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Helpline user survey

June 2014

"My pharmacist told me that my amantadine tablets were not available. My GP could not suggest a replacement. My Parkinson's nurse was on leave. Panic. The helpline cleared a week's worry in less than one minute."

June 2014 survey

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Summary – helpline user evaluation June 2014

Background

The Parkinson's UK helpline is a confidential service providing support to anyone affected by Parkinson's. 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, benefits, health and social care, and emotional support.

User surveys are sent to callers once a year to gather feedback about the service, and to ensure quality monitoring and inform service development. The surveys are normally sent over a two-to-three week period decided in advance. This evaluation method complements other evaluation methods used for the helpline, including impact surveys and call-recording exercises.

This report relates to the surveys covering a three-week period in June 2014.

• A total of 260 surveys were sent to callers during this period, an increase of 55% compared with the May 2013 survey.

• Surveys were sent only to people calling to speak to a helpline advisor, and not callers who were transferred through to other departments in the charity.

• We received 125 completed responses (80 postal, 45 online), making this a larger sample size than the 2013 survey (an increase of 64%).

• The response rate was 45%, which is comparable to the May 2013 response rate of 43%.

• Results for each question are based on the total number of callers answering that question, with figures adjusted where respondents have not answered questions.

Survey respondents

Age groups

The majority of respondents (60%) were over 65 years of age – of these, 5% were over 85 years old.



These age groups reflect the general Parkinson's population and it is positive that the helpline reaches people in all relevant age groups

Ethnic groups

91% of respondents classed themselves as white British, and 1% said they were Black/Black British and 1% Asian/Asian British.



Q15 My ethnic background is

- This breakdown broadly matches the general pattern of the use of the helpline.
- Of the five people (5.5%) who described themselves as being from an ethnic group that wasn't listed, two were Welsh and one said that they were 'indigenous English'. A further one said they were Indian and another Filipino/British. All 'white'/'other ethnic group' respondents rated the service excellent or good, and said they would recommend it to others.

Person with Parkinson's or carer

56% of respondents had Parkinson's themselves and 35% were carers, friends or family members. 7% were professionals. The 2013 survey received no responses from professionals.

Time since diagnosis

46% of callers had been diagnosed for between two and ten years, and 36% had been diagnosed in the last two years or less. 12% were diagnosed between 11 and 20 years. 5% had lived with the condition for over 21 years. Nobody in this category responded to the May 2013 survey, therefore, it is positive to get reponses from people in this group.



The majority of callers said they heard about the helpline service through the website (46%).



Q1 How did you hear about our helpline?

• 17% of callers heard about the service through a health care professional. The remaining heard about it through a mix of channels, including their ISW, friends, branches, *The Parkinson*, literature, with their medication, and from their pharmacist.

As many as 98% of respondents said they had no problem in getting through to an advisor the first time. The helpline's target and 'promise' to callers is that calls are answered on first attempt at least 80% of the time. Therefore, among the users surveyed, the target was exceeded. This mirrors the monthly results, which are measured internally

Reason for call

Callers' reasons for using the helpline service are shown in the following chart.



• 40% of callers rang with a medical query, 19% called to talk generally about living with Parkinson's and 17% for emotional support. For people completing the 'other' category, this was due to a mixture of reasons, including many queries that would be classed as medical'.

Quality of service Welcoming, friendly and fair

All callers thought the helpline adviser was welcoming and friendly.



Q5 Was the person who answered welcoming and friendly?

 As many as 97% found the adviser very or quite friendly, with 3% saying they were 'average'. All callers felt they were treated fairly during their call.

Comments included:

"Calm and reassuring." - Respondent 97

"It's good to know you have some back up at the end of the phone. We feel so isolated struggling with Parkinson's. It's nice just being able to talk to a person." – Respondent 4

Right information and advice

Callers were also asked if they felt that the helpline was able to give them the information and advice they needed.



 58% of callers felt they were completely able to get the information and advice they needed, while 30% answered that the information received 'mostly' met their needs. 8% said we could only answer their query in part, while one person (1%) felt we did not achieve this at all. Of the respondents saying we only met their information needs partly, or not at all, their accompanying comments do not especially reflect this. So it is hard to pick out what would have made a difference to them.

Overall, responses to the survey were largely positive. And, reassuringly, only one caller said they would not recommend the service to other people (this was not mirrored in their other responses so was probably an error on their part).

Comments included:

"Listened. Guided conversation to enable me to reflect on event." – Respondent 11

"My pharmacist told me that my amantadine tablets were not available. My GP could not suggest a replacement. My Parkinson's nurse was on leave. Panic. The helpline cleared a week's worry in less than one minute." – Respondent 97 "Very helpful, he just let me talk about my problems. It's good to have someone outside of my family to talk to." – Respondent 106

Overall rating of the helpline service

A total of 93% rated the service as excellent or good overall, with 7% finding it satisfactory.



Q10 How would you rate the helpline service overall?

• These results are similar to the ones gleaned from the May 2013 survey.

• 95% of callers said they would recommend the service to others.

General comments included:

"It's nice to know these very good people are just a phone call away. It's very reassuring." – Respondent 99

"Very prompt in dealing with and follow up." - Respondent 94

"Personalised and welcoming – wasn't just a general chat offered hope of my mum still living a long and rewarding life. As a son of parent newly diagnosed the helpline was pleasant experience." – Respondent 69

Conclusion

- Overall, the helpline service continues to be highly appreciated by callers.
- Generally, callers have no problem in accessing the service.
- A total of 93% rated the service as excellent or good overall, with 7% finding it satisfactory.
- The results indicate that 95% of respondents would recommend the service to others.
- The helpline continues to reach those from black, ethnic minorities and other white communities (non-British), and respondents to this survey broadly match the make-up of users to the helpline.

Helpline user evaluation June 2014

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, their partners, families and friends and professionals working with people affected. Our trained advisers, including specialist Parkinson's nurses, can provide information and advice about all aspects of living with Parkinson's, such as medical and symptom queries, benefits and employment, social care, equipment and adaptations, etc.

This report presents results and feedback collected through the user survey conducted in June 2014, with some comparisons made with the previous year's survey, as indicated. The survey aims to gather user feedback about the helpline to ensure quality and, combined with the service's other monitoring mechanisms, inform its further development.

Survey respondents

This year, the surveys were sent to 260 callers. Surveys were sent only to people who had called to speak to a helpline advisor, and not callers who were transferred through to other departments in the charity. A total of 125 completed responses (80 postal, 45 online), making this a larger sample size than was used for the last survey, representing an increase of 64% when compared with May 2013.

The response rate was 45%, which is comparable to the May 2013 response rate (43%).

Results for each question are based on the total number of callers answering that specific question, with figures adjusted where some respondents have not answered. Tables show the number of people who answered each question.

Person living with Parkinson's

Table 1 shows that the majority of respondents were people living with Parkinson's (56%), with carers making up 35% of callers.

Table 1: Type of respondents

Answer Choices	Responses
A carer/friend/family member of someone affected by Parkinson's	34.78% 40
A person with Parkinson's	55.65% 64
Other (please give details)	9.57% 11
Total	115

In the 'Other' category, 7% were professionals, including a counsellor and an employer. The remaining 3% were friends or had responded within the incorrect category.

Age

Table 2 shows the age group of those responding. The largest proportion was aged over 65 (55%), while 30% were between the ages of 45 and 64 and 10% were under 44.

Answer Choices	Responses	
24 and under	0.00%	0
25-44	10.00%	11
45-64	30.00%	33
65-84	54.55%	60
85+	5.45%	6
Total		110

Table 2: Age group of respondents

In this survey, we also received responses from those aged 85 and over, which compares very favourably with the May 2013 survey, which did not reach people in this age group. Or at least, people in this age group did not

respond. These age groups are representative of the Parkinson's community generally.

Time since diagnosis

Table 3 below shows how long callers with Parkinson's had been diagnosed for. In this survey, the majority (46%) of our sample had been diagnosed between two and 10 years ago.

Table 3: I (or person affected) was diagnosed

Answer Choices	Responses	
less than 2 years ago	36.36%	36
2-10 years ago	46.46%	46
11-20 years ago	12.12%	12
21+ years ago	5.05%	5
Total		99

The helpline service supports people at varying stages of their Parkinson's journey, and clients are likely to experience a wide range of issues which they require support for. A significant proportion of users (36%), have received a diagnosis in the past two years, meaning we are reaching people who are newly or most recently diagnosed.

Positively too, this survey reached those who have lived with the condition for 21 years and over. The May 2013 survey received no responses from people in this group.

Ethnicity

Table 4 shows that, of those responding, the majority (91%) defined themselves as white British and 3% as white 'other' while 2% were from black and minority ethnic communities.

Table 4: My ethnic background is

nswer Choices	Responses	
Asian or Asian British	0.92%	1
Black or Black British	0.92%	1
Chinese	0.00%	0
Mixed	0.00%	0
White British	90.83%	99
White other	2.75%	3
Other ethnic group (please specify)	4.59%	5
tal		109

Of the five people (5.5%) who described themselves as being from an ethnic group not listed, two were Welsh and one said they were 'indigenous English'. One said they were Indian and another Filipino/British. All non-white/other ethnic group respondents rated the service excellent or good, and said they would recommend it to others.

Contacting the helpline

Have you called the helpline before?

For the first time in a helpline survey, callers were asked if they had called the helpline before.

Table 6: Have you called the helpline before?

Answer Choices	Responses	
No	60.48%	75
Yes, once before	24.19%	30
Twice before	7.26%	9
Three or more times before	8.06%	10
Total		124

While 60% of respondents were calling us for the first time, almost 40% had rung us before. A total of 25% had called us once before, and 8% potentially 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.

How respondents found out about the helpline

Table 7 shows how those responding found out about the helpline service. By far, most people heard about the service through the Parkinson's UK website (46%).

nswer Choices	Responses	
Friend or relative	8.87%	11
Healthcare professional	16.94%	21
Information and support worker	8.06%	10
Newspaper, radio or TV	3.23%	4
Parkinson's UK website	45.97%	57
Other (please specify)	16.94%	21
otal		124

Table 7: How did you find out about the helpline?

A further 17% were told about the service by their healthcare professional and 9% found out through friends and family. Of interest to our media and marketing teams, 3% of respondents say they heard about the service in the media (newspaper, television or radio). This is likely to be related to April 2014's Parkinson's Awareness Week.

Main reasons callers rang the helpline

Previous surveys have not asked why the caller rang, making it hard to understand people's underlying needs. In this survey the question was asked, and 40% of callers rang with medical queries relating to medication, treatments and symptoms.

Table 8: What was the reason for your call

nswer Choices	Responses	
Benefits	10.48%	1
Emotional support	16.94%	2
Information about Parkinson's UK	15.32%	1
Living with Parkinson's	19.35%	2
Medical questions	39.52%	
Newly diagnosed	12.90%	
Social care	7.26%	
Other (please specify)	25.81%	:
tal Respondents: 124		

19% called to talk generally about living with Parkinson's while 17% called for emotional support. Of the 26% of callers who selected 'Other', please see the breakdown of these calls to follow:

Medical – 7 calls	Equipment – 4 calls	Social care – 2 calls
Publications – 5 calls	Driving – 3 calls	Drug supply – 2 calls
Mixed – 7 calls		

Problems getting through

As shown in Table 9 below, 98% of callers responding to our survey said they had no problems getting through to the helpline.

Table 9: Did you have any problems getting through to the helpline?

Answer Choices	Responses
Yes	2.48% 3
No	97.52% 118
Total	121

Of the 2% of callers who said they did have difficulty, one explained that they had in fact used email and not telephone to get in touch. The others (two) said they got our busy tone and were able to get through when they called back later.

Quality of the helpline service

Callers were asked to comment generally on the tone and friendliness of advisors, and also on the quality of information and advice they received. Ultimately, we wanted to know how they rated the service overall, and if they would recommend it to others.

Friendliness and welcoming qualities

These important 'soft skills', while not necessarily essential to fact and information-giving, normally allow callers to feel at ease to talk, and to perhaps open up more than they would otherwise. It is also important that callers feel supported during their call. Many experience professional services, such as consultants and GPs, as distant and generally rushed.

Table 10 below shows that 84% of respondents found the advisor/nurse they spoke to 'very welcoming and friendly', with 13% rating them as 'quite welcoming and friendly'.

Answer Choices	Responses	
Very	83.90%	99
Quite	12.71%	15
Average	3.39%	4
Not particularly	0.00%	0
Not at all	0.00%	0
Total		118

Table 10: Was the advisor you spoke to welcoming and friendly?

A small proportion of callers rated the person they spoke to as just 'average' in this area. These ratings are not as positive as those in the May 2013 survey, where 96% of callers said advisors/nurses were very welcoming and friendly and 4% said they were 'quite' welcoming and friendly. Nobody in the 2013 survey rates advisors as 'average' in this area.

However, of the comments made by respondents all were very good.

"Listened. Guided conversation to enable me to reflect on event." – Respondent 11

"Calm and reassuring." – Respondent 97

"Very helpful, he just let me talk about my problems. It's good to have someone outside of my family to talk to." – Respondent 106

"Above average. A nice surprise, as initially nervous to phone." – Respondent 108

Clearly, the helpline advisors and nurse's approach and tone is one that does often invite and encourage the caller to open up, and shows support and care for the caller.

Fairly treated

All callers said they felt they had been treated fairly during their call.

Table 11: Did you feel you were treated fairly?

Answer Choices	Responses	
Yes	100.00%	119
No	0.00%	0
Not sure	0.00%	0
Total		119

Adequacy of information and advice

Besides providing reassurance to callers and being friendly, it is essential that the information provided by advisors and nurses is accurate and feels adequate to the callers' needs.

Table 12 shows that 58% of those responding felt that they were 'completely' able to get the information and advice they needed, and a further 30% felt they 'mostly' got what they needed in terms of information and advice.

Table 12: Were	you able to get the i	information and	advice you needed?
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Answer Choices	Responses	
Yes, completely	57.76%	67
Yes, mostly	30.17%	35
Not sure	3.45%	4
Partly	7.76%	9
Not at all	0.86%	1
Total		116

Yet 3% of respondents were not sure, a further 8% thought the adequacy of information and advice was just 'average' and a further 1% (one), said they were unable to get the information they needed.

Looking in more detail at the full responses of the person who said we could not give them the information they needed, they stated the reason for their call as 'family problems'. They also stated in other questions that the helpline helped:

- emotional wellbeing = 'a bit'
- understanding/managing Parkinson's = 'helped'
- info about further sources of support = 'helped'

This respondent did not answer the question about recommending the service to others but did give the service an overall rating of 'good'.

The comments from users saying the service only 'partly' met their information needs were:

"Gave us phone number and email address for information and support worker for the relevant area." – Respondent 1 "I was sent a booklet *Driving and Parkinson's*, which told me what I wanted to know." – Respondent 2

"I wanted to know if there was an eye test for disabled people but apparently there isn't. I'm sure my husband's glasses don't work due to him not being able to cope with the test." – Respondent 4

In addition, all users here rated the service overall as 'good', with Respondent 4, for example, commenting:

"It's good to know you have some back-up at the end of the phone. We feel so isolated struggling with Parkinson's. It's nice just being able to talk to a person." – Respondent 4

Looking further at the responses of those who said the helpline 'mostly' met their information needs, comments included:

"Asked questions that we don't have answer to yet eg how do we stop neurons dying?" – Respondent 32

"Advice was in timing of medication. If this does not work, no option given." – Respondent 33

"Wanted name of local information and support worker but the position is vacant in our area." – Respondent 34

These respondents rated the service as 'excellent' (two) and 'good' (one).

All of these responses and comments indicate that generally people feel they helpline meets their information and advice needs.

How much did the helpline help and how?

A further new section was added to the 2014 survey, to get information about the different ways people felt the helpline had helped them.

Table 13 shows the various dimensions people were asked about, and their responses.

	Helped a lot	Helped	Helped a bit	Didn't help	Not applicable	Total
Emotional wellbeing	32.98%	29.79%	9.57%	1.06%	26.60%	
	31	28	9	1	25	94
Inderstanding and managing Parkinson's (treatments,	41.76%	25.27%	7.69%	1.10%	24.18%	
symptoms, etc)	38	23	7	1	22	91
nformation about further sources of support (nurses,	42.70%	26.97%	6.74%	0.00%	23.60%	
groups, etc)	38	24	6	0	21	89
Understanding benefit entitlement	15.19%	8.86%	5.06%	1.27%	69.62%	
	12	7	4	1	55	79
Understanding social care	15.85%	10.98%	6.10%	1.22%	65.85%	
	13	9	5	1	54	8

Table 13: How much do you think the Parkinson's UK has helped you...

Many callers, whilenot primarily calling for emotional help will often comment that they feel helped this way. Here, 73% of callers said using the service helped with their emotional wellbeing, and of these 33% said it 'helped a lot'.

Understanding and managing Parkinson's is a principal reason people call the helpline, with more than 40% of respondents ringing the helpline with medical questions. In this area, 75% found the service helped with 42% of those saying it helped a lot.

Callers to the helpline are often signposted on to further sources of information and support, both internally and externally. In this area, 77% of respondents felt the helpline helped, with 43% saying it 'helped a lot'.

Looking at the full responses of the caller who answered that the helpline did not help in understanding and managing their Parkinson's, we observe their reason for calling was for emotional support and that they rate the service as 'good' and give very positive responses elsewhere. In this case, perhaps 'not applicable' would have been a more appropriate response for them. This is also the case for the other respondents who ticked 'didn't help'.

Recommending the service to others

A sign of a service being valued is often that its users say they would recommend it to other people. Table 14 shows that when asked about this responses were very positive.

Table 14. Would you recommend the se	rvice to others?	
Answer Choices	Responses	
Yes	94.83%	110
No	0.86%	1
Not sure	4.31%	5
Total		116

Table 14: Would you recommend the service to others?

The results indicate that 95% of respondents would recommend the service to others, with 4% saying they are unsure. This compares with 99% saying they would recommend the service, and 1% saying they were unsure, in the May 2013 survey.

When looking at the full responses of callers, who answered that they were unsure if they would recommend the service, all other responses are positive, with overall ratings for the service being 'good' and 'excellent'. It is impossible to get a sense of why they would not recommend the service to others as, based on their responses, they view the service positively. In cases such as these, a further telephone interview could offer some clarity.

Reassuringly, only one caller said they would not recommend the service to other people. But, again, this was not mirrored in their other responses, which were very positive, including rating the service overall as 'excellent'.

How callers rate the service overall

Respondents are given an opportunity to rate the helpline service overall, taking into account all aspects that they have already rated or commented on, and any others they may have in mind. Table 15 shows that the service

generally reaches people's expectations and the vast majority of respondents are very positive about it overall, with 94% of callers rating the service as 'good' or 'excellent'.

Inswer Choices	Responses	
Excellent	55.56%	65
Good	37.61%	44
Satisfactory	6.84%	8
Poor	0.00%	c
Very poor	0.00%	c
otal		117

 Table 15: How would you rate the helpline service overall?

There was a slight lowering of ratings in comparison to the 2013 survey, where 67% of respondents rated the service as 'excellent' and only 3% said it was 'satisfactory', while in in this survey, this increased to 7%. None of the respondents rated the service as 'poor' or 'very poor'.

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. These were their comments:

"Set up a Parkinson's writers' group." – Respondent 125 Comments/action: Comment passed to Creative Arts Project Manager

"Please help us to get an adjustable bed as I have some problems getting up from bed." – Respondent 116

Comments/action: As contact details were provided, this can be followed up by the helpline team.

"Would like information on clubs in the area." – Respondent 106 Comments/action: As contact details were provided, this can be followed up by the helpline team.

"Possibly be there for longer hours!" – Respondent 99

"Listen to your callers and then speak." - Respondent 79

Comments/action: This was the most worrying and critical suggestion. This caller also commented when asked to rate the service overall (he rated it as 'satisfactory': "The first time I rang I wanted to speak with someone re a specific issue. The person who answered seemed more concerned about getting through the crib sheet he had in front of him and told me "let me finish" when I tried to explain what it was I wanted, which I thought was pretty rude for a helpline of an organisation like Parkinson UK. The second chap I spoke to did listen which made it a more successful and pleasant experience." As the caller has not provided contact details, we cannot follow up and get more information. However, this is something the Advisory Services Manager can address with the team. This caller said they would still recommend the service to others, therefore it is likely his second, more positive call provided some reassurance.

"They could perhaps be better informed. When I asked what the results were to the research being done into continuing health care allowance and Parkinson's sufferers, I was told that I would need to go through to another department." – Respondent 74

Comments/action: This call would have been passed through to the Policy and Campaigns team, who could provide the fullest and most upto-date information.

"It would be nice if you could speak to a qualified nurse when you actually ring and not have to wait a day or so. I realise that's asking a lot!" – Respondent 66

Comments/action: This has been suggested previously but under current working patterns and processes is not possible.

"I had to wait a long time for an answer to my question – -over the weekend and a bank holiday Monday. Perhaps more staff are needed." – Respondent 26

Comments/action: The helpline is open for incoming calls only on Saturdays between 10am and 2pm only, and is closed on Sundays, therefore, on bank holiday weekends, these delays will occur unless hours were to change. This is not currently planned.

"Perhaps help you be in touch with local helpline. We found QM Hospital Notts, Parkinson's helpline helpful!" – Respondent 22

Comments/action: It is unclear what the respondent is suggesting here. As we have contact details, this can be followed up.

A further six respondents commented saying there is nothing they would suggest at this stage, with one saying they found the service "invaluable" (Respondent 45).

Other positive comments about the service

"My pharmacist told me that my amantadine tablets were not available. My GP could not suggest a replacement. My Parkinson's nurse was on leave. Panic. **The helpline cleared a week's worry in less than one minute**." – Respondent 97

"It's nice to know these very good people are just a phone call away. It's very reassuring." – Respondent 99

"Very prompt in dealing with and follow up." – Respondent 94

"Personalised and welcoming – wasn't just a general chat offered hope of my mum still living a long and rewarding life. As a son of parent newly diagnosed the helpline was pleasant experience." – Respondent 69 "It's good to know you have some back-up at the end of the phone. We feel so isolated struggling with Parkinson's. It's nice just being able to talk to a person." – Respondent 66

Conclusion

The results of the June 2014 helpline service user survey are positive, and clearly show the value that clients place on the service. 93% of survey respondents rated the service as 'excellent' or 'good', with 7% rating it as 'satisfactory'. 95% would recommend the helpline to others. Callers generally have no problem in accessing the service.

The survey has highlighted what callers generally value about the service:

- speaking to an advisor, 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 and other medical matters