

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



## Peer support service evaluation report 2016

“She has been so helpful, positive and friendly. She was always professional, knowledgeable, experienced and kind. She was able to listen and understand my daily worries and concerns with a bright voice, and lovely laugh.”

**2016 survey respondent**

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## 1. Background

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The Parkinson's UK peer support service is a free and confidential service for people with Parkinson's and carers. The service works by matching the person affected by Parkinson's (the service user) with a trained volunteer who has a similar experience of Parkinson's – someone who understands.

Many people have found that sharing experiences in this way really helps them to find a good way to live with Parkinson's.

Service users can talk to the trained volunteer about anything to do with Parkinson's. This might be:

- personal experience of treatments
- ways of coping with Parkinson's
- ways of caring for someone with Parkinson's

Volunteers are also happy to just have a good chat. All service users are sent an information sheet, which gives details of how the service operates and the name of their peer support volunteer. They also receive a call to confirm the service and arrange a suitable time to call. This is passed on to the volunteer.

The service user can arrange to have up to six sessions with the volunteer.

When the volunteer has made sufficient calls an evaluation form and a pre-paid return envelope are sent to the service user.

## 2. Evaluating the service

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After using the service, all users are asked to complete an evaluation form to provide feedback on their experience. This can be completed by email or by post.

Out of the 90 services users in 2016, we sent out 64 evaluations forms.

This is because:

- we are still providing support to 14 service users
- nine service users didn't provide contact details to receive a form due to confidentiality reasons

We received 32 completed evaluation forms and five forms were returned incomplete. Four people contacted the helpline or their local adviser to provide feedback. These comments can be found under 'Additional feedback' on page 11.

The response rate for feedback and evaluation forms returned is 51%. This is a 3% increase on last year.

## 3. Results

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The results of the responses to the evaluation are as follows:

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

The majority of people heard about the peer support service through the Parkinson's UK website (26%), helpline (26%) or a Parkinson's local adviser (23%).

Parkinson's UK helpline	Parkinson's UK website	Parkinson's Local adviser	Parkinson's UK information event	Parkinson's UK branch or group
26%	26%	23%	0%	6%

Parkinson's UK publications	Friends/relatives	Parkinson's nurse or clinic	Consultant	GP
10%	0%	6%	0%	0%

Other healthcare professional	Social services	Other voluntary organisation	Other
0%	0%	0%	3%

### Was the volunteer who you spoke to polite and friendly?

The majority of people reported that the volunteer they spoke to was very polite and friendly.

Very	Quite	Average	Not particularly	Not at all
94%	6%	0	0	0

Comments included:

"He was fantastic in that he knew just what I had gone through with the deep brain stimulation surgery. He has a very helpful attitude."

"I found her to be kind and understanding – she has lots of suggestions to help with any problems. She always phoned just when I was at a low point, and was just the calm, patient voice I needed to hear. I shall miss our chats and feel I have learnt so much from her about Parkinson's."

"He was most helpful and easy to chat to."

"She has been so helpful, positive and friendly. She was always professional, knowledgeable, experienced and kind. She was able to listen and understand my daily worries and concerns with a bright voice, and lovely laugh."

"Very good, very positive, knowledgeable with experience."

"They were very helpful."

"Very helpful and cheerful."

"She was so helpful, even down to phoning me when she couldn't reach me – continually. She was able to answer my questions and reassure me, always with a positive outlook. An exceptionally nice person."

"She is really lovely and kind. I was amazed how much we have in common. Very similar backgrounds."



**Did you receive the service within the timescale you needed?**

100% of people said they did receive the service within the timescale they needed.

Yes	Not sure	No
100%	0%	0%

Comments included:

“Yes, the volunteer rang within a few days.”

“The volunteer rang even though she had just started a new job. She rang me on a Sunday as I had specified I often go to bed by 8pm. She is very dedicated to her role!”

**Did you feel you were treated fairly?**

100% of people said they were treated fairly.

Yes	Not sure	No
100%	0%	0%

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

Comments included:

“My main concern was about the neurostimulator and how heavy it feels in chest. He said over time I will get used to it. He said to me he has no regrets after having surgery, even after five years.”

“I was having lots of problems with my medication. The volunteer had similar problems when she was first diagnosed. Also it was good to speak to someone who I could talk about the Parkinson’s to and understand my concerns.”

“Information on deep brain stimulation.”

“To discuss the effects of taking Madopar and it producing dizziness.”

“Talk with a partner, hear the experiences on children.”

“I wanted to be able to speak to someone in the same or similar situation to me.”

“Were my signs and symptoms typical of Parkinson’s? What was going to happen to me in the future? To understand the drugs available, etc. To discuss support available for me, choices etc. How can I help myself, diet, exercise etc? How did you cope? How can I cope?”

“Feeling isolated and needed some support and encouragement.”

“Medication and concerns as newly diagnosed.”

“Experience of Duodopa treatment.”

“Advice and opinion on deep brain stimulation [DBS]. The effects both good and bad that DBS had on Parkinson’s symptoms.”

“As I have no contact with anyone with Parkinson’s (due to family circumstances) I am unable to attend the local meetings.”

“How I would find the new treatment and how it would make a difference.”

“I wanted help and the volunteer was brilliant.”

“Fatigue, newly diagnosed feelings, exercise.”

“Just needed to find someone who felt like I did and how they dealt with it.”

“Someone to talk to who was in a similar situation.”

“Up until I spoke to the volunteer I had not spoken to anyone suffering from Parkinson’s. The symptoms I was experiencing were quite different to hers. It was a very pleasant and interesting conversation. However, as our conditions were quite different I was unable to gain any real benefit from her experiences.”

“Newly diagnosed and felt I needed to speak to some who understands Parkinson’s and what it means to be diagnosed. Also finding ways to stay positive.”

“Deep brain stimulation.”

“Wanted to talk to someone ‘not medical’ about how I’m dealing with Parkinson’s.”

“I wanted to speak to someone of a similar age who understands what it’s like to live with Parkinson’s. Find ways to be more positive.”

“To speak to another carer.”

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

More than half of respondents (58%) said they were completely able to get the support they needed, and 23% said they were mostly able to get the support they needed.

Yes, completely	Yes, mostly	Not sure	In part only	Not at all
58%	23%	3%	10%	6%

Respondents were asked to add any comments about the support they received. Many were very encouraging, including these comments:

“It was great just to talk to someone who had gone through deep brain stimulation.”

“You provide an excellent and very valuable service.”

“The support was needed so much when we first spoke. Now months later I realise how much I have benefited from all her help, advice and guidance.”

“I have changed from being low, worried and subdued to being myself again prior to my diagnosis. Now I am enthusiastic, happy and keen to live my life with Parkinson’s.”

“I was able to ask questions and receive answers from someone who had experience.”

“I felt so much better after each call. It made me realise I was not alone.”

“His answers to my queries were helpful and relevant.”

“Exactly what I needed to know.”

“The volunteer I spoke to was diagnosed at a similar age. Hearing her experiences as a young person with Parkinson’s helped me realise life does go on. She still enjoys going out with friends and living an active life.”

“It was very useful. Partly met as there wasn’t a partner so the call was with a mum with Parkinson’s.”

“It is very early days to give an adequate reply.”

Some comments were less favourable, but provided useful areas for learning:

“Don’t think the lady I spoke to and I had much in common. Not her fault.”

“I would like the support for longer.”

“The lady I spoke to was so lovely and kind – but I came away from the call more depressed than I had been. We’d been told that my husband’s Parkinson’s may well be a dormant type and so it was a real shock when it started to progress and her response was: ‘They said that to us and nine years on he has complex Parkinson’s – I think they tell everyone that.’”

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

The majority of people said they would not have liked the information or support in a different format or language.

Yes	No
97%	3%

One person commented:

“It was a little difficult at times to catch what the volunteer was saying. However, he was very patient when I asked him to repeat what he has just said.”

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

More than half of respondents (55%) said the support helped a lot in terms of making choices that improved their life. 14% said it helped a little, and 24% said no change/can't say.

It helped a lot	It helped a little	No change/can't say	It didn't help	It's made things worse
55%	14%	24%	7%	0%

If yes, what choices were they?

Comments included:

"General advice and tips and suggestions on exercise etc."

"It helped me make an informed decision on my next course of treatment."

"The volunteer was able to relay the positive outcome of deep brain stimulation."

"Through discussion I was able to decide to contact my Parkinson's nurse as the volunteer felt he could help me. So after a year, I made another appointment with him. He was able to prescribe drugs for my aches and pains."

"I also spoke to a Parkinson's nurse at Parkinson's UK and at the local hospital."

"Just talking to someone helped."

"I decided to get more help."

"To just get on with life."

"I have to make the choice of undergoing deep brain stimulation or not. His comments were very helpful in this respect."

"To be able to take on – if I got the opportunity – the fitting of the Duodopa medicine equipment."

"Realised/confirmed in practice the value and possibility of achieving walking slowly a greater distance. This lady was walking 4-5 miles a day – wow! I manage some days 2-3km, have secondary cancer too so stamina not good, but hope to do better."

"It helped me realise that life does go on and I'm not alone."

"Helped to talk to someone who has had the operation and what it was like for them. I don't know anybody who has had brain stimulation so this was very helpful."

"I feel more positive about my Parkinson's. Friends and family don't really understand what it's like to have the condition."



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

More than half of respondents (52%) said the support made them feel much more positive about their current situation, and 32% said it made them feel somewhat more positive.

Yes, it made me feel much more positive	Yes, it made me feel somewhat more positive	No change/ can't say	It made me feel somewhat worse	It made me feel a lot worse
52%	32%	10%	6%	0%

Please describe what difference it made, if any.

Comments included:

"I knew after talking to the volunteer I had done the right thing in having deep brain stimulation."

"It made me feel much more confident and in control of my situation, having discussed my future with the volunteer."

"Someone with knowledge and experience of eight years with Parkinson's. We were able to discuss the range of Parkinson's drugs, their dosages, benefits and side effects and how to be more positive. Now I am living with Parkinson's."

"Because I now have more info on deep brain stimulation."

"Using the peer support service helped me to make my mind up on whether to have deep brain stimulation. It had obviously been very successful for him. He balanced this with saying he also knew other people where it didn't help."

"Not the end of the world anymore."

"My current situation changed because the family issues causing me stress were slightly improved."

"It was great to speak with someone who is going through the same procedures. This in turn has raised my spirits."

"I have now allowed myself treats and small amounts of time to see friends etc."

"I have decided to go ahead with deep brain stimulation."

"I felt reassured and less anxious."

"It was good to talk to another carer in confidence over the telephone. She was very helpful. It was very much appreciated."

**Overall, how would you rate the service you received from the peer support service?**

More than 70% of people rated the service they received as excellent.

Excellent	Good	Satisfactory	Poor	Very poor
71%	16%	10%	3%	0%

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

More than 90% of people would recommend the service to other people affected by Parkinson's.

Yes	Not sure	No
90%	7%	3%

**Do you have any suggestions for how the peer support service could be improved?**

Comments included:

"No, you are doing a fantastic job."

"Not at this point in time."

"My husband doesn't want to tell anyone about his condition and won't join a group – which I told the lady I spoke to a few times – but she kept suggesting groups and trying to persuade me to get him to tell people. I really appreciate that this worked for her – but it would have been helpful to have some encouragement and other suggestions."

"Initially I was disappointed that there would be no face to face meetings. However, now I think it is better for both parties to not meet. We were still able to freely discuss my worries and concerns now and in the future."

"Would like to speak to the volunteer once a month, even if it's just for five minutes each month. I believe this would be mutually beneficial."

"Would be nice to continue for longer."

"I experienced a little difficulty understanding everything he said. I thought there was some degree of slurring of speech, which I assumed was Parkinson's related or medication. It may of course be my own ears! I do have problems talking over the phone."

"Telephoning is a bit hit and miss. Maybe more convenient to set a timescale for phoning, eg between 9am and 12pm."

"Only to give me more time. I do feel I need to talk to someone in the same situation on a regular basis. Just 10-20 minutes a week would help me keep going. Caring for someone with Parkinson's is a very long haul. I don't feel friends and family are having much idea about his commitment."

“What I really needed was someone to talk to after a trying day at my son’s. He has a chronic painful condition and is also a house husband to a seven-year-old and a five-year-old when his wife works. My Parkinson’s almost takes a back seat to his problems.”

The following comments were investigated and resolved. The notes under each comment explain what happened:

“The first time I contacted Parkinson’s UK in November 2015, before I had the surgery, I got nowhere. I told the lady that I was about to have deep brain stimulation on 7 December. She replied the person I needed to talk to would not be in until the week after. That first phone call I felt very stupid and was very scared and emotional. The very thought of the brain surgery was too much and I started to cry. I wanted to get off the phone very quick. I had already given the lady my mobile. 10 minutes later, my mobile rang. It was the lady from Parkinson’s UK but I’m sorry her voice was not that friendly. I told her I was ok and don’t take it any further.”

These comments were referring to the volunteer co-ordinator, who was covering maternity leave. The permanent volunteer co-ordinator, who returned to post in January 2016, responded to the service user’s referral and matched them to an appropriate volunteer. The end result was very positive and the service user went on to become a peer support volunteer themselves.

“Recruit partners.”

We do have small number of carers and partners who volunteer for the service. However, we would like to increase our volunteer pool of carers, partners and family members and this has been highlighted in the end of year report within the recommendation for 2017.

“I thought it was to be six contacts by phone. Just would have been nice to have clarified this but the co-ordinator was on holiday so didn’t chase up.”

This comment was picked up by the volunteer co-ordinator and further call backs were arranged with the volunteer.

#### 4. Additional feedback

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Three service users choose to provide verbal feedback, either through the helpline or via their Parkinson’s local adviser.

##### **Service user A – call to the helpline**

The service user rang to say the volunteer she spoke to was very helpful and awe-inspiring and she is extremely grateful for that conversation.

##### **Service user B – email received by Kay Lillie, Parkinson’s Local Adviser**

I’ve received a phone message from the service user to say how wonderful the peer support service is. She said that it’s helped her enormously and that she really got on well with the volunteer.

##### **Service user C – email received by Janatha Whitehouse, Parkinson’s Local Adviser**

Back in June I referred the service user to the peer support service and you matched her with a volunteer called to discuss deep brain stimulation. The service user said that the volunteer was wonderful to talk and found it really helpful.

### **Service user D – complaint via helpline**

The service user contacted the volunteer co-ordinator to raise their concerns regarding the service they had received from a volunteer. They felt that the support provided was not helpful and left them feeling uncertain about the future. This was discussed with the volunteer who felt they shared their own experience and wanted to answer the service user's questions honestly. The volunteer took on board the feedback and further support and training was offered to the volunteer. The service user was later matched with a different volunteer and feedback from this experience was very positive. The service user would now like to become a volunteer.

## **5. Summary**

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Of the 51% of service users who responded:

- 81% said they were able to get the support they needed
- 84% said the support they received made them feel more positive about their current situation
- 87% rated the service as excellent or good
- 90% would recommend the service to others

## **6. Recommendations**

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To date the service has been evaluated positively. However, it would be useful to have a higher return of evaluation forms and many of the forms that were returned were not fully completed. This could be due to service users experiencing problems with writing due to their condition.

It may be worth contacting a selection of service users by telephone to discuss their evaluation of the service in more detail. This can be looked at as part of the 2017 service delivery process.

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**  
(Monday to Friday 9am–7pm,  
Saturday 10am–2pm). Interpreting available.  
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(for textphone users only)

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