

Improving the education of healthcare professionals who manage people with Parkinson's

Workshop outputs, December 2021

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Workshop objectives

To identify areas where **education should be improved for the healthcare professionals** (HCPs) that manage Parkinson's, so that they may better serve the needs of people living with Parkinson's (PwPs), their families and carers – and improve their lives

Participants

There were **eight participants** from eight different European countries who participated in the workshop

Six people with Parkinson's

Two carers

Countries represented

Belgium	Iceland
Czech Republic	Ireland
Denmark	Portugal
Germany	UK

Participants' Parkinson's experience

There were **90 years** of Parkinson's experience among the workshop participants – with an **average of 11.25 years** of living with Parkinson's, ranging from 5 to 18.5 years since diagnosis.

Key insights arising from the workshop (I)

Interactions with multi-disciplinary team (MDT) members can have a significant positive impact on the PwP and their carer. However, the concept of a **MDT team** is not implemented in reality, according to the participants' experience. Instead, it is normally the PwP and their carer who coordinate care with the individual HCPs and other professionals.

Communication between HCPs and PwPs can often be sub-optimal. This is particularly challenging at the time of **diagnosis**, when for the PwP and their carer a diagnosis of Parkinson's is a life-changing moment.

Neurologists need to be better at listening to the needs of people with Parkinson's.

Participants are calling for a change in how people with Parkinson's are **educated to look after themselves better**, so they can stay well for longer and thereby minimise the need for MDT support.

Key insights arising from the workshop (II)

Mind-body interactions – a holistic approach to maintaining a healthy state of mind and body wellbeing – are important. Parkinson's should be addressed beyond just physical symptoms.

PwPs would like to have more focus on the management of the **non-motor symptoms** of Parkinson's, which can often have a greater impact on their quality of life. PwPs want to be empowered to **help themselves** manage their Parkinson's.

Interactions and the **sharing of experience among PwPs** can have a very positive impact, and should therefore be encouraged at all stages of the Parkinson's journey.

The realities of living with Parkinson's are very different depending on the age of the person: for example, a 70-year-old person has different concerns and needs than a 30-year-old.

Findings from the pre-workshop survey

Pre-workshop survey introduction

A pre-workshop survey was completed by all workshop participants. The purpose of the survey was to **identify key themes**, which would then be explored in the workshop.

Aims of the pre-workshop survey:

- To understand the participants' **Parkinson's journey** by gaining insights into the challenges they have experienced at each of the **key stages** of their journey.
- To identify areas for further discussion where we can work to **improve the education of HCPs** so they may better serve the needs of people living with Parkinson's.

MDT interactions with workshop participants – findings from the pre-workshop survey

The pre-workshop survey revealed significant differences in how multi-disciplinary team (MDT) members interact with the participants

- Most participants only have access to a neurologist between **1-3 times a year**, with appointment times being **15-30 minutes**
- Some participants have access to a **Parkinson's Disease Nurse Specialist** (PDNS) up to 2 times a year
- Few participants have access to **other MDT members** such as a physiotherapist, speech therapist, or dietician. These are sometimes funded privately.
- No participants felt they have the support of an **MDT working together** to help manage their Parkinson's

It is **vitaly important** for all MDT team members to work together to help people with Parkinson's achieve a better quality of life.
Each and every interaction is very important, as these **interactions are limited** in both frequency and time.

Diagnosis – findings from the pre-workshop survey

- A diagnosis of Parkinson's should **never be given if a patient is on their own**, according to participants
- A diagnosis is a shock – it is very difficult to expect a person to take in all the information provided. A **follow-up interaction** a few weeks later, to answer any questions and to see how they are coping, would make a huge difference
- A diagnosis of Parkinson's should **never be played down** – it is huge and very significant for every person, and it is important to understand the **potential impact of the disease on daily life**
- The focus at diagnosis is on the motor symptoms and how to deal with them – there is **not enough focus on aspects that may have a greater impact on life** such as exercise, mental health, diet etc
- Providing accurate information at diagnosis is essential – understanding that there are **support groups** and national organisations that provide a wealth of information and support is critical in the early stages
- It is important to **consider the carer** at diagnosis, and for the HCP to help the carer understand some of the challenges of Parkinson's that will present in the months and years ahead

The **way** the diagnosis is delivered has a significant and **long-term impact** on the person with Parkinson's and their carer

First treatment – findings from the pre-workshop survey

- The **neurologist does not seem to really understand the realities of living with Parkinson's** and what is important to the person with Parkinson's
- The neurologist is focused on the **physical symptoms of Parkinson's** and on when/how to take the **prescribed medication**
- Focus is on **symptom management in the short term** without consideration for the long term
- **Medication options are rarely presented** – the neurologist decides on a treatment and informs the patient accordingly, resulting in limited understanding on the rationale of choice of medication
- The patient is not always well informed about the drug and its **potential side effects** – this is particularly important in Parkinson's, where the treatments present what can be considerable side effects in the long term
- **Better understanding of medication** would enable the person with Parkinson's to better manage their condition

Greater discussion and understanding of treatment options at the outset is important, especially for the younger person diagnosed with Parkinson's

Ongoing Parkinson's management – findings from the pre-workshop survey

- Once diagnosis has been delivered, there is **little ongoing management** – and this represents a big gap for people with Parkinson's
- HCP **interactions are mainly focused on medication** rather than discussions on how to manage symptoms of Parkinson's
- Having **access to MDT members** such as occupational therapist, physiotherapist, dietician etc is essential to enable ongoing management of Parkinson's, and to ensure appropriate support is provided. These services can have the highest impact on a person's ability to live well with Parkinson's
- Ongoing management of Parkinson's in **young-onset** needs to be differentiated from the older population – there are very different ongoing management needs
- The role of **support groups** should not be underestimated
- Better understanding of the hard reality of the frustrations and challenges of the **daily fluctuations of Parkinson's** as well as practical tips and guidance would help improve care

With approximately one interaction with a HCP in 6-12 months it is important to help both the HCP and the person with Parkinson's **maximise this interaction**

Treatment change – findings from pre-workshop survey*

- Treatment changes are **generally well explained** as this is the main focus of the HCP as the disease progresses
- It remains important to **explain the rationale for treatment change** and explain possible options
- Understanding of **short- and long-term side effects** prior to treatment change are important, so that the person with Parkinson's can manage their expectations (and the realities of any change)
- Better understanding of the rationale for the treatment and change, and how the medication works, would **enable the person with Parkinson's to better manage their condition**

Greater discussion and **understanding** of rationale for treatment change would help the person with Parkinson's and their carer to feel **more engaged and in control**

* Not covered during the workshop due to insufficient time for discussion

Next steps in Parkinson's progression – findings from pre-workshop survey*

- Participants do a lot of **reading and research** to understand what is coming and how to face it
- This understanding enables a **perceived greater level of control**, to deal with the future “on my own terms”
- The **role of the MDT becomes more important** as Parkinson's progresses
- HCPs need to understand and recognise the **impact on carers** as Parkinson's progresses
- Understanding of options of **what care and support is available** is fundamental

Better preparation for the future would enable people with Parkinson's to achieve a **greater level of control** on their quality of life

* Not covered during the workshop due to insufficient time for discussion

Findings from workshop discussion

Participants were asked to discuss what topics **HCPs should be better educated** about the experience of people living with Parkinson's, and to identify and agree which topics should be considered as a **priority**

Aims of the workshop discussion

- To understand **priority areas** where the education of healthcare professionals should be improved in relation to the following key steps in the Parkinson's journey:
 - **Interactions with the MDT and HCPs**
 - **Diagnosis**
 - **First treatment**
 - **Ongoing Parkinson's management**
- To develop key recommendations – according to the participant's experience – for a **more effective and patient-centered Parkinson's management**

Key findings from introductory workshop discussions (I)

Interactions with the MDT

- Participants reported the **same uneven clinical experience** with regards to their interactions with the MDT. This reportedly creates a sense of 'false comfort' among PwPs
- There is **no perceived multidisciplinary approach** to Parkinson's treatment and care
- Individuals are forced to take responsibility for **coordinating their own care** – they need more support from MDT
- MDT members can be remote and detached, and there is a **lack of communication** among the different MDT team members
- A **coordinator role** to organise the work of the MDT professionals would be beneficial

A coordinated, multidisciplinary approach to Parkinson's treatment and care is needed

Key findings from introductory workshop discussions (II)

Interactions with the neurologist/movement disorders specialist

- The neurologist often appears to be **working in isolation** unless there is a PDNS working alongside
- The neurologist is focused on the **physical symptoms of Parkinson's** and is very focused on medication and when/how to take the prescribed drugs
- The neurologist has **limited time** for the interaction and is mostly focused on their own agenda allowing little time for discussion
- The neurologist **does not seem to really understand** the realities of living with Parkinson's and what is important to the person with Parkinson's
- The neurologist **does not seem to encourage or enable interactions** between the person with Parkinson's and other MDT members such as physiotherapist, speech therapist, dietician. The role of the MDT does not seem to be recognised
- The workshop participants **do not always feel listened to or engaged** in their interactions with the neurologist

Improved understanding by the HCP of the realities of living with Parkinson's is needed

Workshop question 1: interactions with HCPs

When thinking about your interactions with your HCP, in what topics could they be better educated about the experience of people living with Parkinson's (PwPs), so they may better serve the needs of PwPs and improve their lives?

★ HCPs to highlight opportunities for PwPs to receive help and advice from other PwPs

★ More focus on non-motor symptoms to understand what is coming

★ Importance of nutrition and daily exercise

★ HCPs need to allocate more time to appointments

HCPs too focused on drug dose – just increasing levodopa doses

HCPs should not be just prescribing pills but have a holistic perspective

HCPs to understand the role of stress and its impact on Parkinson's

HCPs to understand and highlight the impact of treatments' side effects

PwPs generally need more support from HCPs

Meeting and interacting with other PwPs has huge benefits and needs to be encouraged

HCPs should work together and not in silos – ie, a multidisciplinary approach has the biggest impact

HCPs should highlight the best technology options available to aid PwPs*

The importance of diet – especially of vitamins and minerals intake – should be highlighted

* Added after the workshop by one of the participants

★ Indicates themes perceived as priority by workshop participants

Priority themes arising from question 1: interactions with HCPs

- Increased understanding and communication on the potential benefit of **receiving help and advice from other PwPs**
- Importance of **nutrition and daily exercise**, and the positive impact they can have on the quality of life of PwPs
- The **non-motor symptoms of Parkinson's** often have the greatest impact on PwPs – more education on non-motor symptoms and how to manage them would have a significant benefit
- **More time needs to be allocated to appointments**; having access to a MDT support team will complement and enhance the interactions with neurologists

Workshop question 2: diagnosis

When thinking about your diagnosis, in what topics could HCPs be better educated about the experience of people living with Parkinson's (PwPs), so they may better serve the needs of PwPs and improve their lives?



HCPs should have basic communication skills on how to deliver the diagnosis and explain about the ongoing care needed



For the HCP, delivering a diagnosis is just another days' work. For a PwP and their family, it's their life being turned upside down

PwPs need more support and information on what is coming in future

HCPs should show empathy and understanding of the impact of Parkinson's on the person and their family



Support after diagnosis – PwPs need someone to discuss with soon. A follow-up meeting with a nurse should be booked immediately

Shock – HCPs should explain the potential Parkinson's journey and what the condition actually is

PwPs are just starting a journey – HCPs need to be able to help explain this journey and what to expect



Priority themes arising from question 2: diagnosis

- PwPs need adequate **support after the diagnosis** – they need someone to discuss their experience with shortly after diagnosis is given. Ideally a **follow-up meeting with a nurse**
- How the diagnosis is given has a **huge impact** on a PwPs' Parkinson's journey:
 - HCPs should have **basic communication skills** on how to deliver the diagnosis and explain about the ongoing care needed
 - HCPs should understand that a **Parkinson's diagnosis is a life-changing event**

Workshop question 3: first treatment

When thinking about your first treatment, in what topics could the HCP be better educated about the experience of people living with Parkinson's (PwPs), so they may better serve the needs of PwPs and improve their lives?



The role of exercise should be discussed



PwPs should be able to understand the impact of medicine on their daily and work life; these aspects need to be considered when making treatment decisions, to allow for more flexibility

PwPs should receive clearer guidance about pills packaging, management etc.

Information on drugs' side effects should be clearer

There should be more discussion on the impact of Parkinson's on daily life, work and driving



Different available options should be presented – there is generally a lack of information on what medicines are available, especially for young PwPs

Treatments should be tailored to individual needs – one size does not fit all

Parkinson's is very different and one may (or may not) get certain symptoms. A balanced explanation is difficult but needed



Priority themes arising from question 3: first treatment

- The role of **exercise** should be discussed – as physical activity can have the most significant impact on a PwP's Parkinson's journey
- PwPs need to understand the **impact of medication on daily and working life** – this needs to be taken into account when making treatment decisions. Greater flexibility is required, as a **one-size-for-all approach does not fit all**
- HCPs should present treatment options and provide enough information about these, so PwPs can make an **informed choice**. This is especially important in **young-onset Parkinson's**

Workshop question 4: ongoing Parkinson's management

When thinking about your ongoing interactions with your HCP in what topics could the HCP be better educated about the experience of people living with Parkinson's (PwPs), so they may better serve the needs of PwPs and improve their lives?



HCPs should empower PwPs to carry on their normal life – help them holistically instead of focusing just on drugs



An adequate understanding of PwPs' experiences can't be conveyed in a 5-minute consultation in the neurologist's office

HCPs should share top tips for managing Parkinson's from other PwPs

HCPs should understand PwPs' experiences in relation to mood swings – and their difficulties in controlling/coping with them



The role of MDT members and the value they add should be highlighted

Any health issue experienced by PwPs is blamed on Parkinson's – but other possible concurring health conditions should be taken into account

Better understanding of support available – such as support tools or complementary therapies



HCPs should encourage social/daily activities – as these have a big impact on PwPs's quality of life



We are not just a case – we have feelings. Please listen to us!

Family members and carers have an important role and need more support

PwPs need help with aspects such as pain management and other non-motor symptoms



Carers should be taught how to help manage PwPs

PwPs should be informed about clinical trials options



Indicates themes perceived as priority by workshop participants

Priority themes arising from question 4: ongoing Parkinson's management

- PwPs should be **empowered to carry on their normal life** – HCPs should help them holistically instead of focusing only on drugs
- An **adequate understanding of a PwP's experience** can't be conveyed in a 5-minute consultation in the neurologist's office
- HCPs should **encourage social/daily activities** – as these have a big impact on the person's life
- The **role of MDT members** and the value they add should be highlighted
- **Carers** should be taught how to help manage PwPs
- We are not just a case – we have feelings. **Please listen to us!**

Future considerations

The **differences in education needs** for HCPs when managing and treating younger PwPs vs older PwPs should be taken into account

Participants to this workshop were generally younger. The **different needs of older PwPs** may need to be considered separately

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