

PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.



# Parkinson's UK peer support evaluation report 2017

“The person I spoke to was fantastic. I believe this person has played a major role in helping me get on with my life with my Parkinson’s.”

## 2017 survey respondent

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## Background

During 2017, delivery of the peer support service was significantly affected by a number of long term staffing issues. This created difficulties for the delivery of the service and prevented any volunteer recruitment throughout the year. In total, 84 people were matched with a volunteer – which was lower than in 2016.

A total of 25 evaluation forms were returned – the number is lower than in previous years.

## Feedback from service users

### 1. How did you hear about the peer support service?

How did you hear about the helpline?	Response percentage	Response total
Parkinson's UK helpline	20.8%	5
Parkinson's local website	20.8%	5
Parkinson's local adviser	29.2%	7
Parkinson's UK information event	0%	0
Parkinson's UK branch or group	4.2%	1
Parkinson's UK publications – please specify	8.3%	2
Friends or relatives	0%	0
Parkinson's nurse or clinic	8.3%	2
Consultant	0%	0
GP	0%	0
Other healthcare professional – please specify	0%	0
Social services	4.2%	1
Other voluntary organisation – please specify	0%	0
Other – please specify	4.2%	1

### 2. Was the volunteer you spoke to polite and friendly?

Was the volunteer you spoke to polite and friendly?					
Very	Quite	Average	Not particularly	Not at all	Response total
100% (25)	0% (0)	0% (0)	0% (0)	0% (0)	25

Comments included:

“The volunteer was wonderful.”

“Very pleasant and easy to talk to. Very willing to talk about his experience, helped a lot.”

“[X] was really easy to talk to and we quickly built up a good rapport. She was very encouraging and I definitely benefited from our conversations. At least in part, Jane motivated me to start personal training at my local gym and to join the Rock Choir, both of which have been of great benefit to me. She also, not necessarily intentionally, opened my mind to trying out Neupro patches (she uses them) and they have been brilliant for me too. In short, Jane was fantastic.”

### 3. Did you receive the service within the timescale you needed?

Did you receive the service within the timescale you needed?	Response percentage	Response total
Yes	96%	24
No	4%	1

### 4. Did you feel you were treated fairly?

Did you feel you were treated fairly?	Response percentage	Response total
Yes	100%	25
Not sure	0%	0
No	0%	0

### What was your main concern for using the peer support service?

Comments included:

“Deep brain stimulation (DBS) and general concerns.”

“Experience of Duodopa.”

“Was awaiting a DBS operation and wanted to ask about this as she had had the operation a year before.”

“Just wanted first-hand knowledge about deep brain stimulation and if it was as expected.”

“To hear from someone with Parkinson’s so I would know what to expect.”

“Just to chat to others and not feel as alone. I think not having a partner makes doing things much more difficult.”

“I felt I was different now I had Parkinson’s. That I was never going to be able to do things like before. That nothing could help me. Basically, my life was over!! Also, I was going to end up crippled and that nothing would relieve the tremors.”

“To share my concerns with someone else in the same boat as myself.”

### 5. Where you able to get the support you needed?

Were you able to get the support you needed?					
Yes, completely	Yes, mostly	Not sure	In part only	Not at all	Response total
75% (18)	20.8% (5)	4.2% (0)	0% (0)	0% (0)	24

Comments included:

“It really helped to chat with someone who had already been through the same thing.”

“After my first call, a lady called Chris arranged for a lady who is receiving the Duodopa treatment to telephone me. On the same day as my first call she very kindly – and with a lot of patience – answered all of my questions about living with Duodopa.”

“Jane helped me put things into perspective and prioritise things with her calm, friendly and knowledgeable approach.”

## 6. Would you have liked the information or support in a different format or language?

Would you have liked the information or support in a different format or language?	Response percentage	Response total
Yes	8.3%	2
No	91.7%	22

Comments included:

“Because she was 20 years younger than me and never had been very ill before getting Parkinson’s, so the likes of the operation failing were greatly reduced for her.”

“She was a very optimistic person. I liked her attitude. After the op she had gone back to work and was driving.”

“Not sure about that one!”

## 7. Did the support you received help you make any choices that improved your life in some way?

Did the support you received help you make any choices that improved your life in some way?					
It helped a lot	It helped a little	No change/ can’t say	It didn’t help	It made things worse	Response total
60.9% (14)	30.4% (7)	8.7% (2)	0% (0)	0% (0)	23

Comments included:

“It helped me consider options regarding medication and support.”

“I just felt better knowing that someone else had gone through it and was so positive.”

“We wanted to have first-hand knowledge of DBS as a very daunting thing to have done and just helps to here anyone’s first-hand experience.”

“If in the near future I am offered this treatment (Duodopa), the information I have received means that I am better informed.”

“I am (was) normally a very organised and meticulous person. I was finding it difficult to accept that this was no longer the case because I physically can’t manage. Jane helped me accept that things take longer, or that it is alright to ask for help and not feel defeated.”

“It did help me reflect on my decision.”

“Take each day at a time and stop trying so hard that it hurts!!!”

“To start personal training, join Rock Choir and start using Neupro patches.”

“Exercise was top of the list. Going forward in all parts of life. Realising you can carry on after a diagnosis. And you can lead a normal life.”

“Maybe but I have little choice in what I can do or am able to do.”

“Living in the ‘here and now’ and coping better with the impact of the diagnosis.”

## 8. Did the support you received make you feel more positive about your current situation?

Did the information and/or support you received make you feel more positive about your current situation?	Response percentage	Response total
Yes, it made me feel much more positive	54.2%	13
Yes, it made me feel somewhat more positive	29.2%	7
No change/can't say	16.7%	4
It made me feel somewhat worse	0%	0
It made me feel a lot worse	0%	0

Comments included:

“I now feel a lot less anxious about undergoing this procedure and living with it.”

“Jane made me realise that there was still a positive purpose to life – just in a different way.”

“I felt that I was failing my husband because I have not been coping. Angela helped me to realise that in fact we were doing very well in the circumstances and that you can't out-think Parkinson's as it is so unpredictable!”

“Jane was very encouraging and fun to talk to and I just felt more positive after the calls.”

“Not to think about the limitations of my condition, but to maximise my potential.”

“That things can get better. Life can be OK. That it's not all downhill.”

## 9. Overall, how would you rate the service you received from the peer support service?

Overall, how would you rate the service you received from the peer support service?						
	Excellent	Good	Satisfactory	Poor	Very poor	Response total
	75% (18)	20.8% (5)	4.2% (1)	0% (0)	0% (0)	24

The service was rated very highly by those people who responded, with over 96% rating it as good or excellent.

## 10. Would you recommend the peer support service to other people affected by Parkinson's?

Would you recommend the peer support service to other people affected by Parkinson's?			
Yes	Not sure	No	Response total
95.8% (23)	4.2% (1)	0% (0)	24

## 11. Do you have any suggestions for how the peer support service could be improved?

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A number of suggestions were made for improving the service. Several people asked if the contact could be extended.

Comments included:

“Do not limit contact if rapport is established.”

“I think more than the allocated time – calls could be a few more.”

“Yes, would like more sessions.”

“I don’t think it’s fair that you can’t remain friends after your conversations. As it would be nice to stay in contact if you got on really well with the person you’re talking to.”

This is something that has often been raised, however the service was specifically designed as short term support rather than ongoing befriending. The limit of six sessions helps to prevent service users becoming dependent on the volunteer and ensures we can offer support to as many people as possible without overloading the volunteer team. We also ask volunteers not to disclose their full names and contact details to ensure their privacy and wellbeing.

The importance of matching service users carefully with an appropriate volunteer was also flagged up:

Comments included:

“Usually age does not matter to me but in this instance it did. But I am glad you put me in contact with someone who had first-hand experience of this operation and was frank about it.”

This is something the peer support team will always try to achieve. However, it is not always possible given the size of our volunteer pool. During 2018, we are working to recruit more volunteers to help increase our ability to make suitable matches.

### Summary

This was a difficult year for the service, however the feedback demonstrates it was highly valued by those who used it. People’s feedback illustrates the impact that talking to another person who has been through a similar experience can have.

Comments included:

“Things can get better. Life can be OK. That it’s not all downhill.”

### Recommendations

- Overall, the service is able to have a significant impact on those who use it. Recruiting and supporting volunteers is key to ensuring that the service can continue to deliver this.
- Recruit more volunteers to help ensure we can match everyone with a suitable volunteer.
- Explore options for delivering online training for volunteers.

Develop peer support models for our volunteers to enable them to debrief within a confidential setting.

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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Saturday 10am–2pm). Interpreting available.  
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