

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



Parkinson's UK helpline evaluation report 2017

“Absolutely brilliant from start to finish.”

2017 survey respondent

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1. Background?

The helpline forms part of Parkinson's UK's wider information and support services. It provides confidential information and support to everyone affected by Parkinson's, including people living with the condition, and their partners, families and friends, as well as professionals working with people affected.

Our trained advisers, such as specialist Parkinson's nurses, can provide information and advice about all aspects of living with Parkinson's. This incorporates queries about medical issues, symptoms, benefits and employment, social care, and equipment and adaptations.

This report presents results and feedback collected via the user survey conducted in November 2017. The survey aims to gather user feedback about the helpline to ensure quality and inform its further development (alongside other monitoring mechanisms).

2. Survey respondents

This year, the surveys were sent to 145 individuals who contacted the helpline by telephone.

A total of 92 surveys were received back, although nine were not fully completed, which is a response rate of around 63%.

Surveys were sent only to people who had contact with a helpline adviser, and not callers who were transferred through to other departments in the charity.

This is significantly higher than in previous years and a good response rate for any survey.

3. Who responded to the survey?

What is your connection to Parkinson's?	Response percentage	Response total
I have Parkinson's	54.3%	44
I am a carer, partner or family member of a person with Parkinson's	43.2%	35
Other – please specify	2.5%	2

The majority of surveys that were returned came from people with Parkinson's, although surveys were also received from carers.

The helpline also receives calls from people who have not yet been diagnosed but are worried about possibly having Parkinson's – and this was reflected in one of the responses.

Time since diagnosis	Response percentage	Response total
Less than 2 years	23.1%	18
2–10 years	55.1%	43
11–20 years	17.9%	14
21 years and over	3.8%	3

The service was used by people at all stages of the Parkinson's journey, from people who had been newly diagnosed to those who had been living with Parkinson's for over 20 years.

Age of callers to the helpline	Response percentage	Response total
Under 18	0%	0
18-24	0%	0
25-34	2.5%	2
35-44	6.2%	5
45-54	6.2%	5
55-64	33.3%	27
65-74	29.6%	24
75 and over	22.2%	18

It is also good to see that the service is used by callers from a range of ages.

What is your ethnicity?	Response percentage	Response total
White – English/Welsh/Scottish/Northern Irish/British	88.6%	70
White – Irish	3.8%	3
White – Gypsy or Irish Traveller	1.3%	1
Any other white background – please specify	1.3%	1
Mixed or multiple ethnic groups – white and black Caribbean	0%	0
Mixed or multiple ethnic groups – white and black African	0%	0
Mixed or multiple ethnic groups – white and Asian	0%	0
Any other mixed or multiple ethnic background – please specify	1.3%	1
Asian/Asian British – Indian	0%	0
Asian/Asian British – Pakistani	1.3%	1
Asian/Asian British – Bangladeshi	0%	0
Asian/Asian British – Chinese	0%	0
Any other Asian background – please specify	0%	0
Black/black British – African	0%	0
Black/black British – Caribbean	0%	0
Any other black/African/Caribbean background – please specify	1.3%	1
Other – Arab	0%	0
Any other ethnic group – please specify	1.3%	1

Although 88% of people identified themselves as white British, there is also a range of other ethnic identities represented. This is a significant increase when compared with the results of the 2016 survey, where 95% of respondents identified themselves as white British.

4. How did callers hear about the helpline?

How did you hear about the helpline?	Response percentage	Response total
Parkinson's UK website	32.9%	26
Parkinson's local adviser	19%	15
Parkinson's UK information event	1.27%	1
Parkinson's UK branch or group	8.9%	7
Parkinson's UK publications – please specify	13.9%	11
Friends or relatives	2.5%	2
Parkinson's nurse or clinic	11.4%	9
Consultant	3.8%	3
GP	0%	0
Other healthcare professional – please specify	0%	0
Social services	1.3%	1
Other voluntary organisation – please specify	2.5%	2
Other – please specify	2.5%	2

The local adviser teams continue to be a substantial source of referrals to the helpline. However, the percentage of people saying the website was the way they heard about the helpline has declined significantly – from almost 50% to 32%. This may be due to the fact the improved layout of the site means that more visitors to the website are able to find what they need and don't need to ring the helpline.

It is good to see that the number of people saying they had been given details by their consultant has increased since the 2016 survey. This is a reflection of the wider work being done by Parkinson's UK.

5. Have you contacted the helpline before?

Have you contacted the helpline before?	Response percentage	Response total
No	53%	44
Yes, once before	20.5%	17
Yes, twice before	4.8%	4
Yes, three or more times before	21.7%	18

These figures are similar to those from previous years. They reflect the fact that while we continue to reach new people affected by Parkinson's, others have included the helpline as part of their ongoing network of support.

6. Getting through to the helpline

Did you have any problem getting through to us?	Response percentage	Response total
Yes	6%	5
No	94%	78

We know from user feedback that the ability to get through to an adviser on the helpline easily is very important.

This was reflected in some of the comments made in response to this question.

Comments included:

“Not really a problem getting through but the lines were so busy I had to leave a voicemail and await a call back, which was approximately 24 hours later. This is not a criticism as the service must be in high demand, but I guess when you call a helpline with questions on your mind you kind of want to speak about what is on your mind at the time.”

“Sometimes more resources should be provided to cover staff being off on holiday or sick.”

Although 94% of people did not have any problems getting through, the fact 6% did is concerning and is being addressed in service planning for 2018.

7. Customer service and user satisfaction

Was the nurse and/or adviser you spoke to polite and friendly	Response percentage	Response total
Very	96.3%	79
Quite	3.7%	3
Average	0%	0
Not particularly	0%	0
Not at all	0%	0

The overall satisfaction with the service remains high – over 96% of people rate the service as good or excellent while 97% say they would recommend it to others.

Comments included:

“I spoke to Lisa who was very helpful and gave me the assistance and reassurance I required. She should be commended for her helpful manner and willingness to listen.”

“The person I initially spoke to was extremely helpful and most empathetic. She gave me Ian Adams’s details and booked a phone call for me with him. He also was very helpful and supplied me with great advice and emailed me additional information.”

“Didn’t make you feel silly even if the questions might have been silly.”

Did you feel you were treated fairly?	Response percentage	Response total
Yes	98%	82
Not sure	1.2%	1
No	0%	0

Overall, how would you rate the service you received from the helpline?					
Excellent	Good	Satisfactory	Poor	Very poor	Response total
81.7% (67)	14.6% (12)	2.4% (2)	1.2% (1)	0% (0)	82

Would you recommend the service to other people affected by Parkinson's?	Response percentage	Response total
Yes	97.6%	80
Not sure	2.4%	2
No	0%	0

8. Reason for contact

The range of issues that people raise when contacting the helpline is demonstrated below.

What sort of information or support did you contact us for? Please select all that apply.	Response percentage	Response total
Medical advice	42.2%	35
Signposting – who to contact	12%	10
Social care advice (eg care home, local authority home adjustments)	15.7%	13
Benefits advice and other financial issues	41%	34
Employment advice	9.6%	8
Emotional support or someone to talk to	15.7%	13
Creative or therapeutic activities (eg yoga, singing, tai chi)	2.4%	2
Newly diagnosed	15.7%	13
Respite care information	4.8%	4
Access to health services	8.4%	7
Carers' issues	9.6%	8
Housing issues	3.6%	3
Contact with local groups	7.2%	6
Daily living aids and equipment	2.4%	2
Holidays and travelling	0%	0
Other	6%	5

There seems to be a reduction in the number of people contacting the helpline for medical advice when compared with the 2016 survey. There is also a substantial rise in the numbers of people wanting advice on benefits.

Did you get the information and advice you needed?	Response percentage	Response total
Yes, completely	73.5%	61
Yes, mostly	22.9%	19
Not sure	2.4%	2
In part only	1.2%	1
Not at all	0%	0

Despite the range of information and support requested, respondents felt they got what they needed, with over 96% reporting that they either completely or mostly got what they needed.

Comments included:

“This was my first enquiry and the advice given was excellent and kindly given.”

“I was completely happy with the telephone conversation and felt able to say anything that was a concern and be given good advice.”

“The help and advice about benefits was really informed and very helpful. I was given all the information I needed, along with contact details and a telephone number. Very pleased – thank you so much.”

However, the limitations of what the helpline service is currently able to offer was also highlighted in the comments made.

Comments included:

“It is a pity you don’t have the information about the NHS Parkinson’s nurse for our area. The person who we were speaking to was very helpful but you don’t have the information about the NHS nurse – who we had previously phoned twice but only got a answerphone. We left our number but we didn’t hear from them at all – our phone calls were over three weeks ago.”

This is a question frequently asked by callers to the helpline. However, the lack of up-to-date information on NHS nurses, and their referral criteria, means we need to refer callers on to local support for answers to their questions.

9. Impact of information

How much do you think the Parkinson’s UK helpline has helped you with the following?

As in 2016, the survey asked people to give more detail about the areas where they felt the helpline had made an impact.

Improving emotional wellbeing	Response percentage	Response total
Helped a lot	45.3%	29
Helped	26.6%	17
Helped a bit	4.7%	3
Didn't help	1.6%	1
N/A	21.9%	14

Improving understanding and management of Parkinson's (treatments, symptoms etc)	Response percentage	Response total
Helped a lot	42.9%	30
Helped	21.4%	15
Helped a bit	10%	7
Didn't help	1.4%	1
N/A	24.3%	17

Information about further sources of support (nurses, support groups etc)	Response percentage	Response total
Helped a lot	36.7%	22
Helped	16.7%	10
Helped a bit	6.7%	4
Didn't help	1.7%	1
N/A	38.3%	23

Better understanding of benefit entitlement	Response percentage	Response total
Helped a lot	35.4%	23
Helped	21.5%	14
Helped a bit	3.1%	2
Didn't help	3.1%	2
N/A	36.9%	24

Better understanding of employment rights	Response percentage	Response total
Helped a lot	15.5%	9
Helped	6.9%	4
Helped a bit	0%	0
Didn't help	1.7%	1
N/A	75.9%	44

Better understanding of social care	Response percentage	Response total
Helped a lot	15.5%	9
Helped	12.1%	7
Helped a bit	3.4%	2
Didn't help	3.4%	2
N/A	65.5%	38

More than 70% of people who responded to the survey commented that the helpline had improved their emotional wellbeing. This highlights the importance of advisers responding to the emotional content of the calls, as well as to the need to provide information.

Comments included:

"Having a listening ear and someone who really knew what they were talking about. Very informative and knowledgeable and who took time to explain. Very reassuring."

Other comments on the more practical benefits respondents gained from their contact with the helpline are shown below:

"The advice we received enabled us to successfully claim benefits to which we were entitled. This at the point when we were beginning to become desperate for financial assistance due to my condition."

"My query was about the possibility of vitamin supplements clashing with Parkinson's medication. The negative answer means I can take the supplement to try to ease a joint problem I have."

"It has given us information regarding medication so that we can ask to try a new drug regime."

"It identified ways I could help myself."

"I was able to know my employment rights."

"Possible reduction of drugs after error by pharmacy."

"After speaking to your nurse, I feel my route via my local Parkinson's nurse and the rest of my medical team is now much more clearly defined – to enable me to have an acceptable reduction in, and balance of, my symptoms."

The survey also asked if the information and support helped respondents make choices. This is often a difficult question for helpline callers to answer as they are sent out very soon after the call. This means people often haven't had time to act on the information given.

Comments included:

"Too early to say which benefit I might be entitled to."

"Asked about additional treatments, so nothing yet!"

The survey also highlighted that even where callers get appropriate information this may not lead to changes, due to the wider health and social care systems.

Comments included:

"The advice given made me realise the Employment and Support Allowance (ESA) benefits fiasco isn't a problem unique to me but still doesn't help me trust or have faith in the ESA department at all."

"Suggestion to contact Parkinson's nurse resulted in a wait for 14 days before an answer was received by letter."

"We have no Parkinson's nurse in our area, which is a great shame."

Did the information and/or support help you make any choices that improved your life in some way?	Response percentage	Response total
Helped a lot	55.1%	43
Helped a little	24.4%	19
No change or can't say	17.9%	14
Didn't help	2.6%	2
Made things worse	0.0%	0

Despite this, it is encouraging that almost 80% responded it had helped either a lot or a little.

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. Although the overall level of satisfaction with the service was high, there were a number of specific suggestions either directly relating to the helpline or other parts of the charity.

Comments included:

"More cover for staff already working so when they are off sick or on holiday there will not be a gap in assistance."

"Not the helpline in itself, but they often had difficulty contacting people within Parkinson's UK. I now know and understand that your resources in terms of staff numbers are limited and this means you have to wait until they are free to call you or return from holiday."

"I was given the name and contact number of my local adviser. I have left a message for him to contact me but to no avail – no call back from him."

"Lady who answered my call was good – shame local adviser out of reach though."

Action taken

As a result of this feedback, the helpline team has reviewed the staffing model and is now making more use of "bank" staff. These staff are able to offer support to cover leave, sickness and peak periods. The helpline team is now working to ensure we are given up-to-date details about our local adviser teams, including information on long-term sickness and vacant posts

This means we have access to accurate information, even where this has not been updated on the website. This will help to ensure that we can offer callers up-to-date and accurate information. In turn, this should hopefully reduce some of the frustration people have expressed when they've been unable to get in touch with the relevant member of staff to deal with their issues.

11. Conclusion

Overall, the service received positive feedback and it is clear the helpline is able to make a significant difference to the lives of people affected by Parkinson's. However, it is important we continue to look at the service we offer, to ensure we offer the best possible value to those who call us.

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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