

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



A path through Parkinson's Self-management programme evaluation report 2016

“Outstanding opportunity to talk, be listened to, explore feelings and meet people with such a positive outlook on life.”

2016 participant

Contents

1. Background	3
2. Attendance of self-management groups in 2016	3
3. How people heard about the programme	3
4. Demographic information	4
5. Regular attendance of a local Parkinson's UK group	4
6. How people rated the experience	4
7. Outcomes	5
8. Action plans	5
9. Other comments	6

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 of discussion, activity and self-reflection delivered over three or six consecutive weeks, building up to a final session of action planning for the future.

Led by trained volunteer facilitators with first-hand experience of Parkinson’s (and occasionally staff), each self-management group is made up of eight to 12 people – these can be partners, carers and people who have been living with Parkinson’s for varying lengths of time.

Groups are free to attend as the cost of the programme is met by Parkinson’s UK. To date, Parkinson’s UK has run 104 self-management groups attended by 1,152 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 the self-management group.

2. Attendance of self-management groups in 2016

477 people attended 40 groups in 2016 and the overall attendance level was 91%.

Of those who attended, 313 (66%) were people living with Parkinson’s and 164 (34%) were partners or carers.

The length of diagnosis of those 313 people with Parkinson’s was as follows:

Less 1 year	1-2 years	2-5 years	5-10 years	10+ years	Not known
12%	14%	25%	31%	15%	4%

This 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.

Mailing from Parkinson’s UK	Parkinson’s UK website	Parkinson’s UK local adviser	Local Parkinson’s UK group	Parkinson’s nurse	Facilitator	Social Media	Other
37%	21%	14%	14%	3%	2%	1%	8%

4. Demographic information

- 50% of people who attended the self-management groups were aged 65–74.

35–44	45–54	55–64	65–74	75+
0%	3%	18%	50%	28%

- There was an almost even mix of men and women.

Male	Female
49%	51%

- 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 Caribbean
92%	2%	3%	1%	1%	0.5%

- The majority of participants (79%) did not consider themselves to have a disability except Parkinson's.

Yes	No	Not disclosed
21%	79%	0%

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

The majority of participants (56%) did not regularly attend a Parkinson's UK local group.

Yes	No	Not disclosed
44%	56%	0%

6. How people rated the self-management programme

This feedback is from the 409 participants who completed a participant feedback form at the end of their self-management group in 2016.

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

78% of respondents rated being part of the group as excellent.

Excellent	Good	OK	Not very good	Poor
78%	19%	3%	0%	0%

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

	Agree	Disagree
Six or three weeks was the right number for me	97%	3%
It was helpful to talk in this way	99%	1%
The pace of the group was right for me	95%	5%
I got the chance to have my say	100%	0%
This felt like the right group for me to be in	97%	3%

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

7. Outcomes

The self-management programme continues to deliver the following eight outcomes for people with Parkinson's, partners and carers:

- Feelings of increased acceptance and the ability to move forward.
- Feelings of increased confidence, resolve, positivity and control.
- Feeling more connected and less alone.
- Feeling armed with information and knowledge.
- An understanding of the value of planning and taking action for the future.
- Feeling able to create a personal action plan for things such as exercise, dance and other therapeutic activities.
- Greater self-awareness and insight, including into relationships.
- Improved speech and confidence in talking to others.

8. Action plans

Parkinson's UK defines self-management as:

"A process of enabling people with Parkinson's, their partners and carers to work out and do what they, as individuals, can do in order to take control, live positively and achieve a quality of life that is meaningful for them."

The final session of each self-management group builds on previous discussions to help people work out up to three actions that are most meaningful to them.

The action plans that emerge cover a wide range of topics. The most common topic in 2016 was fitness and exercise (25%).

Fitness and exercise	Hobbies	Social	Change in attitude	Local group	Therapeutic activities	Relationships	Holidays	Other
25%	14%	10%	7%	7%	5%	6%	4%	22%

The 22% of actions that fell into the “other” category included topics such as volunteering, work, research, getting help, carers/partners taking time out for themselves, legal and financial planning.

9. Other comments

The majority of comments are great testimonials and tell us more about how people found their self-management group.

“This course has been hard, thought provoking, personally challenging but without doubt the most helpful course I have ever been on – it has opened my eyes to a future that, though different to that imagined, will be ours, full of new opportunities. But that is what life and living is all about.”

“Not really much of a talker but found it easy to take part.”

“The self-management course has exceeded my expectations.”

“Before attending, I didn’t want to meet others with Parkinson’s. Now I feel the opposite as I think we can give each other lots of help.”

“It is probably a lifetime programme and this has been a starter/taster on which to build.”

“Amazing volunteers run this course. Good to set time aside just to think about Parkinson’s.”

“A very valuable experience. Facilitators created a good ambiance and a safe space and I felt I ‘grew’ with the course.”

“It was beneficial to come to this course and plan to do some things to make life more interesting!”

“I enjoyed being part of the group and hope I was able to contribute as much as I learned.”

“It was professionally organised, well run, open and honest discussion.”

“Excellent course, excellent facilitators, excellent group, very worthwhile.”

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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