

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



Helpline evaluation report

November 2015

“The nurse was extremely friendly, reassuring, easy to speak to, understanding and most of all, informative and helpful.”

November 2015 survey respondent

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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 2015. The survey aimed to gather user feedback about the helpline to ensure quality and, combined

with the service's other monitoring mechanisms, to inform its development.

The survey was sent to more than 200 callers. Surveys were only sent to people who had called to speak to a helpline adviser, and not callers who were transferred through to other departments in the charity.

A total of 59 surveys were received, which is a response rate of about 26%. This is lower than in previous years. This could be related to the revised version of the form, which is slightly longer than the previous one.

Response rates will be monitored next year and the form reviewed if necessary.

2. Who responded to the survey?

We received responses from people with Parkinson's, carers and family members and professionals. This is comparable to the breakdown in previous years.

- The majority of respondents (61%) said they have Parkinson's, while 27% identified as a carer, partner or family member.

What is your connection to Parkinson's?	Response percent	Response total
I have Parkinson's	61.02%	36
I am a carer, partner or family member of a person with Parkinson's	27.12%	16
Other – please specify	11.86%	7

- 44% percent of respondents were over 65 years of age.

How old are you?	Response percent	Response total
Under 18	0%	0
18-24	0%	0
25-34	0%	0
35-44	10.2%	6
45-54	20.3%	12
55-64	25.4%	15
65-74	33.9%	20
75 and over	10.2%	6

- Almost 70% of respondents were women.

What is your gender?	Response percent	Response total
Female	68.97%	40
Male	31.03%	18
Other	0%	0
Prefer not to say	0%	0

- The ethnicity of respondents was overwhelmingly White British. There was one response from an individual of Asian (other) background. This does not reflect the overall use of Parkinson's UK's helpline services, where approximately 6% of users identify their ethnic background as non-White.

What is your ethnicity?	Response percent	Response total
White – English, Welsh, Scottish, Northern Irish or British	91.53%	54
White – Irish	3.39%	2
White – Gypsy or Irish Traveller	0%	0
Any other White background – please specify	3.39%	2
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	0%	0
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	0%	0
Any other Asian background – please specify	1.69%	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 callers hear about the helpline?

- The majority of people (55%) heard about the helpline through the Parkinson's UK website.
- Other respondents heard about the helpline through a variety of other channels, including a Parkinson's nurse or clinic (almost 9%), a Parkinson's local adviser (7%), a Parkinson's UK branch or group (7%), or Parkinson's UK publications (7%).

How did you hear about the helpline?	Response percent	Response total
Parkinson's UK website	55.36%	31
Parkinson's local adviser	7.14%	4
Parkinson's UK information event	1.79%	1
Parkinson's UK branch or group	7.14%	4
Parkinson's UK publications – please specify	7.14%	4
Friends or relatives	1.79%	1
Parkinson's nurse or clinic	8.93%	5
Consultant	1.79%	1
GP	0%	0
Other health care professional – please specify	0%	0
Social services	0%	0
Other voluntary organisation – please specify	1.79%	1
Other – please specify	7.14%	4

As in previous years, this shows the importance of the website in directing people affected by Parkinson's to the helpline. However, a range of other avenues are also of value. Comments included:

"I first learnt about Parkinson's UK and the helpline through a chance encounter with a Parkinson's fundraising and information awareness event at my local supermarket. I was given a sticker, which I attached to the inside flap of my shoulder bag, and also an invitation to attend a Parkinson's UK local group meeting in my particular borough, which I later did..."

"From *The Parkinson* magazine, which I have received regularly over the last 16-plus years since I was diagnosed with the disease."

4. Have callers contacted the helpline before?

- Almost 51% of respondents were calling us for the first time.
- In total, almost 24% of respondents had called us once or twice before, and 25% were more regular callers, having called three or more times.
- Repeated use of the helpline service is a positive sign as it would indicate that people feel the service can provide them with the information and support they need.

Have you contacted the helpline before?	Response percent	Response total
No	50.8%	30
Yes, once before	13.6%	8
Twice before	10.2%	6
Three or more times before	25.4%	15

5. Getting through to the helpline

- Almost 95% of respondents said they had no problems getting through to the helpline.
- This is slightly lower than in previous years, although still significantly higher than our target of answering 80% of all incoming calls.

Did you have any problem getting through to us?	Response percent	Response total
Yes	5.08%	3
No	94.92%	56

6. Customer service and user satisfaction

- The majority of respondents (74%) rated the service they received from the helpline as excellent, with the rest rating it as good.

Overall, how would you rate the service you received from the helpline?	Response percent	Response total
Excellent	74.1%	43
Good	25.9%	15
Satisfactory	0%	0
Poor	0%	0
Very poor	0%	0

- The vast majority of respondents (98%) said the nurse or adviser they spoke to was very polite and friendly.

Was the nurse and/or adviser you spoke to polite and friendly?	Response percent	Response total
Very	98.2%	56
Quite	1.8%	1
Average	0%	0
Not particularly	0%	0
Not at all	0%	0

Comments included:

“She was very pleasant and helpful, and I did not feel rushed.”

“The nurse was very helpful, professional and friendly.”

“What I experienced was something I can only describe as exceptional.”

These comments highlight the empathy and professionalism of the helpline advisers, which is essential for the delivery of a high quality service.

- Almost 97% of respondents would recommend the service to others, with 3% saying they were unsure. This is an improvement on the 2014 survey where 95% said they would recommend the service, and 5% said they were unsure.

Would you recommend the service to other people affected by Parkinson's?	Response percent	Response total
Yes	96.6%	57
Not sure	3.4%	2
No	0%	0

- All respondents (100%) said they felt they were treated fairly by the advisers they spoke to.

Did you feel you were treated fairly?	Response percent	Response total
Yes	100%	58
Not sure	0%	0
No	0%	0

7. Reason for contacting the helpline

- The majority of respondents (almost 69%) said they called the helpline with a medical query. Other reasons included: signposting (21%), benefits advice and other financial issues (17%), and emotional support (14%).

What sort of information or support did you contact us for? Please select all that apply.	Response percent	Response total
Medical advice	68.97%	40
Signposting or whom to contact	20.69%	12
Social care advice (eg care home, local authority home adjustments)	6.90%	4
Benefits advice and other financial issues	17.24%	10
Employment advice	3.45%	2
Emotional support or someone to talk to	13.79%	8
Creative or therapeutic activities (eg yoga, singing, tai chi)	1.72%	1
Newly diagnosed	10.34%	6
Respite care information	5.17%	3
Access to health services	8.62%	5
Carers' issues	5.17%	3
Housing issues	0%	0
Contact with local groups	3.45%	2
Daily living aids and equipment	1.72%	1
Holidays and travelling	0%	0

Comments included:

“Our GP refused to prescribe the neurologists’ suggested prescription, leaving us high and dry. Completely bewildered, I rang for advice as to how to move things forward. I received advice fast.”

“In my case, I have not been diagnosed with Parkinson’s but have worrying symptoms. I was directed to my GP for advice as I am already on medication for other problems. I had a very interesting chat with your nurse and I think her advice and help has been helpful.”

“I understand that my concerns over poor care are completely justified, that I am not being too sensitive and can move forward with my father-in-law’s care issues to put in place a more suitable and regulated form of care with confidence.”

“Very helpful. This is something we are completely in the dark about and were given advice and information required. As much information as I could have expected. Only a neurologist, specially qualified in Parkinson’s, could have given me more detailed information.”

- Respondents reported that they completely (61%) or mostly (34%) got the information and advice that they needed.

Did you get the information and advice you needed?	Response percent	Response total
Yes, completely	61.0%	36
Yes, mostly	33.9%	20
Not sure	0%	0
In part only	3.4%	2
Not at all	1.7%	1

- The majority (65%) reported that the information they received was very easy to understand, while 28% said it was easy to understand.

How easy to understand was the information that you received?	Response percent	Response total
Very easy	64.9%	37
Easy	28.1%	16
Not sure or can’t say	5.3%	3
Quite difficult	1.8%	1
Very difficult	0%	0

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

For the first time, 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 understanding and management of Parkinson's, 40% said the helpline helped a lot, and 30% said it helped.
- Emotional wellbeing was another area where the helpline was reported to have helped (33%) or helped a lot (29%).
- In terms of information about further sources of support, 28% said the helpline helped a lot, and 19% said it helped.

Improving emotional wellbeing	Response percent	Response total
Helped a lot	28.6%	14
Helped	32.7%	16
Helped a bit	6.1%	3
Didn't help	0%	0
N/A	32.7%	16

Improving understanding and management of Parkinson's (treatments, symptoms etc.)	Response percent	Response total
Helped a lot	40%	20
Helped	30%	15
Helped a bit	8.0%	4
Didn't help	4.0%	2
N/A	18.0%	9

Better understanding of benefit entitlement	Response percent	Response total
Helped a lot	19.1%	9
Helped	8.5%	4
Helped a bit	2.1%	1
Didn't help	2.1%	1
N/A	68.1%	32

Better understanding of employment rights	Response percent	Response total
Helped a lot	9.1%	4
Helped	2.3%	1
Helped a bit	2.3%	1
Didn't help	2.3%	1
N/A	84.1%	37

Better understanding of social care	Response percent	Response total
Helped a lot	8.9%	4
Helped	6.7%	3
Helped a bit	4.4%	2
Didn't help	0%	0
N/A	80%	36

Information about further sources of support (nurses, support groups etc.)	Response percent	Response total
Helped a lot	27.7%	13
Helped	19.1%	9
Helped a bit	2.1%	1
Didn't help	2.1%	1
N/A	48.9%	23

9. Impact of information

- Overall, 68% of those who responded said that the information and support that they received helped them to make choices that improved their life in some way.

Did the information and/or support help you make any choices that improved your life in some way?	Response percent	Response total
Helped a lot	47.2%	25
Helped a little	20.8%	11
No change or can't say	30.2%	16
Didn't help	1.9%	1
Made things worse	0%	0

Comments included:

"I have a better informed plan about how our family can help mum."

"Am due to see GP to change medication."

“Neurologist has given very, very cautious advice which would probably have meant my Parkinson’s would have been less well-managed for many weeks.”

“The helpline advice confirmed all that I had read before and will enable me to talk to my GP with evidence.”

However, in some cases the provision of information was not enough to bring about change, possibly because the surveys were sent out very shortly after the call was made.

Comments included:

“Unfortunately, despite the helpline helping me with information on specialist nurses, the hospital did not really take my enquiry regarding being referred to the Parkinson’s nurse and it fell on deaf ears.”

“Too early to say.”

“Too soon to assess impact of information on my attitude towards any potential problems the disease will throw up.”

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:

“No, I think it does not need improvement.”

“I was pleasantly surprised to get a call back so soon after my request the previous day.”

“None at all. I wasn’t expecting to find this service, and to find it so easily and get so much advice from qualified people, and so quickly. I was delighted. Thank you.”

“I’d just like to say I am so glad your helpline service exists and I can call for advice as symptoms and other problems present themselves.”

Other feedback did highlight areas that could be addressed. Comments included:

“Support service rang me but I was not awake. They said they would ring back. That was 16 November. They didn’t ring again. What’s the point of anything if they don’t bother?”

Due to confidentiality, helpline advisers will not leave a message when returning a call unless they have explicit permission to do so. It is likely that further attempts to make contact were in fact made but the advisers were unable to get through.

The helpline voicemail message does ask people to say if it is ok to leave messages but this may be worth reviewing to see if it can be made clearer.

“That calls are sorted as to how urgent the call is. I was told that I would be contacted in 48 hours – which could have been too late as I was worried about whether I had taken my Parkinson’s tablets and what would happen if I had under or overdosed on tablets. As it happens the nurse contacted me within a few minutes and reassured me that it would have a negative effect.”

“Far too long waiting for call back. Several hours.”

Where callers need to speak to one of our specialist advisers, the service works on a call back basis. This is essential as a way of managing a variable demand for support. The service period that has been standard for the helpline is 48 hours, although calls are often returned more quickly than this. However we recognise that this can create anxiety. As a result of this feedback we have looked again at how we manage our nursing service and now offer a call back from our nurses within a 24-hour period as standard.

“Japanese – I know this is a big ask, so fully understand it is very difficult to provide.”

Helpline advisers do have access to interpretation services so this might have been a possibility. The team have been reminded about the service and how to access it. They are encouraged to be proactive about bringing it to the attention of callers if they think it might be helpful.

11. Conclusion

The results of the 2015 helpline user survey are positive, and clearly show the value that clients place on the service.

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

These figures show a slight increase in satisfaction levels compared with 2014.

The things that callers 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 availability of accurate information and advice at the end of the phone.
- The ability to speak to a nurse about symptoms.

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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