

Improving how we talk about Parkinson's dementia

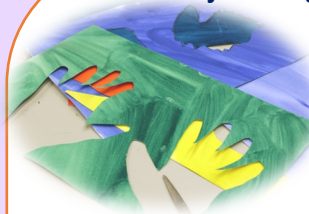
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Background: Dementia is six times more likely in people with Parkinson's than in the general population¹. However, people with Parkinson's and those working in the community avoid talking about it, due to worries about negative reactions from patients and a taboo around dementia. However, if we don't talk about it, people do not receive the treatment and support that they need.

Our aims:

1. Identify the roots of discomfort linked with dementia in Parkinson's through creative workshops
2. Use outputs from the workshops to co-produce a pair of booklets:
 - An information resource for people living with Parkinson's to access information and available support
 - A clinical toolkit for healthcare professionals to help to diagnose and manage Parkinson's dementia
3. Ensure the resources are relevant to underrepresented groups.

Project Stage 1: Creative Workshops



We worked with people living with Parkinson's, family members and artists to plan and deliver a series of creative workshops to explore fears associated with dementia.

Who participated?

34 participants, including people with Parkinson's, Parkinson's dementia, and family members, shared their attitudes towards dementia through art and conversation. 44% of people identified as Asian, Black or Mixed ethnicity.

"Clinicians are reluctant to open a can of worms when talking about Parkinson's dementia"

Workshop participant



Insights from participants

70% of people with Parkinson's and 81% of family members shared that they were worried about thinking and memory changes. However, only 38% of people with Parkinson's and 30% of family members had raised these concerns with a doctor.



During the workshops, people with Parkinson's and family members shared how they would wish to learn about dementia: in what format, when, from whom, and what excellent support through the process would look like.

"I volunteer with a wider Parkinson's group and while everything else is discussed, dementia isn't. It would be very helpful to have a new way of talking about dementia without scaring everyone"

Workshop Participant

Project Stage 2: Content co-development

Using outputs from the workshops, together with people with Parkinson's and family members, we co-developed a pair of booklets:

- A booklet designed for people living with Parkinson's to access information on dementia in Parkinson's and available support.
- A toolkit designed for healthcare professionals on how to recognise and manage dementia in specialist clinics.

We used focus groups to give everyone a voice: people with Parkinson's, their loved ones, and healthcare professionals working with the Parkinson's community

They shaped every aspect of the booklets, feeding into the content, structure, format and design.

"Include practical advice, such as driving, benefits, council tax, power of attorney – all will be implicated when receiving a diagnosis"

Caregiver input in resource development

Project Stage 3: Wider consultation

Once the draft booklets had been developed, we shared them with the wider Parkinson's and specialist community, for their review and feedback.



18 healthcare professionals formed our expert reviewer group. This included Parkinson's nurses, geriatricians, psychologists, neurologists, physiotherapists, and psychiatrists from around the UK who fed back on both resources.

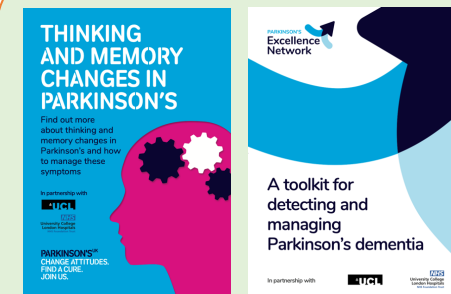
Project Stage 4: Resource launch and embedding

Once the booklets were finalised, we launched an awareness campaign together with Parkinson's UK to share them with the Parkinson's community.



Both booklets are embedded within Parkinson's UK's information resources for people living with Parkinson's and healthcare professionals.

Our outcomes



"The resources produced are wonderful and will help open up conversations on this vital issue." Claire Bale, Associate Director of Research, Parkinson's UK

Core team



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