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

Helpline evaluation report

November 2016

> “Whenever I have spoken to a member of the helpline team I have always felt reassured and helped by them. They have never rushed the conversation along, like I find so many other organisations do! Very helpful, lovely people.”
>
> **2016 survey respondent**

Contents

1. Background

The Parkinson's UK helpline is a confidential service providing support to anyone affected by Parkinson's, including families, carers and professionals.

Our trained advisers, including specialist Parkinson's nurses, can provide information and advice about all aspects of living with Parkinson's, such as medication, symptoms, employment and benefits, health and social care, and emotional support.

The helpline forms part of Parkinson's UK's wider information and support services.

This report presents results and feedback collected through the user survey conducted in November 2016. The survey aimed to gather user feedback about the helpline to ensure quality and, combined with the service's other monitoring mechanisms, inform its further development

The survey was sent to 241 individuals who contacted the helpline by email and telephone. Surveys were only sent to people who had contact with a helpline adviser, and not service users who were transferred through to other departments in the charity.

A total of 108 surveys were received back, which is a response rate of around 44%. This is significantly higher than in previous years.

2. Who responded to the survey?

The majority of respondents said they have Parkinson's (52%), although surveys were also received from carers and professionals.

What is your connection to Parkinson's?	Response percent	Response total
I have Parkinson's	51.55%	50
I am a carer, partner or family member of a person with Parkinson's	38.14%	37
Other – please specify	10.31%	10

The helpline also receives calls from people who have not yet been diagnosed but are worried about possibly having Parkinson's. This was reflected in these responses:

"Sister of man with classic Parkinson's symptoms who won't seek help."

"I believe I may have Parkinson's, although I have yet to be diagnosed neurologically."

Most respondents were diagnosed less than two years ago (35%) or between two and ten years ago (48%). However, 17% of service users who responded had been diagnosed for longer.

How long ago were you (or the person you know) diagnosed	Response percent	Response total
Less than 2 years	34.8%	31
2-10 years	48.3%	43
11-20 years	13.5%	12
21 years and over	3.4%	3

The majority of respondents (78%) were 55 or over. This reflects the age group most directly affected. The calls from younger people were largely made up of family members.

Age of callers to the helpline	Response percent	Response total
Under 18	0.0%	0
18-24	0.0%	0
25-34	1.0%	1
35-44	5.2%	5
45-54	15.6%	15
55-64	30.2%	29
65-74	31.3%	30
75 and over	16.7%	16

95% of respondents to the survey identified themselves as White British, with the remainder coming from a variety of other backgrounds. Although the helpline did not monitor the ethnicity of service users during 2016, the survey results for ethnicity are close to the overall diversity figures recorded in previous years.

What is your ethnicity?	Response percent	Response total
White – English, Welsh, Scottish, Northern Irish or British	94.68%	89
White – Irish	0%	0
White – Gypsy or Irish Traveller	0%	0
Any other White background – please specify	1.06%	1
Mixed or multiple ethnic groups – White and Black Caribbean	0%	0
Mixed or multiple ethnic groups – White and Black African	1.06%	1
Mixed or multiple ethnic groups – White and Asian	0%	0
Any other Mixed or multiple ethnic background – please specify	1.06%	1
Asian or Asian British – Indian	0%	0
Asian or Asian British – Pakistani	0%	0
Asian or Asian British – Bangladeshi	0%	0
Asian or Asian British – Chinese	1.06%	1
Any other Asian background – please specify	1.06%	1
Black or Black British – African	0%	0
Black or Black British – Caribbean	0%	0
Any other Black, African or Caribbean background – please specify	0%	0
Other – Arab	0%	0
Any other ethnic group – please specify	0%	0

3. How did service users hear about the helpline?

The majority of respondents (50%) heard about the helpline through the Parkinson's UK website.

As in previous years, this shows the importance of the website in directing people affected by Parkinson's to the helpline.

Only 2% of respondents said they were informed about the helpline by their consultant. 15% of respondents said they heard about the service from their nurse. However this may be because many Parkinson's specialist nurses leave the helpline number on their answerphones.

How did you hear about the helpline?	Response percent	Response total
Parkinson's UK website	49.50%	50
Parkinson's local adviser	11.88%	12
Parkinson's UK information event	2.97%	3
Parkinson's UK branch or group	2.97%	3
Parkinson's UK publications – please specify	4.95%	5
Friends or relatives	2.97%	3
Parkinson's nurse or clinic	14.85%	15
Consultant	1.98%	2
GP	0.99%	1
Other healthcare professional – please specify	0%	0
Social services	0%	0
Other voluntary organisation – please specify	0.99%	1
Other – please specify	5.94%	6

A number of people commented on how easy it was to find our information online:

"Searched Google."

"Pretty easy to find when searching for Parkinson's on Google."

"Internet search."

4. Have service users contacted the helpline before?

The majority of respondents (52%) had not used the service before.

26% of respondents had used the service two or more times before.

Have you contacted the helpline before?	Response percent	Response total
No	51.9%	54
Yes, once before	22.1%	23
Twice before	9.6%	10
Three or more times before	16.3%	17

5. Getting through to the helpline

We know from previous user feedback that it is important for service users to be able to get through to an adviser easily, and achieving this is an important focus of service delivery. It is therefore significant that 96% of respondents said that they did not experience any problems getting through to us.

Did you have any problem getting through to us?	Response percent	Response total
Yes	3.88%	4
No	96.12%	99

Comments included:

"I rang at 9 o'clock in the morning and got an adviser straight away."

6. Customer service and user satisfaction

97% of respondents said the adviser they spoke to was polite and friendly.

Was the adviser you spoke to polite and friendly	Response percent	Response total
Very	97.1%	100
Quite	1.9%	2
Average	1.0%	1
Not particularly	0.0%	0
Not at all	0.0%	0

99% of respondents also said that they felt they were treated fairly by the adviser they spoke to, with only one person saying that they were not sure. They did not leave any comment saying why this was the case.

Did you feel you were treated fairly?	Response percent	Response total
Yes	99.03%	102
Not sure	0.97%	1
No	0.00%	0

97% of respondents would recommend the service to others, with only 3% saying they were unsure. This is a slight improvement on 2015.

Would you recommend the service	Response percent	Response total
Yes	97.0%	96
Not sure	3.0%	3
No	0.0%	0

The comments made by respondents reflect the impact that this level of customer service has on service users:

"The nurse was very calming and made me less scared."

"Whenever I have spoken to a member of the helpline team I have always felt reassured and helped by them. They have never rushed the conversation along, like I find so many other organisations do! Very helpful, lovely people."

"All conducted in a highly helpful, professional and sympathetic nature."

95% of respondents rated the service as either excellent or good.

how would you rate this service?					
Excellent	**Good**	**Satisfactory**	**Poor**	**Very poor**	**Response Total**
79.6% (82)	15.5% (16)	3.9% (4)	1.0% (1)	0.0% (0)	103

7. Reason for contacting the helpline

The telephone service team offer a range of support services including access to Parkinson's specialist nurses, social care, benefits and employment advice.

The majority of respondents (68%) said they called the helpline for medical advice. Other popular reasons included: benefits advice and other financial issues (22%), being newly diagnosed (16%) and signposting (15%).

What sort of information or support did you contact us for? Please select all that apply.	**Response percent**	**Response total**
Medical advice	67.96%	70
Signposting: who to contact	14.56%	15
Social care advice (eg care home, local authority home adjustments)	7.77%	8
Benefits advice and other financial issues	22.33%	23
Employment advice	5.83%	6
Emotional support or someone to talk to	12.62%	13
Creative or therapeutic activities (eg yoga, singing, tai chi)	0.97%	1
Newly diagnosed	15.53%	16
Respite care information	0.00%	0
Access to health services	4.85%	5
Carers' issues	6.80%	7
Housing issues	0.97%	1
Contact with local groups	1.94%	2
Daily living aids and equipment	1.94%	2
Holidays and travelling	1.94%	2
Other	4.85%	5

8. Impact of information

Respondents reported that they completely (73%) or mostly (23%) got the information and advice that they needed.

Did you get the information and advice you needed?	Response percent	Response total
Yes, completely	73.1%	76
Yes, mostly	23.1%	24
Not sure	1.9%	2
In part only	1.9%	2
Not at all	0.0%	0

Comments included:

"Very helpful in assisting me to try and come to terms with the condition."

"I have rang since and got more information. Each time it has been very helpful, and put my mind at ease. They have put us in touch with the people we needed."

9. What aspects of living with Parkinson's did the helpline help with?

As in 2015, the survey asked people to give more detail about the areas where they felt the helpline had made an impact. Several options were given:

- Improving emotional wellbeing.
- Improving understanding and management of Parkinson's (treatments, symptoms etc).
- Better understanding of benefit entitlement.
- Better understanding of employment rights.
- Better understanding of social care.
- Information about further sources of support.

Not all options were relevant for all respondents. However, the helpline has made a clear impact in many areas:

- In terms of improving emotional wellbeing, 49% said the helpline helped a lot, and 24% said it helped.
- In terms of improving understanding and management of Parkinson's, 39% said the helpline helped a lot, and 33% said it helped.
- In terms of information about further sources of support, 40% said the helpline helped a lot, and 23% said it helped.

Improving emotional wellbeing	Response percent	Response total
Helped a lot	48.8%	42
Helped	24.4%	21
Helped a bit	5.8%	5
Didn't help	1.2%	1
N/A	19.8%	17

Improving understanding and management of Parkinson’s (treatments, symptoms etc.)	Response percent	Response total
Helped a lot	39.1%	36
Helped	32.6%	30
Helped a bit	6.5%	6
Didn’t help	0.0%	0
N/A	21.7%	20

Information about further sources of support (nurses, support groups etc.)	Response percent	Response total
Helped a lot	39.7%	31
Helped	23.1%	18
Helped a bit	7.7%	6
Didn’t help	1.3%	1
N/A	28.2%	22

Better understanding of benefit entitlement	Response percent	Response total
Helped a lot	30.7%	23
Helped	10.7%	8
Helped a bit	0.0%	0
Didn’t help	2.7%	2
N/A	56.0%	42

Better understanding of employment rights	Response percent	Response total
Helped a lot	10.0%	7
Helped	11.4%	8
Helped a bit	0.0%	0
Didn’t help	0.0%	0
N/A	78.6%	55

Better understanding of social care	Response percent	Response total
Helped a lot	10.1%	7
Helped	11.6%	8
Helped a bit	4.3%	3
Didn’t help	1.4%	1
N/A	72.5%	50

The survey also asked if the information helped service users make choices that improved their life with Parkinson's. 46% of respondents said the helpline helped a lot, and 30% said it helped a little.

Did the information help you to make choices that improved your life with Parkinson's	Response percent	Response total
Helped a lot	45.8%	44
Helped a little	29.2%	28
No change or can't say	24.0%	23
Didn't help	0.0%	0
Made things worse	1.0%	1

Some people commented that the impact had been significant:

"My wife had just been advised to try 'neupro patches'. The discussion with your nurse helped us decide to give it a try."

"The information gave me extra confidence to travel!"

"I now feel able to contact the GP rather than feel as if it may be a waste of time."

"The information I was given helped me understand the various types of medication available in the treatment of Parkinson's and the advantages and disadvantages of particular medications."

The impact of the new specialist support offered through our Benefits and Employment team was commented on by a number of respondents:

"I was successful in achieving a Personal Independence Payment award on appeal, which I don't believe I would have got through by myself, and that is where the adviser gave me exceptional help to ensure my success."

"Helped me through appeal to my benefit entitlement. I couldn't have done it on my own."

"It improved the level of benefit."

"Had been thinking of nothing but how I was going to finish this claim form to the extent of being unable to sleep."

The surveys were sent out to service users very shortly after their call was made, so in some cases it was too soon to see any improvement:

"Too early to say!"

"Awaiting visit from local adviser so will not be able to comment until then."

"Too soon to tell if her advice is working."

Respondents were also asked about the emotional impact of the contact. 84% of respondents said the information and/or support made them feel more positive about their current situation.

Did the information and/or support make you feel more positive about your current situation?	Response percent	Response total
Yes, it made me feel much more positive	34.00%	34
Yes, it made me feel somewhat more positive	50.00%	50
No change/can't say	15.00%	15
It made me feel somewhat worse	1.00%	1
It made me feel a lot worse	0.00%	0

10. Recommendations for service improvement

Respondents were asked to make suggestions if they felt there was anything that could be done to improve the helpline service. Given the overall level of satisfaction with the service there were few specific suggestions.

Comments included:

"The helpline service is good as it provides independent advice. I'm not sure whether improvements could be made without it losing its impartiality."

"I don't think it needs any improvement."

"It cannot be any more helpful than it is. Thank you."

"The helpline is quick and efficient, I was phoned back very quickly, the nurse was very knowledgeable about the medication I was asking about."

A number of people commented on the helpline hours:

"Personally think it's already a very good service. I'm unsure about the hours you can contact it, I think it's up until 8pm? It would be good if it was later, but I do appreciate it's not always practical for lots of reasons to offer extended hours. I think it's a very valued service."

"Maybe lengthen the opening hours if possible. Thank you for your help."

There were also a number of comments that appear to refer to our written information:

"Possibly to simplify information and consider patients who are not so positive in their attitude or so willing to self-help."

11. Conclusion

The results of the 2016 helpline evaluation are positive, and clearly show the value that clients place on the service.

- 95% of respondents rated the service as either excellent or good.
- 97% would recommend the helpline to others.
- 96% had no problem getting through to the helpline.
- 96% completely or mostly got the information and advice that they needed.

These figures are comparable with the results from 2015, although a slightly smaller percentage rated the service as good or excellent.

The things that service users generally value about the service remain similar to previous years:

- Speaking to an adviser or nurse who is patient, friendly and supportive, and who is able to offer reassurance.
- A service that offers an opportunity to discuss issues in confidence, with more time and without the constraints sometimes experienced when speaking to other professionals, such as consultants and GPs.
- Callers feel emotionally supported and many make use of the listening ear aspect of the service.
- The in-depth support that is offered by our Benefits and Employment team is also clearly valued.

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.

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free confidential helpline **0808 800 0303**
(Monday to Friday 9am–7pm,
Saturday 10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
(for textphone users only)

hello@parkinsons.org.uk
parkinsons.org.uk