

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



A path through Parkinson's Self-management programme evaluation report 2015

“Beginning at a very negative point, after three weeks I am totally changed. My attitude is one of motivation now rather than lacklustre acceptance. Thank you, I wish we had three more weeks.”

2015 participant

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1. Background

Parkinson's UK has been delivering a peer-led self-management programme called *A Path through Parkinson's* since 2013. It was developed in close collaboration with people with the condition.

A Path through Parkinson's enables people to share experiences and discuss the practical and emotional impact of the condition. The programme is made up of six sessions delivered over three or six consecutive weeks.

Each self-management group is made up of eight to twelve people – these can be partners, carers and people who have been living with Parkinson's for varying lengths of time.

Each self-management group is led by trained volunteer facilitators with first-hand experience of Parkinson's.

To date, Parkinson's UK has run 64 self-management groups attended by 675 people.

The following data has been gathered from participants at three points:

- When registering their interest in attending a self-management group.
- Anonymous demographic monitoring forms completed at the end of their self-management group.
- Anonymous participant feedback forms completed at the end of their self-management group.

2. Attendance of self-management groups in 2015

349 people attended 32 groups in 2015 and the overall attendance level was 91%.

Of those who attended, 183 (52%) were people living with Parkinson's and 166 (48%) were partners or carers. Seven of the groups in 2015 were groups for partners and carers only.

The length of diagnosis of those 183 people with Parkinson's was as follows:

Less 1 year	1-2 years	2-5 years	5-10 years	10+ years	Not known
11%	12%	27%	26%	17%	7%

The wide spread of length of diagnosis is encouraging and we take from it that people do not see self-management as only relevant at a specific stage of Parkinson's.

3. How people heard about the programme

We know that people may have heard about the programme from more than one source and that this may not be fully represented by the results below.

Parkinson's UK local adviser	Parkinson's UK website	Local branch or support group	Parkinson's nurse	Friend or colleague	Mailing from Parkinson's UK	Local charity	Other
13%	10%	16%	3%	1%	49%	2%	6%

4. Demographic information

- 45% of people who attended the self-management groups were aged 65-74.

35-44	45-54	55-64	65-74	75+
1%	5%	29%	45%	20%

- Most participants were women, making up 60%.

Male	Female
40%	60%

- In terms of the ethnicity of those attending, the majority (92%) identified as White British.

White British	White Irish	White other	White mixed	Indian	Black African	Black Caribbean
92%	1%	1%	1%	3%	1%	1%

- The majority of participants (81%) did not consider themselves to have a disability except Parkinson's.

Yes	No	Not disclosed
18%	81%	1%

5. Regular attendance of a local Parkinson's UK branch or support group

The majority of participants (58%) did not regularly attend a local Parkinson's UK branch or support group.

Yes	No	Not disclosed
41%	58%	1%

6. How people rated the self-management programme

This feedback is from the 308 participants who completed a participant feedback form at the end of their self-management group in 2015.

Overall, how would you rate being part of this group?

Very good	Good	OK	Not very good	Poor
77%	19%	4%	0%	0%

Do you agree or disagree with the following statements? (See table overleaf)

Some of those who disagreed that six or three weeks was the right number of sessions thought that the content could have been delivered in fewer sessions, but probably a majority wanted more sessions.

	Agree	Disagree
Six or three weeks was the right number for me	271	33
It was helpful to talk in this way	303	3
The pace of the group was right for me	288	18
I got the chance to have my say	306	1
This felt like the right group for me to be in	296	6

7. Narrative

In addition to the above we also gathered replies to the following questions:

- What did you enjoy or value most?
- What did you enjoy or value least?
- Overall, what did you get out of being in this group? Eg things you have learned, realised, plan to do or felt.

In 2015, we reviewed hundreds of participant comments. As a result of attending, people said they felt:

- armed with information and knowledge
- more confident, positive, in control and able to move forward
- less alone as a result of meeting others.

Participants also said they gained:

- greater self-awareness and insight
- a personal action plan for doing specific things such as exercise, hobbies and therapeutic activities.
- improved speech as a result of talking in the group.

8. Other comments

Participants left other comments in their feedback, such as thanking and praising volunteer facilitators, providing feedback on the venue and summing up their experiences.

Some of their comments are great testimonies:

“I would recommend this course to everyone, even if they are shy or uncomfortable with public speaking, because with encouragement they will settle down and thoroughly enjoy the laughter and meeting brave people – and be inspired to carry on enjoying life.”

“Beginning at a very negative point, after three weeks I am totally changed. My attitude is one of motivation now rather than lacklustre acceptance. Thank you, I wish we had three more weeks.”

“The course is brilliant. I have got out of it things I had never considered. I have plans now which I believe will improve my husband’s life and my life.”

“I have faced up to reality this past three weeks. That is only a good thing. Learning to face Parkinson’s and not giving into something I can’t change.”

“This course has been one the best I’ve ever undertaken.”

“Initially I thought this wasn’t for me. As it is, I conclude what the course delivered was right, delivering things I hadn’t considered before.”

“Well worth going on – everybody should do it.”

“Very enjoyable and thought-provoking.”

“Will change how I view Parkinson’s and how I live my life.”

“I feel as though I am more confident in facing the future.”

“It was directed extremely well and helped us to approach sensitive subjects.”

Every hour, someone in the UK is told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day
when no one fears Parkinson's.**

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Free confidential helpline **0808 800 0303**
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