

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



Parkinson's UK self-management programme evaluation report 2017

“Great to meet others with the same issues as myself. Good to talk and understand more about Parkinson’s. Very worthwhile and would recommend programme.”

2017 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 who have the condition.

A path through Parkinson's enables people to share experiences and discuss the condition's practical and emotional impacts. 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.

In 2017, Parkinson's UK began developing two alternatives to face-to-face groups.

To date, Parkinson's UK has run 137 self-management groups attended by 1,513 people.

The following data has been gathered from participants at four 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.
- Anonymous follow up surveys six months after attendance to measure impact.

2. Attendance of self-management groups in 2017

A total of 369 people attended 33 groups in 2017 and the overall attendance level was 90%.

Of those who attended, or were given a place but didn't attend, 64% were people living with Parkinson's and 34% were partners or carers.

The following table shows the length of diagnosis of 246 people with Parkinson's:

Less 1 year	1-2 years	2-5 years	5-10 years	10+ years	Not Known
11%	12%	23%	26%	11%	17%

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

3. How people heard about the programme

How people heard about the programme	
Parkinson's UK local adviser	22%
Social Media	1%
Parkinson's UK website	14%
Facilitator	2%
Local Parkinson's UK group	12%
Parkinson's nurse	3%
Friend/colleague	3%
Mailing directly from Parkinson's UK	26%
Parkinson's UK waiting list	14%
Other	2%

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 above.

4. Demographic information

35-44	45-54	55-64	65-74	75+
2%	8%	24%	45%	22%

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

Male	Female
53%	47%

There was an almost even mix of men and women.

White British	White Irish	White Other	White mixed	Indian	Chinese
92	1	2	1	3	1

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

Yes	No	Not disclosed
29%	70%	1%

The majority of participants (70%) did not consider themselves to have a disability except Parkinson's.

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

Yes	No	Not disclosed
41%	59%	0%

The majority of participants (59%) did not regularly attend a Parkinson's UK local group.

6. How people rated the self-management programme

Excellent	Good	OK	Not very good	Poor
74%	22%	4%	0%	0%

The feedback above is from those participants who completed a participant feedback form at the end of their self-management group in 2017. Overall, 96% of respondents rated being part of the group positively.

Do you agree or disagree with the following statements?		
	Agree	Disagree
Six or three weeks was the right number for me	88%	12%
It was helpful to talk in this way	99%	1%
The pace of the group was right for me	92%	8%
I got the chance to have my say	99%	1%
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 and impact

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

- 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

To understand the longer-term impact of the programme, attendees are invited to complete an online follow-up survey six months after. To date, 416 people have been asked to complete the survey and the cumulative response rate is 54%.

The degree to which attending a face-to-face self-management group may help individuals make life improving choices does depend on people's particular challenges or circumstances at the time. For some individuals, gaining a greater understanding of Parkinson's – and some of the challenges – may not feel positive. With support, we hope people can assimilate learning and awareness and see the degree of control they can bring to their current situation.

Would you recommend attending a self-management group to other people affected by Parkinson's?

Did attending the self-management group help you make any choices that improved your life in some way?	
Yes, it helped a lot	40%
Yes, it helped a little	45%
Not sure/can't say	11%
It didn't help	3%
It's made things worse	0%

Did attending the self-management group make you feel more positive about your current situation?	
Yes, it helped a lot	33%
Yes, it helped a little	50%
Not sure/can't say	11%
It didn't help	5%
It's made things worse	1%

Has the self-management programme helped you better manage day-to-day life with Parkinson's (as a person with the condition or as a partner or carer)?	
Yes, it helped a lot	27%
Yes, it helped a little	48%
Not sure/can't say	17%
It didn't help	7%
It's made things worse	1%

Yes	Not sure	No
89%	11%	0%

We know people are very thoughtful about this question and rightly recognise that a face-to-face group isn't right for everyone.

8. Action plans

Parkinson's UK defines self-management as a "process of enabling people with Parkinson's, 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".

Action plans	
Fitness and exercise	27%
Hobbies	13%
Social	10%
Holidays	6%
Relationships	5%
Change in attitude	5%
Local group	4%
Independence	4%
Diet and health	3%
Time out	3%
Other	20%

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. Cumulatively, the most common topic is fitness and exercise (27%). The 20% 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 give us more information about how people found their self-management group.

Comments included:

"It has helped me greatly mentally and emotionally. Thank you so very much."

"The group was very balanced, open and friendly. People felt comfortable in discussion."

"A well-organised course."

"Very thought provoking, leaving me with a sense of a way forward."

"Meeting everyone has been valuable."

"Excellent course – well run! Time well spent."

"Really enjoyed all the sessions and have made some good friends."

"The self-management group is very subtle, in no way onerous, and quite unique in its approach to a very complex and individual condition."

Every hour, two people in the UK are 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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