

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



Peer support service evaluation report 2015

“It has been the thing that has helped me most – to be able to talk to someone who knows what I am feeling and why. Her support and help has made coming to terms with the Parkinson’s easier.”

2015 survey respondent

Contents

1. Background	3
2. Evaluating the service	3
3. Results	3-6
4. Further information	7
5. Recommendations	7
6. Conclusion	7

1. Background

The Parkinson's UK peer support service is a free and confidential service for people with Parkinson's and carers. The peer support 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.

2. Evaluating the service

When the volunteer has made sufficient calls, an evaluation form and a pre-paid return envelope are sent to the service user. Some service users say that they do not wish to receive any information due to confidentiality issues, which means they are unable to evaluate the service they have received.

There were 80 completed client referrals in this evaluation period. Sixty-nine evaluation forms were sent out. Of these, 35 were returned. This is a 48% response rate.

3. Results

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 and the Parkinson's UK helpline.

Healthcare professional	Friend/relative	Local advisor	Helpline	Website	Media	Other (The Parkinson)	No response
4	2	1	10	11	0	3	2

Was the volunteer who you spoke to friendly and supportive?

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

Very	Quite	Average	Not particularly	Not at all	No response
29	1	2	0	0	2

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

“My peer support adviser has been a life saver. She has helped me understand what is going on with me. She has been the one aspect of this journey that has been positive.”

“She was very supportive and caring and shared her own experiences. She was a wonderful listener and was a great help to me during a difficult time.”

“The gentleman who called me was extremely helpful, patient and nothing was any trouble to him. During my conversation it came across to me that I was talking to a very competent support worker and he gave me the feeling that he cared.”

“I found her friendly and informative. She was a great source of tranquillity when I was a mess.”

“I found her easy to talk to and ask questions – I wanted to share.”

“A very nice friendly woman.”

“We were a good match and shared a lot of common ground – my peer support adviser was empathetic and I felt really listened to.”

“Very nice person and very understanding.”

“Excellent – very helpful and very informative.”

“She was friendly and able to make me feel I could confide in her.”

“She was empathetic, friendly and supportive – an ideal person to talk to.”

“She has been wonderful to talk to. She has listened and given excellent advice.”

“She was very supportive and caring. She shared her own experiences and was a wonderful listener. She was a great help to me during a difficult time.”

“She has been so helpful, polite and friendly. She was always professional, knowledgeable, experienced and kind.”

Some comments were less favourable. However, this feedback was investigated and the issues were resolved as follows:

“My peer support adviser only phoned once.”

This was followed up with the volunteer and the service user. The volunteer was experiencing problems with their condition and was experiencing memory problems. Due to this they decided to resign from the service.

“Reliable and pleasant but I do not want to be negative but I found the experience depressing – no fault of the mentor who knows very little about me, nor do I know enough of him to judge.”

The volunteer who was matched had always had a good approach but had been severely affected by a deterioration in their condition. The volunteer contacted the service to explain that they were aware that they had not handled the call as well as they should have. They felt they were no longer suited to the peer support service. Further training and support was offered to the volunteer, but they decided to withdraw from their volunteering role.

Did you feel using the service helped you in any way?

The majority of people reported that using the peer support service helped them in some way.

Yes	Not sure	No
27	4	2

If so, how? (Multiple choice question)

Many service users reported that using the peer support service helped them feel less isolated. Others reported that they felt reassured and less anxious.

I understand more about Parkinson's	I feel less isolated	I feel more confident in managing my condition	I felt reassured and less anxious
12	21	9	15

Would you return to the service if you felt a need for further help?

The majority of people reported that they would return to the service if they felt a need for further help.

Yes	Not sure	No	No response
27	1	2	2

Would you recommend the service to others?

The majority of people reported that they would recommend the service to others.

Yes	Not sure	No
28	1	2

Overall how did you find using the service?

The majority of people reported that, overall, they found using the service to be excellent.

Excellent	Good	Satisfactory	Poor	Very poor
17	8	4	2	0

Respondents were asked to add additional comments about the service. Again, many were very encouraging, including these comments:

“The help came at the right time as I was feeling extremely low. It is helpful to talk to people who are removed from the everyday situation.”

“Very discreet, always rang when she said she would.”

“It has been the thing that has helped me most – to be able to talk to someone that knows what I am feeling and why. Her support and help has made coming to terms with the Parkinson’s easier. I have my ups and down days, but her calls have helped me to understand this unpredictable condition.”

“I found it a very good service because it helps you to realise that you are not on your own – others are going through similar experiences. Learning how other people coped is a great source of support.”

“Not knowing anyone with Parkinson’s, the ability to talk to someone who has the condition was invaluable and helped me to develop the strength to talk to family and friends about the future.”

“I would be really grateful if you could contact him to say how pleased I was with what he did.”

“We got on really well on the phone – she felt like a good friend and I could say anything.”

“She got my mojo back.”

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

“It would be helpful if my peer support adviser could keep in touch.”

“I only rated the service as poor as I felt the person was not forthcoming and I wanted a service that was face-to-face and so to be linked to someone nearer.”

“I am not sure how you match people, I feel it would be much better if the mentor was local and was aware of local facilities or problems in Parkinson’s care. I feel strongly that personal face-to-face meetings would be a vast improvement.”

“There was a delay at the beginning.”

“I wish the service offered more calls.”

In one case, the feedback was investigated as follows:

“It took many calls from the volunteer before he could reach me and the service doesn’t allow me to call him back. I suggest an appointment time for the two parties so that such a huge amount of time is not wasted.”

The service user had stated that she was out and about as she was preparing to go on holiday. She was unable to give a specific time and when she did she was unavailable. This meant a number of calls from the volunteer, who was happy to persist.

4. Further information

How long ago were you diagnosed?

Less than 2 years	3-10 years	11-20 years	21 years	Not relevant	No response
7	12	3	0	2	7

I am aged:

24 and under	25-44	45-64	65-84	85+	No response
0	1	8	13	0	9

My ethnic background is:

White British	White other	Mixed	Chinese	Asian or Asian British	Black or Black British	Other ethnic group	No response
23	0	0	0	1	0	0	7

5. Recommendations

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 did not contain more detailed comments about the service. 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 depth. The evaluation form could be adapted to Survey Monkey, the online evaluation tool. This could make evaluation of the service a simpler process and service users would have a range of options for feeding back their experience of the service.

6. Conclusion

The results of the 2015 peer support service user survey are positive, and clearly show the value that clients place on the service. Of the people who responded to each question:

- 81% felt that the service helped them.
- 84% would return to the service for further help.
- 90% would recommend the service to others.
- 81% rated the service as excellent or good.

The respondents who suggested the service was poor gave their reasons, which were investigated and issues were resolved.

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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