

# THE PARKY CHARTER

**A five point national plan.**

We, the Movers and Shakers, are 6 individuals who are not afraid to say what we think. And we have been saying it. In the pub, to each other initially, but in the last 11 months we have been saying it more widely in our podcast about Parkinson's: Movers and Shakers.

Selected by both The Times and The Guardian amongst their top podcasts of 2023 and winner of the Broadcasting Press Guild Award 2024 for "Best Podcast of the Year", we find ourselves (much to our surprise) as the voice of Parkinson's. We have received thousands of letters from People with Parkinson's (PwPs) telling us how life is for them.

We are getting a solid sense of how Parkinson's care looks around the country and it is not a pretty picture: unfair, uneven, unfair and unsatisfactory.

We have been making the podcast since March 2023 and have become known for approaching the condition with humour and we hope good grace.

But in the course of almost 30 episodes we have become aware of many shortfalls in the way that people with Parkinson's are treated. Some of the stories we hear are shocking and disturbing.

Parkinson's is the fastest growing neurological condition in the world. In the UK, 153,000 people are living with it and, by 2030, there will be closer to 175,000 of us. Parkinson's affects every one of us differently. All this suggest that this growing, degenerative complex condition, for which there is as yet no cure, isn't being treated with the seriousness it deserves by the Government and some parts of the NHS.

It is time for us to stand up and be counted. Physically if we can, metaphorically if we can't.

We want NHS promises kept and to be given realistic hope of a cure.

If the humanitarian cry is not loud enough, let us try the economic rationale. This is a long and debilitating illness. It takes loved ones out of the workplace and costs a great deal. This can be achieved at zero net cost according to the Michael J Fox Foundation with present expenditure on finding a cure and looking after sufferers, being replaced in the long run by zero expenditure once a cure is found.

Given our high profile careers in media and the law we are well aware change rarely happens without making a fuss, so in this election year we intend to raise something of a stink and both move and shake the powers that be.

**HERE IS OUR FIVE POINT CHARTER**



# 1

## **SPEEDY SPECIALISTS**

Parkinson's slows many of us down - but that doesn't mean we should be stuck in the NHS slow lane. We hear many complaints about the time it takes to be diagnosed and then the long gap between appointments with the consultant. The NHS (NICE) guidelines are perfectly clear - every person referred by their GP for a possible Parkinson's diagnosis should see a neurologist or geriatrician within 18 weeks. This often doesn't happen - it should be policed and enforced. After diagnosis there should be a maximum of a year between neurological appointments.



# 2

## **INSTANT INFORMATION**

When first diagnosed every PwP should be given, as of right, a leaflet containing essential information about Parkinson's. At the very least, this should be the Parkinson's UK pamphlet. But the newly diagnosed PwP should also be given information which is relevant, personal and local. This should include a contact number for their Parkinson's nurse, including a date for a first appointment, and other available help including local support groups.



# 3

## **PARKINSON'S PASSPORT**

People with this yet incurable degenerative condition should never be denied benefits because they 'might get better' - instead when diagnosed they should be given a "Parkinson's passport" which would give an automatic right to certain benefits, free prescriptions, a 'blue badge' and other clearly defined services. Any remaining services or entitlements which do require assessment must be undertaken by an assessor trained in an understanding of the complexities of the symptoms of Parkinson's, especially the variable and intermittent nature of some symptoms.



# 4

## **COMPREHENSIVE CARE**

Even an assured annual meeting with a neurologist can only help people with this complex, unpredictable, multifaceted condition to a limited degree – every PwP should have a personal plan ensuring regular access to, advice from, and treatment by, a multidisciplinary team including Parkinson’s nurses, physiotherapists, nutritionists and speech therapists.



# 5

## **QUEST FOR A CURE**

Parkinson's is incurable - but it doesn't have to stay that way. Hunting for a cure is a long-term goal but produces many shorter term benefits. The Government should commit to a major increase in funding for research into Parkinson's from today's modest level (£6.7 million in 2021/22).