the start of carers week as a representative for Parkinson's UK. The MPs attended a "speed networking" event where they heard from about the challenges carers face.

Mrs Taylor said: "I never expected Parkinson's to enter our lives, but when it did we knew it would have an impact.

"Something I feel strongly abo-ut is the financial impact Parkinson's can have.

"There is so much expense and cost to having a condition like Parkinson's and the benefits system only offers meagre support.

"Bob had to give up work, and I had to become the main breadwinner."

For motre details visit parkinsons.org.uk or call the free helpline on 0808 800 0303.

Elizabeth Taylor met MPs such as Robin Walker

Reigate and East Lancashire groups' Parkinson's nurse campaign

Parkinson's nurse is welcomed

By Hannah Ramsden
hannah.ramsden@jpress.co.uk
Twitter:@hannahr83

An announcement by health bosses that a dedicated Parkinson's disease nurse is set to start work in East Lancashire later this year has been welcomed by Burnley's MP.

Mr Gordon Birtwistle said he has been working in partnership with the East Lancashire Clinical Commissioning Group, for the past two years, to secure the community-based post.

In December last year the East Lancashire CCG submitted a business case to Parkinson's UK, this has now been approved and funding has been allocated for two years. The CCG will then continue funding after this period.

Mr Birtwistle said: "It is absolutely fantastic news that East Lancashire has secured a community Parkinson's disease nurse, it is much needed.

"Sufferers should be able to receive specialist care in their own homes, tailored to their needs. It should make a great difference to the lives of patients."

MP GORDON BIRTWISTLE

IN BRIEF

Parkinson's group's fear

EAST SURREY: The Reigate Parkinson's UK group is concerned about plans to replace a specialist nurse with a therapist with a particular interest in the disease.

First Community Health is currently recruiting after its previous nurse retired but is struggling to fill the role.

But according to Phillip Greenhill, managing director of not-for-profit organisationFirst Community Health, the recruitment process will not lead to a reduction in patient care.

Bury support group raises Parkinson's awareness

Support Mayor visits group's open day

Supporters at the event, and below, Mayoress of Bury, Shirley Rabbitt with Alison Jennings, organiser, and Mayor of Bury Cllr Sharon Briggs

BURY Support Group Parkinson's UK welcomed two VIPs when they staged a successful open day.

Mayor of Bury, Cllr Sharon Briggs, accompanied by the mayoress Shirley Rabbitt, gave their backing to the organisation and the event which was held at the Bolton Road Methodist Church in Bury.

Attractions at the open day included stalls selling a variety of goods, and games.

Group secretary Alison Jennings said: "Around 80 people attended, and the event was most successful. We were delighted to welcome the Mayor and Mayoress."

Access to drugs and treatments campaign

Urgent call for new drugs to treat causes of Parkinson's

L-dopa, first used 50 years ago, delays the symptoms but is the only effective treatment

by Robin McKie
Science Editor

Deryal Wood was 45 when she first began to suffer tremors in her hands. Her symptoms slowly worsened and she was diagnosed nine years ago as having early onset Parkinson's disease. "I was given the drug L-dopa. The tremors disappeared," she said.

But the tremors returned a few years later and doctors had to increase her dosage. "The side-effects became horrible. My legs would freeze and I would fall over. I would suffer terrible muscle cramps every couple of hours," said Wood, who lives with husband David and daughter Fay in Bexley, Kent.

As Wood's symptoms worsened, she was offered treatment called deep brain stimulation, which involves placing electrodes deep into a patient's brain. That has brought her tremors and movements back under control so that she can lead a fairly normal life. "However, it does not control the depression, insomnia or exhaustion that I also experience because of Parkinson's. Patients like me want something that slows down or halts the degeneration in our brain cells and so stops the disease," she said.

It is a view shared by a rising number of doctors and scientists who believe action needs to be taken to discover a new class of drugs to tackle the degenerative nerve ailment. Current medicines treat only the symptoms, they say. They should be supplemented with agents that directly attack its underlying cause.

To date, these efforts have failed, despite intense efforts by pharmaceutical companies which have spent billions on the quest. "Drug companies have produced absolutely nothing to help with the degenerative process of Parkinson's over the past two decades," said Dr Tom Foltynie, at University College London's Institute of Neurology. "We desperately need to take a new approach."

Foltynie was speaking last week as scientists marked the 50th anniversary of the first use of levodopa, perhaps better known as L-dopa, the most effective drug ever created to treat Parkinson's. It can extend patients' quality of life for years, but eventually loses its effectiveness, as it has with Wood.

About 130,000 people in Britain are affected by Parkinson's disease which is caused when brain cells, which make a chemical messenger called dopamine, start to die. As a result, messages

Eastern region's Parkinson's Awareness Week

Blue was this at Diss Mere's Mouth?

A blue figure was causing quite a stir in Diss on Friday. Many passersby were unsure whether it was human or mannequin - but this blue character was knitted by volunteers, aiming to raise awareness for Parkinson's UK during Parkinson's Awareness Week. The figure had been placed in various locations, including Attleborough and Norwich across Norfolk during the week. For more information on the charity, visit www.parkinsons.org.uk

EXAMPLE

Add simple headline that easily shows the issue

FOR IMMEDIATE RELEASE

22 January 2014

Put the important information and statistics near the top

Sum up the main point in first paragraph

People with Parkinson's in East Surrey to be left without vital support
People living with Parkinson's in East Surrey will be left struggling and without vital support following changes to their specialist nurse service, a leading charity has warned.

A Parkinson's UK petition signed by over 1,000 people urges the East Surrey Clinical Commissioning Group to rethink a decision to swap the current Parkinson's specialist nurse for a specialist practitioner who will provide support in a wide range of conditions, not just Parkinson's.

Members of the Parkinson's UK Reigate group will hand in the petition to the Group at their Board Meeting at Tandridge District Council offices, on 30 January at 1pm.

Use a quote from someone with authority on the issue

Lucy McGrath, Parkinson's UK Influence and Service Development Officer for the South East, said the decision could leave people with Parkinson's in East Surrey with a far poorer quality of life:

"Changing the current specialist Parkinson's nurse post in this way will inevitably reduce the support offered to people with Parkinson's, leaving them without the expert help they desperately need and increasing the chances of them ending up in hospital.

"Parkinson's nurses are critical to managing this complex and fluctuating condition, and it's vital that the 300 plus people with Parkinson's living in East Surrey continue to have access to their specialist knowledge and support."

Have a human face to your story

Pam Rodger, 70 from Caterham cares for her husband Ian, 72, who has been living with Parkinson's for 11 years. She says a specialist nurse is hugely important to managing Ian's condition.

"The idea of losing access to a specialist Parkinson's nurse is making us very anxious, as the expertise makes such an enormous difference to our lives. While you see a consultant once every six months, if you're lucky, our nurse was always there to turn to if we thought something might be wrong.

Use both facts and opinions

Longer quotes are likely to be edited. Try to stick to a couple of paragraphs

"Last year I was getting worried about Ian when he started putting clothes on back to front, and doing other little things out of the ordinary. I mentioned it to our Parkinson's nurse and after asking him some questions she immediately decided he needed to see a dementia specialist. We got a diagnosis of mild dementia within a matter of weeks which meant we could start him on medication quickly – which would never have happened without our nurse. '

ENDS

Include other information of interest eg photo opportunity below content

Further information: Members of the Parkinson's UK Reigate group, including Pam Rodger will hand in the petition at the Tandridge District Council offices, on 30 January. Photographers are welcome to attend for a photo opportunity at 1pm.
Media contact: **xx@parkinsons.org.uk**

Add a media contact

Notes to editors
Every hour, someone in the UK is told they have Parkinson's.
It affects 127,000 people in the UK – which is around one in 500 of the population.
300 plus people in East Surrey are living with Parkinson's: NICE guidelines suggest one Parkinson's nurse per 300 people with Parkinson's. Parkinson's is a degenerative neurological condition, for which there currently is no cure. The main symptoms of the condition are tremor, slowness of movement and rigidity.

Parkinson's UK is the UK's leading charity supporting those with the condition. Its mission is to find a cure and improve life for everyone affected by Parkinson's through cutting edge research, information, support and campaigning.

For advice, information and support, visit **parkinsons.org.uk**
or call our free, confidential helpline on **0808 800 0303**

2. WRITTEN CAMPAIGNS

Letter-writing

The easiest start to a campaign is to write a letter or email. This can be a very simple letter to a politician or other decision maker that states your concerns and what you want to change.

When you're first getting your campaign together, you might want to write to your target (the decision maker) to tell them about your concerns and ask for a meeting. If you don't get an answer you can write to someone else who may influence them. This could be your local paper or a politician.

You can also ask your supporters to write to your target. This will increase the pressure on them.

How writing letters can help

- It lets you outline your concerns to decision makers.
- It helps you find out the decision maker's point of view.
- It's an easy thing for your supporters to do.
- Your supporters can share their own experiences to strengthen your campaign.
- It's a simple way to demonstrate the strength of public feeling, particularly if the letters keep coming.

If possible avoid template letters that people just sign and send on to decision makers.

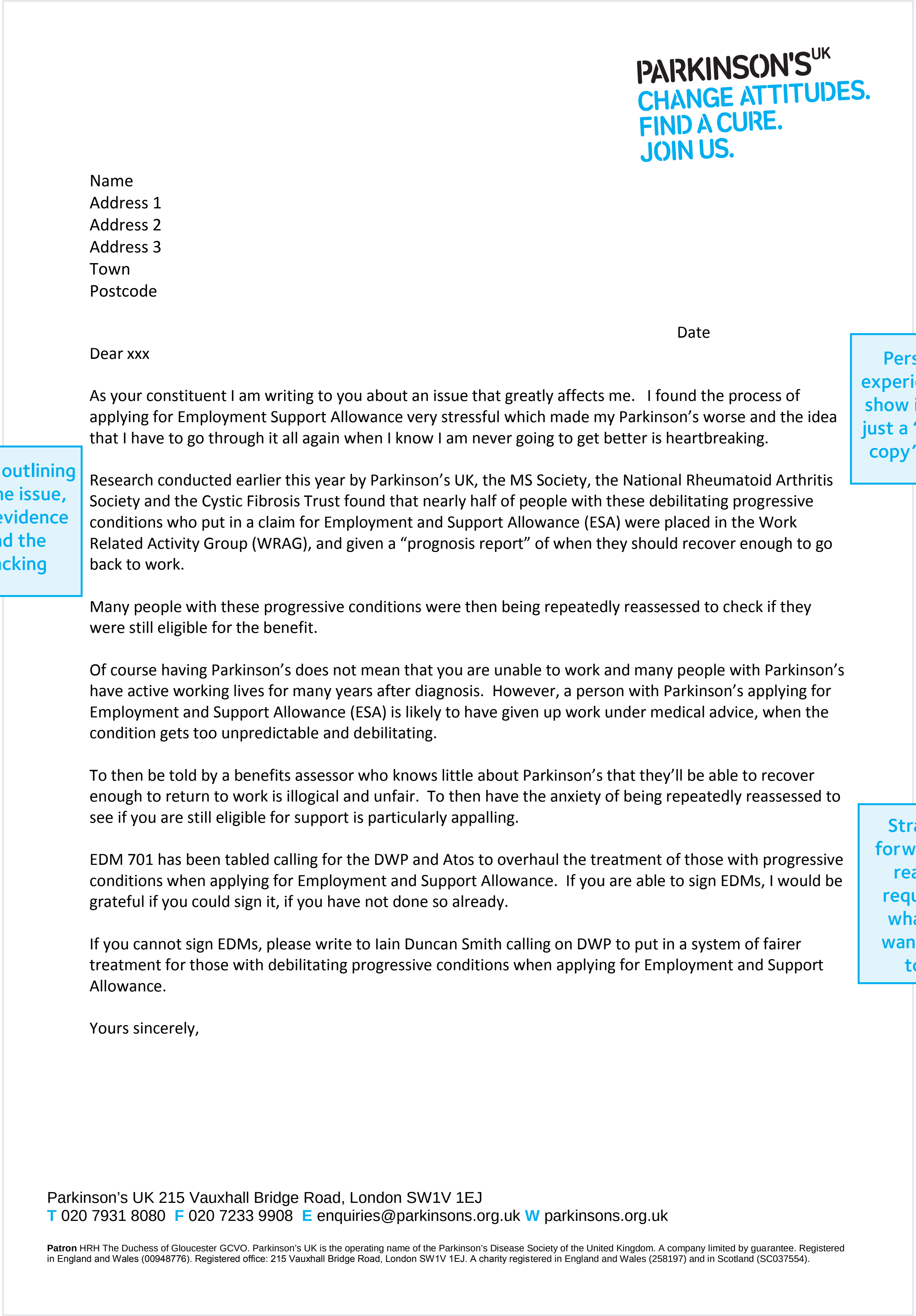
Personal messages have a much greater impact. You can provide bullet points of the main messages you would like supporters to include.

Top tips for writing letters

- ✓ **Identify exactly who your target is and address the letter/email to them.**
- ✓ **Keep it short and clear with a direct request.**
- ✓ **Individual letters with personal experiences are better than the same template letter sent again and again.**
- ✓ **Make it clear what points and evidence needs to be included in the letter.**
- ✓ **Get as many people as possible to write a letter – there is power in numbers.**
- ✓ **If writing to a politician, make sure you tell them you are a constituent and include your address to show this or that the issue (eg the hospital) is in their constituency.**
- ✓ **Ask for a reply in the letter.**
- ✓ **Ask supporters to share any replies with you.**

See page 20 on how to identify targets.

EXAMPLE



PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Name
Address 1
Address 2
Address 3
Town
Postcode

Date

Dear xxx

Personal experience to show it's not just a 'carbon copy' letter

As your constituent I am writing to you about an issue that greatly affects me. I found the process of applying for Employment Support Allowance very stressful which made my Parkinson's worse and the idea that I have to go through it all again when I know I am never going to get better is heartbreaking.

Clear outlining of the issue, the evidence and the backing

Research conducted earlier this year by Parkinson's UK, the MS Society, the National Rheumatoid Arthritis Society and the Cystic Fibrosis Trust found that nearly half of people with these debilitating progressive conditions who put in a claim for Employment and Support Allowance (ESA) were placed in the Work Related Activity Group (WRAG), and given a "prognosis report" of when they should recover enough to go back to work.

Many people with these progressive conditions were then being repeatedly reassessed to check if they were still eligible for the benefit.

Of course having Parkinson's does not mean that you are unable to work and many people with Parkinson's have active working lives for many years after diagnosis. However, a person with Parkinson's applying for Employment and Support Allowance (ESA) is likely to have given up work under medical advice, when the condition gets too unpredictable and debilitating.

To then be told by a benefits assessor who knows little about Parkinson's that they'll be able to recover enough to return to work is illogical and unfair. To then have the anxiety of being repeatedly reassessed to see if you are still eligible for support is particularly appalling.

Straight-forward and realistic request of what you want them to do

EDM 701 has been tabled calling for the DWP and Atos to overhaul the treatment of those with progressive conditions when applying for Employment and Support Allowance. If you are able to sign EDMs, I would be grateful if you could sign it, if you have not done so already.

If you cannot sign EDMs, please write to Iain Duncan Smith calling on DWP to put in a system of fairer treatment for those with debilitating progressive conditions when applying for Employment and Support Allowance.

Yours sincerely,

Parkinson's UK 215 Vauxhall Bridge Road, London SW1V 1EJ
T 020 7931 8080 **F** 020 7233 9908 **E** enquiries@parkinsons.org.uk **W** parkinsons.org.uk

Patron HRH The Duchess of Gloucester GCVO. Parkinson's UK is the operating name of the Parkinson's Disease Society of the United Kingdom. A company limited by guarantee. Registered in England and Wales (00948776). Registered office: 215 Vauxhall Bridge Road, London SW1V 1EJ. A charity registered in England and Wales (258197) and in Scotland (SC037554).

WRITING LETTERS BROUGHT ATTENTION TO OUR CAMPAIGN

Barbara Marsden

“I was part of the East Lancashire campaign for a Parkinson’s nurse and helped with the letter-writing. I wrote letters to the Clinical Commissioning Group (CCG), my MP and my GP. The letter had facts and figures in it about why we needed a Parkinson’s nurse and the money it could save the NHS. We all personalised the letters as well with a bit about how not having a Parkinson’s nurse affected us. It meant the letters stood out more than if they were just all the same.

My GP rang me up and agreed that there was a need and would see what he could do. It helped to contact him because he knew me and so understood the need for a Parkinson’s nurse.

I would recommend that people involve as many people as possible. Don’t just aim your campaign at one person – attack from all sides.

The new CCG offered an opportunity for our campaign as we had been trying for years to get a Parkinson’s nurse, but when it was set up they really listened. After our letters, they invited us all to a meeting where they decided that they would hire a Parkinson’s nurse.”

Petitions

Petitions are a very simple and effective way of showing the number of people who support your campaign.

How petitions can help

Signing a petition is an easy way for people to show their support, so you're likely to get a good response. Most people will support you in this way.

A petition can also help you reach new people as you can collect email addresses too. Then you can email people about your campaign to show them how their support has helped, as well as asking them if they want to get involved in your campaign.

Who is the target of your petition?

This is the decision maker who can make the change you want to see. You will need their name and job title. There are different processes for petitioning people – for example, governments or parliaments and local authorities may have their own official petition system you could use. However they can be hard to use, so you may want to create your own.

Many local authorities will tell you how to petition them on their website. We can also help. Email the Parkinson's UK Policy and Campaigns team at **campaigns@parkinsons.org.uk**

Online petitions

These can be very effective as people share them with their friends. You can also publicise them on your blog, Facebook, Twitter and other social media. Remember to include a link.

If you need to make your link shorter, visit **bitly.com** which will do it for you.

If you would like to set up a petition, contact
campaigns@parkinsons.org.uk
or call **020 7963 9349**.

Top tips for petitions

- ✓ **Make your petition statement short and clear, saying who you want to act and what you want them to do.**
- ✓ **Try to make it positive so you don't put people off signing. Focus on how your campaign will improve lives.**
- ✓ **Get your petition out there.**
- ✓ **Put your petition online too and tell people about it on social media – remember to include a link to it.**
- ✓ **Create a simple fact sheet or leaflet about your campaign for people who are considering signing your petition.**
- ✓ **Arrange a time to deliver your petition and tell the local press – it's a great photo opportunity and will get you more publicity.**

EXAMPLE

PARKINSON'S UK CHANGE ATTITUDES. FIND A CURE. JOIN US.

Petition for Parkinson's nurse for East Surrey

Parkinson's is a progressive neurological condition with no cure. Parkinson's nurses are needed to advise on complex medications, which are crucial to managing Parkinson's. These nurses also save the NHS money through reduced hospital admissions and consultant appointments.

We understand that there are plans to replace the current Parkinson's nurse post in East Surrey with a Nurse or Therapist for Neurological Conditions with a special interest in Parkinson's.

We believe this proposed change will weaken the support being offered to people with Parkinson's and we ask East Surrey CCG/First Community to appoint a full-time Parkinson's nurse to bring East Surrey into line with NICE guidelines for the Management and Treatment of Parkinson's. This should ensure that all people affected by Parkinson's in East Surrey can access the specialist support and advice such a nurse can give.

Name	Address	Signature

This petition helped to defend the Parkinson's specialist nurse in East Surrey

P.T.O.

Please return to: Parkinson's UK, 215 Vauxhall Bridge Road,
London SW1V 1EJ

3. IN PERSON CAMPAIGNS

Meetings

Meetings with decision makers give you the opportunity to put your message across directly. As decision makers are often very busy, you are likely to only have a short time with them, so make it count!

Try to arrange a meeting at a crucial point in your campaign. For example, you could meet a politician before a debate or vote.

See pages 53–55 for how to contact politicians.

How meetings can help

Talking person to person gives you the opportunity to explain your concerns and solution. It also means that the decision maker has to answer your points.

If they are against change, the points you make can hopefully move the discussion forward.

Events and stunts

An event is a great way to get people's attention and raise awareness of your campaign. There are lots of different types of events you can hold. If you have a clear aim for your event it will make it easier for you to choose what type of event will be the most effective.

How events and stunts can help

An event can:

- raise awareness of your campaign
- tell the public what you're asking for
- create interest with your local media (especially if local decision makers attend)
- give focus to your campaign so you have something to lead up to, such as a petition handover
- make decision makers aware of the strength of local feeling

Top tips for successful meetings

Before the meeting

- ✓ Think carefully about what you want to say and write down the key points to take with you.
- ✓ 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.
- ✓ Decide what you are going to ask the decision maker to do.

At the meeting

- ✓ Make notes during the meeting or just afterwards to record what was said and who said it.

After the meeting

- ✓ Write to the people you have met afterwards, thanking them for coming to the meeting. 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 four weeks later to find out what's happening.

See pages 38–40 on inviting the media to your event.

Top tips for holding an event

- ✓ Be creative and make sure your message is clear.
- ✓ Put a team together and give each person a responsibility such as organising a venue, inviting speakers, producing publicity or speaking to the media.
- ✓ If you're having speakers, check the date with them first to make sure they can attend.
- ✓ You may want to invite a speaker from Parkinson's UK, who can give an overview of the issue – contact campaigns@parkinsons.org.uk
- ✓ Your venue should be accessible for people with disabilities, on public transport and affordable.
- ✓ If you are having a general meeting, elect a chairperson who can chair it.
- ✓ Give plenty of notice to everybody, including the media. See page 40 on working with the media for useful tips.
- ✓ Have somewhere that people can sign up to become a supporter and learn more about your campaign.
- ✓ Make sure that people with Parkinson's have somewhere to sit down and the time to ask a question if they want to.
- ✓ At a speaker event, take notes of what is said, including questions that are asked, who asked them and the answers given.

If you want to raise awareness of your campaign

You could hold a public event with speakers who will talk about your issue. If you include fun stuff, such as a cake sale, barbecue and children's activities, people will be more likely to come.

Public events are a great opportunity to demonstrate the level of public concern about your campaign issue to decision makers.
Try to hold your event at the right time to exert pressure on your target – for example, before an important meeting where they'll make a decision on the issue you're concerned about. Remember to tell your local media.

If you want to demonstrate public support for your issue

You could organise a publicity stunt. To raise awareness of Parkinson's in your high street, you could do a 'freeze flash mob' where people gather together in one place and suddenly freeze at the same time.

Make sure you get any necessary permissions from your local council if you plan to do a stunt or protest. You may need to get these a few weeks in advance, so check early.

EVENTS ARE A GREAT WAY TO ENGAGE MORE PEOPLE ABOUT PARKINSON'S

> "Last year, for Parkinson's Awareness Week we had a stand for the Get It On Time campaign in the local shopping centre. We had leaflets and posters and the press came along and took pictures. It raised awareness amongst local people of the issue. It was a great way of reaching new people. It also meant more people knew about the branch and came along to meetings.
>
> Events are a great way to invite important local people to learn more about you. For our branch inauguration, we had the mayor and local councillors. It means they understand Parkinson's better, which will hopefully inform their decisions later. Focus on the people you know and they will help you reach others. You have to keep pushing and opening doors."

Jimmy McLean
Chairman of Ballymena and District Branch

4. LOBBYING

Lobbying is when you ask your Assembly Members (AM), MP or local councillors to do something for you.

Politicians

Your elected representatives have to talk to you because they have a duty to you as a constituent. Even if they are not the target of your campaign, you should still contact them to ask for their support as they could help you access decision makers.

How to get in touch

You can:

- write
- email
- visit their local surgery
- invite them to a meeting or event

Make sure you tell them the problem is in their constituency and/or that you are a constituent.

What your politicians can do

As well as dealing with your issue in their assembly or parliament, politicians can help your campaign by publicly lending their support.

They can

- raise your issue with the local organisation who controls it
- raise awareness of your campaign – the local media will be interested in stories that involve your local politicians
- attend or speak at your event – politicians welcome the opportunity to speak to their constituents as you all have votes!

If they do attend, make sure you take a picture. You can share this on social media.

Top tips on meeting with politicians

Be prepared. Make a list of the key points of your campaign and take your evidence with you. Be clear about exactly what you want them to do.

Make your concerns relevant. Your elected representative is more likely to get involved if you can show why your campaign should be important to them.

You can:

✓ use personal stories to demonstrate the problem/issue

✓ appeal to their interests – find out if they support a cause that relates to yours

✓ show how your issue fits in with the bigger picture, such as government policy or the total number of people affected in their constituency

✓ suggest a solution – don't just stick to the problem

Be realistic and focused – don't ask for too much at once!

Be polite – you're more likely to be listened to.

Make notes of what was said so that you can refer back to it later.

Follow up – stay in touch so you can build a relationship.

See page 50 on holding a successful meeting/event.

MEETING OUR MP HELPED GET OUR VOICES HEARD

Bridport and District Branch of Parkinson’s UK

> “We invited our MP to a branch meeting to increase his awareness of his constituents’ experiences of living with Parkinson’s. We hoped that this would inform any decisions he was called up to make related to people living with Parkinson’s. Our members felt that our MP listened extremely carefully to all that was discussed and has followed up with letters to Ministers and the NHS Dorset Clinical Commissioning Group. We feel this has been a successful collaboration and far exceeds our original expectations. We recommend that other branches make contact with their member of parliament.”

Who should you contact?

Some policy decisions, including those about the NHS and health, social care and transport, are the responsibility of each of the individual governments in Wales. It is best to speak to your AMs about issues where the decisions are made in Wales.

Decisions about welfare and benefits, among other things, are dealt with by the UK Government so your MP will be able to help.

If you are not sure please contact us, and remember if you are campaigning on a local issue, your MP and AMs should be interested regardless.

See page 44 on help writing letters.

Welsh Assembly

You can find out the details of your AMs by putting in your postcode at **assemblywales.org**

Remember there are five Assembly Members representing each person in Wales – one constituency and four regional members.

If you know their name already you can write to them at:
<name of AM>
The National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

AMs all have an email address following the formula **firstname.surname@assembly.wales** Or you can call the Welsh Assembly Information Line on **0845 010 5500**.

What can my AMs do to support my campaign?

They can:

- write to the relevant minister in the Welsh Government or make an appointment to see them
- ask Assembly Questions about the issue you have raised (these can be written or asked in the chamber)
- raise matters with relevant committees at the Assembly
- table a Statement of Opinion about the issue you've raised (this can be supported by other AMs if they agree)
- host an event or sponsor a Member's debate on the subject of your issue
- introduce a Member's Bill to change the law

Petitions

You can set up an online petition to the Welsh Government at **assemblywales.org/gethome**

Petitions can result in:

- a National Assembly legislative or scrutiny committee holding an inquiry on the issue
- individual Assembly Members taking action themselves, for instance, by asking questions of Ministers or seeking time to debate an issue in the Assembly

UK Parliament

You can find out the details of your MP by putting in your postcode at **parliament.uk**

If you know their name already you can write to them at:
<name of MP>
House of Commons
London
SW1A 0AA

Most MPs use email and you will find the address on their website. Or you can call the House of Commons Information Office on **020 7219 4272** to get your MPs details.

You can also call the House of Commons Switchboard on **020 7219 3000** to be put through to your MPs office.

What can my MP do to support my campaign?

They can:

- write to the relevant government minister or make an appointment to see them
- ask Parliamentary Questions about the issue you have raised (these can be written or asked in the chamber)
- ask for a debate (these can be on local or national issues that a particular MP feels strongly about – a relevant minister will always attend to respond on behalf of the Government)
- table an Early Day Motion (this is like a petition backbench MPs can sign if they agree)
- write to other decision makers

Local government

As many decisions about health and social care are made locally, 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.

Your local councillor(s) is a good way of making contact with the council as they have a duty to you as one of their constituents. However, there may be specific decision makers you want to target such as the Council Leader or a councillor with a responsibility for your issue.

Councillors can also bring media attention to your cause and take up individual cases with council officers.

HOW DO I FIND OUT ABOUT MY LOCAL COUNCIL AND COUNCILLORS?

- Visit **gov.uk/find-your-local-council**
- Visit your council website.
- Attend council meetings that are open to the public and/or read their minutes.

Single Integrated Partnership Plan

Your local authority will have a Single Integrated Partnership Plan. These set out how they will work with other public sectors to improve local people's lives. Health is a key area. You should see if this links in with your issue as it could be a good opportunity to ask for change.

HOW DO I LOBBY MY COUNCIL?

Local councillor(s)

You can lobby your councillors by:

- letter
- arranging a meeting
- going to their surgery
- holding a 'mass lobby' of your council, when lots of people meet with their councillors – you should arrange this with your councillor.

Council meetings

Members of the public are entitled to attend certain council meetings, and there are sometimes opportunities to speak at them.

Council officers

Paid council staff or officers are key people in the development of policy. They advise the council and committees on the issues involved. You can talk to them directly or influence them through your councillors.

Local health decision makers

If you want to change local health services you should speak to some of the organisations listed below. Some are decision makers and some are groups who may support you.

Local Health Boards

Local Heath Boards (LHBs) decide and provide healthcare services in each area. They cover hospitals, GPs and community services.

NHS Trusts

There are currently three NHS Trusts in Wales:

- the Welsh Ambulance Services Trust
- Velindre NHS Trust (specialised services)
- Public Health Wales (public health)

Community Health Councils (CHC)

They make sure the needs of local people are represented in the local services provided, and must be consulted on any change. They also monitor the quality of services and help individuals who have problems or complaints.

Every CHC has public meetings that you can attend or you can contact their office.

Contact details and dates of upcoming meetings are available from your GP or at **wales.nhs.uk/ourservices/directory/communityhealthcouncils**

Get in touch

If you want some advice/support, we'd be happy to help. If you get an agreement, let us know – it could make a difference to our national campaigns. Contact **campaigns@parkinsons.org.uk**

See page 67 on how to contact these groups.

CASE STUDY: DR COLIN SANDERS

> “It was clear that people with Parkinson's were not getting their medicines on time at the local hospital, so we contacted the director of nursing at the Health Board about the issues. She paid attention to our concerns and set up a meeting with the assistant director of nursing and other important people. We shared our experiences with them and now there is a working group between the Health Board and Parkinson's UK to sort out the problem.
>
> It's really important to try and get hold of directors and assistant directors on Health Boards as they make the decisions.”

KEEPING MOTIVATED

Change doesn't happen overnight so don't be dispirited if you don't get what you want right away. Every step you take brings you closer to your aim and it's important to celebrate each one.

Checking back on your progress will also show you how far you've come and help you work out what you need to do next.

MAINTAINING MOMENTUM

Keep your supporters keen

It's essential to tell your supporters how things are going and show them how they're making a difference. If you haven't had a recent success, tell them about your plans to move things forward so they feel part of the campaign.

Celebrating your achievements

Look back at your original goals to see how well you're doing. Go through them with a traffic light system:

- green for complete
- orange for moved forward
- red for not started

Every green or orange goal is a success, so celebrate! The reds will help you identify your next steps.

The effect of your work may not always be clear. Here are ways you can tell if you're making a difference.

- Look back at your correspondence with decision makers. Has their tone changed? Have they now conceded some of your points?
- Look at your feedback from supporters, targets or service users. Has your work made a difference to them/the way they talk about things?
- Do a survey of people affected by what you are trying to change to see if they have seen any improvement.

Remember your work is raising awareness of Parkinson's and the needs of people affected by the condition. That can only be a good thing.

How you can move forward

Seeing what you've achieved will help you identify how to move forward. Have you learnt anything new that could tell you why you haven't achieved a particular goal? It may be too big, so you could break it down into smaller goals.

Who have you reached?

Write down all of the people you've come into contact with. Next to their name note how involved they are with the campaign. Are they informed, supportive, a main player? Are there any people on your original list of people to contact who don't feature on this updated list? Think about:

- what new thing can you do to reach them?
- is there anybody on your list that can help you more than they are currently?

What are the barriers?

If you have achieved all of your goals but not got what you have asked for, you need to find out why. Try to write down all the barriers that could be in the way of change. How can you overcome these? Is there a different route you can take that addresses these barriers? Do you need to contact different people?

You may need to set new goals as you did in the beginning of your campaign. Ask your supporters what you should do next. They might come up with ideas you hadn't thought of!

Remember it can take time to change things. Sometimes you just need to keep asking and keep the pressure up.

SUCCESS

Congratulations! You did it! You should be very proud of yourself.

Before your well deserved rest, just take some time to wrap up and evaluate your campaign.

Make a list of:

- all of your successes and how you achieved them
- any mistakes made during the campaign and what you learnt from them

This will help you or others in your area if they need to take further action or plan another campaign.

The final steps

1. Get agreement in writing
   Make sure the change you've been promised is in writing. If it is going to take some time to be implemented, think about if you want to stay involved to make sure it continues as you wish and ask to be kept up to date with progress.

2. Thank your supporters
   a) Send a general message out (on social media, by email, or your blog – whatever ways you have contacted people before about your campaign) thanking everyone involved, and telling them what they helped to achieve.

   b) Send personal messages to those who have been instrumental in the success of the campaign.

3. Thank the decision makers
   You may have had to fight hard for your changes but be gracious in success and thank those who have given you what you asked for.

4. Tell us all about it!
   The Policy and Campaign team at the UK office (**campaigns@parkinsons.org.uk**) or your local staff would love to hear all about your campaign. We might be able to use what you've learnt to help someone else take action in their area.

5. Stay involved
   Your campaign may be over but you and your supporters may want to stay involved. You could join your local Healthwatch or patient participation forum so your voice is always heard.

We hope that you have found this toolkit useful and are fired up to ask for the services that people with Parkinson's deserve.

We would love to hear about your activities. We are always here if you need help too.

Please contact:
campaigns@parkinsons.org.uk
or **020 7963 9349**.

There are other contacts that you might find useful in the next section.

WE PERSEVERED AND WON!

Nick Howorth

Leonard Cheshire
Gloucestershire House
Campaign Action Group

“The Campaign Action Group found that it was getting increasingly difficult to cross the road where we lived because of the traffic. We felt the road really needed a zebra crossing.

The first thing we did was gather evidence with a road count to show there was a lot of traffic. We also talked to all the people who lived in the street about their opinions. Then we started to lobby the council. It was really important to get the key contact in the right department. That way, we always knew our information was being targeted at the person who could make the decision.

It took us five years to get the crossing but we kept up the pressure so the council knew we wouldn’t go away. We won changes along the way such as widened pavements and dropped kerbs, which kept us motivated, but we knew we needed to focus on exactly what we were campaigning for. It has made such a difference to have the crossing in place, it was worth all of the work.”

RESOURCES

KEY CONTACTS

Wales team
Staff in Wales work to provide local support, fundraising and campaigning.
wales@parkinsons.org.uk
0344 225 3784

Local groups
Find the local group near you at
parkinsons.org.uk/localgroups

Or get in contact with our Local Networks team on **020 7963 3929**
localnetworks@parkinsons.org.uk

Policy and Campaigns team
Supports people who want to campaign and improve services and also leads our work influencing the Government. Your first point of contact for anything raised in this toolkit.
Wales: **cpo.wales@parkinsons.org.uk**
UK: **campaigns@parkinsons.org.uk**
020 7963 9349
parkinsons.org.uk/campaigns

Digital team
Looks after the Parkinson's UK website and social media.
web@parkinsons.org.uk

Marketing team
Helps develop and promote the messages of Parkinson's UK. Has a 'recipe book' of the different materials available.
marketing@parkinsons.org.uk

Media and PR team
Can help with anything TV, radio and newspapers related.
Wales: **cpo.wales@parkinsons.org.uk**
UK: **pr@parkinsons.org.uk**
020 7963 9370

Helpline
Provides support and guidance for people affected by Parkinson's.
hello@parkinsons.org.uk
0808 800 0303

Fundraising team
Supports people to raise money for Parkinson's UK and run their own activities.
fundraising@parkinsons.org.uk

Printing company
City Digital Limited (CDL)
Printers for Parkinson's UK branded resources.
www.citydigital.net/client-login
Rob Hood **01732 466 978**
rhood@citydigital.net

Government offices
Welsh Assembly
assemblywales.org

The National Assembly for Wales,
Cardiff Bay
Cardiff CF99 1NA

Welsh Assembly Information Line
0845 010 5500

Health decision makers
Welsh local boards
www.wales.nhs.uk/ourservices

Welsh NHS trusts
www.wales.nhs.uk/ourservices

Patient participation organisations

Patient Opinion

Website to share all experiences of health and social care services that are fed back to these services.
www.patientopinion.org.uk

Wales: Community Health Councils

wales.nhs.uk/ourservices/directory/communityhealthcouncils

Other neurological charities you can work with

Wales Neurological Alliance:

Umbrella organisation for neurological charities in Wales.
www.walesneurologicalalliance.org.uk
info@walesneurologicalalliance.org.uk

Alzheimer's Society

www.alzheimers.org.uk
Devon House
58 St Katharine's Way
London E1W 1LB
020 7423 3500
enquiries@alzheimers.org.uk

Epilepsy Society

www.epilepsysociety.org.uk
Chesham Lane
Chalfont St Peter
Buckinghamshire SL9 0RJ
01494 601 300

Motor Neurone Disease Association

www.mndassociation.org
PO Box 246
Northampton NN1 2PR
01604 250505
enquiries@mndassociation.org

Multiple Sclerosis Society

www.mssociety.org.uk
MS National Centre
372 Edgeware Road
London NW2 6ND
020 8438 0700
supportercare@mssociety.org.uk

Multiple System Atrophy Trust

www.msatrust.org.uk
51 St Olav's Court
City Business Centre
Lower Road
London SE16 2XB
0333 323 4591

The Progressive Supranuclear Palsy Association

www.pspassociation.org.uk
PSP House
167 Watling Street
West Towcester
Northamptonshire NN12 6BX
01327 322410
psp@pspassociation.org.uk

The Stroke Association

www.stroke.org.uk
Stroke Association House
240 City Road
London EC1V 2PR
020 7566 0300
info@stroke.org.uk

ACTION PLAN TEMPLATE

Aims:

Key audiences and partners:

Campaign resources to create:

Evidence needed:

Goal	**Action**	**Key dates/ deadlines**	**Priority**	**Person Responsible**	**Achievements**
Example Collect 150 signatures asking for Parkinson's nurse	Example Run stall in high street to collect signatures	Example Budget meeting 16 November	Example High	Example Liam	Example 200 signatures collected New volunteer signed up at stall

NOTES

FEEDBACK FORM

Please let us know whether this toolkit has been useful, or if there are other materials we could produce to support you in campaigning for change in your local area.

Name .... Group ....

Address ....

Telephone .... Email ....

Has this toolkit been helpful? Yes ☐ No ☐

What section was the most helpful for you?

Getting started ☐ Planning your campaign ☐ Taking action ☐
Keeping motivated ☐ Key contacts ☐

Did the experiences from people affected by Parkinson's in the toolkit inspire you to get involved in campaigning? Yes ☐ No ☐

Was there anything you thought was missing from the toolkit? Yes ☐ No ☐

Please tell us what. ....

Was there anything in the toolkit you thought shouldn't be there? Yes ☐ No ☐

Please tell us what. ....

Do you have an experience you would like to share with other campaigners interested in improving life for people affected by Parkinson's? Yes ☐ No ☐

Please add details below in comments box. ....

Do you need any other materials to help you to campaign? Yes ☐ No ☐

Please add details. ....

Please add any other comments

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

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

Wales