

Campaign for people living with Parkinson's

After our letters and people going to the Clinical Commissioning Groups they invited us all to a meeting where they decided that they would hire a Parkinson's nurse.

Barbara Marsden



## YOU'LL BE SURPRISED AT WHAT YOU CAN DO

#### Do you want to...

- improve services for people living with Parkinson's?
- change the way the Government treats people with Parkinson's?
- get a Parkinson's nurse for your area?
- have a say in the decisions that affect you?

Many people have successfully campaigned to change things for the better. You can too.

#### You can

- start a campaign with others
- · do something on your own
- join an ongoing campaign

#### We'll help

We've produced a campaign toolkit with everything from how to get started to how to influence the right people. To save money it's online but you can easily print it off:

parkinsons.org.uk/campaigntoolkit or call 020 7963 9349

## 1. PLAN YOUR CAMPAIGN

All campaigns need a good plan.

### What do you want to do?

You need a simple goal or message such as:

- a Parkinson's nurse for your area
- better local health and social care for people with Parkinson's
- disabled parking on your high street

#### Who will help you?

These could be people like:

- your local Parkinson's group parkinsons.org.uk/localgroups
- disability rights groups
- local health and social services users and staff

### How will you do it?

You can do anything from a simple petition to a big campaign. Our campaign toolkit will give you an idea of what works.

### Timing is everything!

It's easier to stop something happening than to get a decision reversed. Build your campaign around important dates when decisions are made.

## 2. BUILD SUPPORT

Your campaign needs to reach:

#### 1. Decision-makers

These could be politicians, councillors or health and social care planners.

- People who can reach decision-makers
   These could be GPs, NHS staff, journalists or councillors.
- **3. People who will partner your campaign**These are people with similar aims, such as disability rights campaigners.

## 4. Supporters

Anyone likely to agree with what you want to do.

How to get people on side:

- Tell them what the problem is.
   Use petitions, social media, letters and meetings.
- Have evidence to back you up.
   You'll need facts, real-life stories and proof of public support.
- Tell people exactly what you want them to do.
   Be clear do you want them to sign a petition or attend a local meeting?

## 3. TAKE ACTION

There are many ways to make your voice heard.

- Send letters to newspapers and politicians
   Our campaigns toolkit has templates you can use.
- Start petitions
   More people will sign to make a positive change rather than to agree that something is wrong.
- Arrange meetings with decision-makers
   Take evidence to back up your argument and spell out what you want them to do.
- Use social media like Twitter, Facebook, YouTube and blogging It's the easiest way to reach a lot of people.
- Organise events and stunts
   Anything from meetings to public events.
- Lobby politicians and NHS bodies for support
   Our campaigns toolkit tells you how.

## 4. KEEP IT GOING

It takes time to change things. Here's how to keep up the momentum.

## Celebrate your achievements Don't forget small victories like good feedback from supporters – they all count!

## Take it one step at a time Break your goal down into small steps and tick each one off as you achieve it.

- Be persistent
   If you don't get an answer, try again and remind them you have been in touch before.
- Remember everything you do counts
   Everything you do raises awareness of the issue with someone.

## YOU REALLY CAN DO IT

Our campaigns toolkit has lots of success stories. All these campaigns were started by someone like you.



## NICK'S STORY

Where we lived, we found it increasingly difficult to cross the road to get to the bus stop 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. We found it was really important to get the key contact in the right department. That way we always knew that our information was being targeted at the person who could make the decision to put in a new zebra crossing.

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 concentrate on exactly what we were campaigning for to win our crossing.

It has made such a difference to have the crossing in place, it was worth all of the work.

Nick Howorth

# WE'LL HELP YOU EVERY STEP OF THE WAY

We have staff at UK office who can help support your campaign, so please get in touch.

020 7963 9349 campaigns@parkinsons.org.uk

Don't forget to tell us about your successes so we can use it to inspire others.

facebook.com/parkinsonsuk tweet@parkinsonsuk

We are now receiving 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.

## **Bob Adams**



Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

## Parkinson's UK

215 Vauxhall Bridge Road London SW1V 1EJ

Free\*confidential helpline **0808 800 0303** (Monday to Friday 9am–8pm, Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303** 

(for textphone users only)

\*calls are free from UK landlines and most mobile networks.

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