

Political advocacy: a way to achieve better outcomes for people with Parkinson's disease and their families

A workshop on engaging effectively with your local authorities

EPDA Members Meeting | 15 November 2017

WORKSHOP AGENDA



What you can achieve by engaging with your national governments



Sharing advocacy good practice examples from our membership



Parkinson's advocacy across Europe: Introducing our member survey and why it matters to you

Open discussion

WHY POLITICAL ADVOCACY MATTERS

People with Parkinson's and carers are voters like anyone else – their voice deserves to be heard.

- Your government can introduce **mandatory clinical guidelines and care pathways** for treatments
- It controls **reimbursement of drugs**, which means that it can directly shape the kinds of treatments available to patients
- It can fund **medical research and training** for non-neurologist healthcare professionals
- It can **gather experts to exchange the latest in clinical research** at the expense of the state
- Politicians can use their public image and visibility to **raise awareness of the impact of Parkinson's on the patient and the carer**, thereby helping to reduce stigma

SHARING GOOD PRACTICES FROM OUR MEMBERSHIP



UK

Local advocacy to retain PD nurses
National action on welfare for people with PD and their carers



Finland

Developing the care path with the support of former Social and health minister Maija Perho



Slovenia

Parliamentary briefings on healthcare gaps, notably long waiting times for check ups



Norway

Building political support for ParkinsonNet



Spain

Working with politicians to improve access to neurologists

SHARING GOOD PRACTICES FROM OUR MEMBERSHIP



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

Natasha Burges

Senior Parliamentary and Public Affairs Adviser Parkinson's UK

Saving Attendance Allowance (AA)

Ensuring critical welfare stays in place to support older people with Parkinson's in the UK

What the problem was

Proposed changes to Attendance Allowance could leave people with Parkinson's without financial support they need.

- Government wanted to devolve responsibility for AA to local authorities
- Money for AA no longer to come from central Government but from Local Authorities which would have to fund the system and payments through business rates.
- 34,000 people with Parkinson's in receipt of AA and rising

What we did

Targeting influential stakeholders

- Held a drop in session in Parliament
- Met with potential allies
- Mapped where recipients were likely to be
- Met with MPs at Party conferences
- Asked supporters to write to their MPs asking them to contact local councils

What the outcome was

We won!

- Government shelved their plans
- Huge relief and joy from supporters who were eager to get campaigning
- Parkinson's UK was congratulated on social media by the shadow Work and Pensions Minister and MPs from the governing Party

Saving Attendance Allowance (AA)

Ensuring critical welfare stays in place to support older people with Parkinson's



Debbie Abrahams ✓
@Debbie_abrahams

It's a win! Govt plan to devolve
[#AttendanceAllowance](#) now shelved.
Great mtg with [@parkinsonsuk](#) and
others on this at Labour conf '16



Heidi Allen ✓
@heidiallen75

Absolutely the right decision, great
news! [@ParkinsonsUK](#) [twitter.com/pennymordauntm...](#)

Penny Mordaunt MP ✓ [@PennyMordaunt](#)
[@CommunitiesUK](#) announces that
Attendance Allowance will not be devolved
to Local Authorities. TY to all who
responded to the consultation.

19/01/2017, 15:01

14 Retweets 23 Likes

SHARING GOOD PRACTICES FROM OUR MEMBERSHIP



Hanna Mattila

Executive Director of the Finnish Parkinson Association

A GOOD PATH

Developing the care path of people living with Parkinson's in Finland



What the problem was

Better orientate people living with Parkinson's in the healthcare system after diagnosis

- Ageing of population creates pressure for the healthcare system
- Supporting a person living with Parkinson's disease requires resources from multiple stakeholders

What was our objective

Maintaining the functionality of people living with Parkinson's

- A whole re-think the use of resources in the healthcare was needed

What we did

Modelling the care path

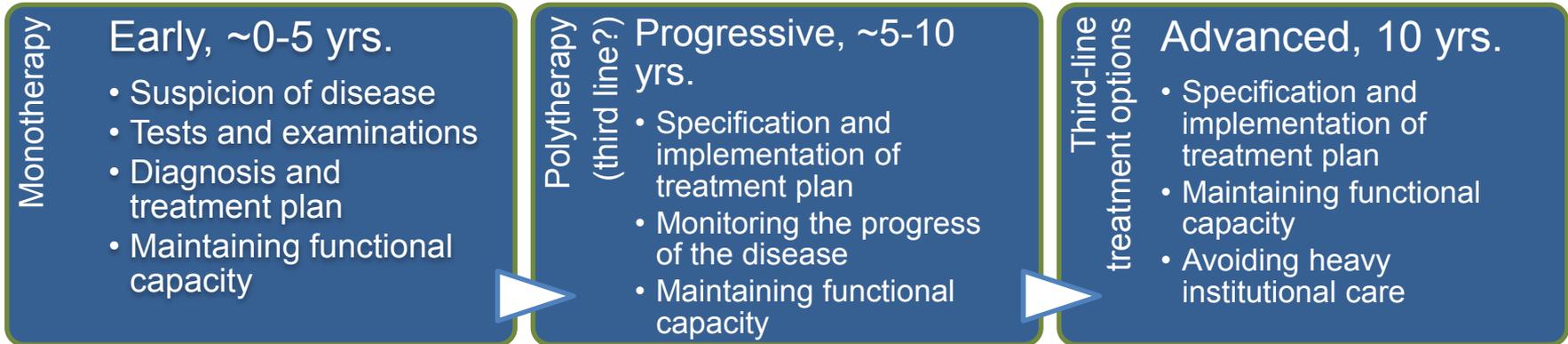
- The Finnish Parkinson's Association developed the "Good Care Path", a generic lean model of PD process in healthcare environment in Finland
- A Good Path national steering group was created and led by the former social and health minister Maija Perho to influence the decision-making process on healthcare systems
- A series of events were held in 30 different places in Finland, the Finnish Parkinson's Association was invited to speak in front of policy-makers, and the Good Path was also presented at the Finnish Parliament
- In parallel, a cost-benefit analysis study of Parkinson Disease's care chain in Finland was launched to show decision-makers how Good Path can help reduce costs.

What the outcome was

Raising awareness and influencing the development and organisation of healthcare in Finland

- Through the series of events and studies, the Finnish Parkinson's Association disseminated information about its "Good Path" to ensure its uptake by decision-makers in the Finnish healthcare system and its good use for people with Parkinson's.

Generic, lean model of PD process in health care environment in Finland



What brings value for person living with PD:

Reason for symptoms quickly
Suitable treatment for each patient
Information of disease

Preservation of quality of life and functional capacity
Limited amount of disturbing symptoms
Self-care and awareness of treatment

What to develop to increase value and decrease waste:

Treatment planning

Diagnostic and referrals

Monitoring and adjustment

Suitable medication

Right treatment in right time and place with right resources!

SHARING GOOD PRACTICES FROM OUR MEMBERSHIP



Magne Wang Fredriksen

Secretary General of the Norwegian Parkinson's disease Association

Norges Parkinsonforbund

SHARING GOOD PRACTICES FROM OUR MEMBERSHIP



Laura Carrasco Marín

Director of the Parkinson's disease association in Madrid

Asociación Parkinson Madrid

“UNIDOS” project: Parkinson patients support



What the problem was

Real integrated care for Parkinson´s disease

- Neurologists and associations collaborate mutually but not continuously in the attention of the patients with Parkinson´s.
- The perspective is different from each point of view.
- Every stakeholder works separately for the wellbeing of the person with PD.

What we did

Got in touch with the Scientific Association of neurologist of Madrid

- We wanted to know which are the barriers that cause the lack of collaboration
- We wanted to know how to work together for the people with Parkinson´s and their families
- We developed a methodology in order to gather the feelings and thoughts from the neurologists and the association´s professionals

What the outcome was

The collaboration will improve the attention of people with Parkinson´s

- A huge list of very interesting collaborative task to develop in the very next future.
- The Asociación Parkinson Madrid´s Board, have prioritized and decided to focus on two challenges:
 - 1 - Work with Madrid´s Association of Neurology and Public administration of the region of Madrid in order to secure the equal access rights to special resources
 - 2 - Prepare the appointment with the neurologist previously from the association. (In order to gather all the crucial information for helping in clinical decision taking)

What we did: Methods

Getting the help:

- We looked for the collaboration of the Madrid's Association of neurology (AMN).
- Several meetings have taken place with their Board.

Discussion groups developed by the Madrid Parkinson's association

- February and April 2016.
- 9 groups with a total of 19 neurologists participating
- Throughout all discussion groups there is a Neurologist from AMN and association professionals from Comunidad de Madrid (social workers, therapists, psychologists...)

Written report:

- Finished by the end of May 2016.
- Content: categorization and reorganization of topics obtained by the discussion groups
- Function: to provide a working tool to enable the AMN and Madrid Parkinson's association to decide and discuss about the possibility of generate new alternatives for Parkinson's patients



Concrete actions - Preparing the appointment with the neurologist



Work with Madrid's Association of Neurology and public administration of the region of Madrid in order to secure the equal access rights to specialize resources

- The Madrid association demanded to the public health administration of Madrid to create a work table with the three stakeholders.
- The demand was accepted and in February 2017 the first meeting was held.
- Nowadays is going to have a new impulse after the dismissing of two important politicians of public administration.

Concrete actions - Preparing the appointment with the neurologist



Introduction:

- In the Spanish Public Health System patients with PD have appointment with their neurologist from every 4 months to 1 year.
- Every appointment lasts a maximum of 20 minutes.
- It's difficult for the neurologist to collect all the information needed to take a clinical decision.

Possible Solution:

- The support of the association.
- A team of social workers experts in Parkinson's disease (socio-health profile) set an appointment 15 days before the neurologist appointment. The meeting takes around 1 hour.
- The professional team makes questions to detect social and clinical changes and focus on special alarm situations such as: delusions, falls, motor fluctuations, etc.

Web platform:

- Developed with the support of UCB.
- Developers are creating a platform in which all the information is collected by the social workers.
- This web platform can be accessed through tablets, mobile and PCs.
- The patient decides with whom to share the information under their own responsibility. (By sending an email or just showing the screen of his device).

What the outcome was

Information exchange: Reports

Awareness about associations and resources

Politic incidence and right defense

Awareness initiatives

Early onset Parkinson

Volunteer acts and services

Formation program

Research and Document elaboration

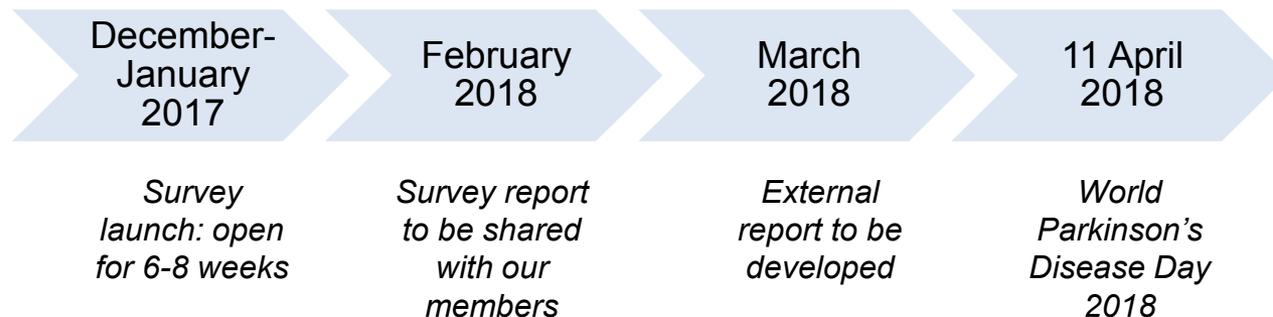


Parkinson's advocacy across Europe – our member survey and why it matters to you

OBJECTIVES To gather information about what issues you face when advocating for people with Parkinson's and their families.

WHAT DOES IT MEAN FOR OUR MEMBERS?

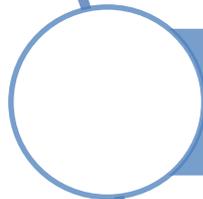
We hope that this will help us to better support you in the future, whether it's through connecting you with other member organisations or advising you on potential funding partners. A short report will be developed on the state of government action on Parkinson's next year. You can use this as a tool to engage your national policymakers.



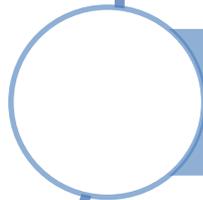
Parkinson's advocacy across Europe – tips and tricks on how to engage



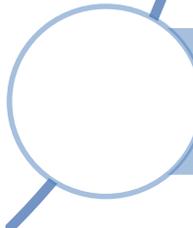
Understand **where the power lies**. Create a “stakeholder list” of people within the government that are setting the priorities for healthcare, and how to contact them



Identify what exactly is **not working in your health system** – is there not enough public funding for PD research? Are treatments not evenly and widely available? This can help you to set objectives

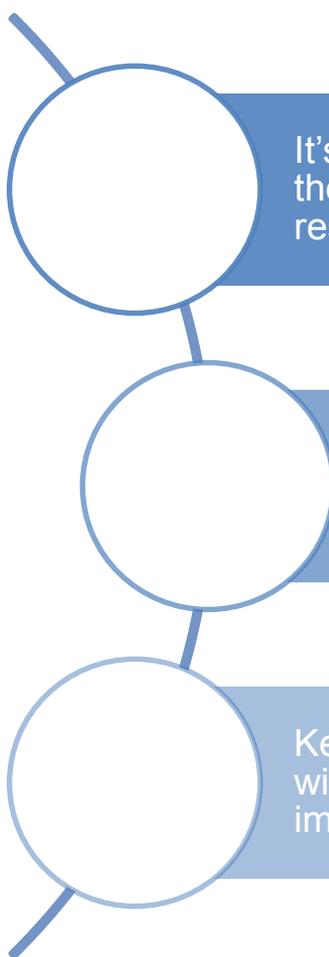


Get in early. Don't wait for new policies to be developed - ask for a meeting with your Health Ministry / health authority to gather insights about the government's priorities, and where Parkinson's may fit in



Create **materials** that can support your case, like evidence on diagnosis and treatment gaps, or a “position paper” which sets out why this needs to happen

Parkinson's advocacy across Europe – tips and tricks on how to engage



It's important that **key people in the government** know who you are. Invite them to your events, Tweet them with your call to action, and send them research or other projects that you support

Go to the government with **good practice examples** of what is working well in other countries and could be replicated at home

Keep in mind the **seniority of the people** you are speaking with. A discussion with an MP or Cabinet Member may be more political than technical. This also impacts who you bring to the meeting from your side

OPEN DISCUSSION