

Helpline service-user survey

May 2013

“It was a joy for the phone to be answered by a real, live, person who immediately knew who best to transfer the call to. Both individuals were helpful and spoke in a calm manner that seemed genuinely friendly and helpful, with no hint of either the patronising tone that is often extended to someone who needs help, or of 'reading from a script' that is associated with call centres. Wonderful!”

- May 2013 survey respondent

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Summary

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 twice a year to gather feedback about the service, and to ensure quality monitoring and inform service development. The surveys are sent over a two to three week period, decided in advance. This normally takes place in April/May and again in Oct/Nov each year.

This report relates to the surveys covering a three week period in April/May 2013.

- A total of 168 surveys were sent to callers during this period, the majority by post, with a minority completed online as a web survey (approx. 12)
- We received a total of 72 completed surveys (63 postal, 9 online), making this a larger sample size than the previous year's surveys (an increase of 44% compared with October 2012 and 67% for February 2012). However, more surveys were sent out on this occasion - 168 compared with an average of 120.
- The response rate was 40% by post and 75% via the web survey.

Survey respondents

- The majority of respondents (54%) were over 65 years of age.
 - 7% of respondents were from black and ethnic minority backgrounds or white non-British, which mirrors the current ethnic breakdown of callers.
- However, this is a very significant increase on **all** previous surveys, where the

response rate was 100% white British. All non-white British respondents rated the service excellent (80%) or good (20%), and considered the information provided very adequate (80%) or quite adequate (20%) to their needs. 100% would recommend the service to other people.

- 39% of respondents had Parkinson's themselves and 56% were carers, friends or family members. This is not comparable to the make-up of general caller type, where people with Parkinson's tend to slightly outnumber carers/family members. For example, in 2012, 36% of callers were pwp compared with 31% carer/family.
- None of the respondents identified as professionals working with people with Parkinson's.
- 36% of callers had been diagnosed less than two years ago, 46% had had Parkinson's for between three and ten years. 21% of callers had lived with the condition for between 11 and 20 years but no person living with Parkinson's for 21 years or over responded to the survey.

Contacting & accessing the service

- The majority of callers said they heard about the helpline service either through a healthcare professional (24%) or through the charity's website (25%). 21% of callers heard about the service through a mix of channels, including *The Parkinson*, literature, from their pharmacist, etc.
- 94% of respondents said they had no problem in getting through to an advisor first time. The helpline's KPI for calls answered on first attempt is 80%; therefore, among the service users surveyed, we exceeded our target. 6% callers stated they did have difficulty getting through but their accompanying comments suggested the issues were with the fact they had to wait for a further call-back from a nurse or specialist advisor. Only one respondent said they were unable to actually get through first time.
- The current version of the survey does not ask caller the reason for their call; therefore we cannot carry out analysis at this level.

Integrated information and support service

- 14% of respondents heard about the helpline through their ISW. This is a slight drop on surveys from Oct 2012 (19%) and February 2012 (16%). This finding is unlikely to be an emerging pattern and not indicative of any genuine reduction in ISWs referring callers to the helpline. However, it will be important for the monitoring of future data.

Quality of service

- 68% of callers felt the helpline provided very adequate information to their needs. 25% felt it was quite adequate, with 3% feeling the information provided was inadequate.
- 100% of clients felt the helpline advisor was friendly and polite.
- Only one caller was unsure if they would recommend the service to other people.
- 96% rated the service as excellent or good overall, with 3% finding it just satisfactory and one caller (1%) finding the service poor.
- These results are similar to figures from the last survey (Oct 2012).

Conclusion

- The helpline service continues to be extremely well appreciated overall by callers.
- Most callers have no problem in accessing the service.
- 96% rated the service as excellent or good overall, with 3% finding it just satisfactory and one caller (1%) finding the service poor.
- 99% of callers would recommend the service to others.
- The helpline service reaches those from black, ethnic minorities and other white communities (non-British), and, for the first time, a proportion of respondents to the survey were from one of these communities (7%). All rated the service very highly.

- Some callers feel frustrated by having to wait for a call-back from a nurse, which can take up to two working days.
- The current survey can be reviewed and improved and a list of recommendations are being considered for future evaluations.

Our responses generally mirror the findings of the Age UK July 2012 '*Your call is valuable to us*' report, where older people placed most value on helpline services that had 'humanbeings' answering calls within five to six rings, with opening hours that match our own. The most valued aspect of a service was where advisors showed empathy and seemed to really listen to a caller and not rush them. Our feedback confirms our callers generally feel this way and value this as well. Ideally, they prefer advisors that can answer all the questions and issues, although are happy to be transferred to 'specialists' if required. The full Age UK report can be accessed here from the Age UK website (www.ageuk.org.uk)

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 advisors, 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 covers the survey conducted in May 2013, with some comparisons being made with previous surveys as indicated. The survey aims to gather service-user feedback about the helpline to ensure quality and, combined with the service's monitoring data, inform its further development. The information gathered is useful for the charity as a whole and can provide an excellent source of case studies.

Survey respondents

This year the surveys were sent to a total of 168 callers. We received a total of 72 completed surveys, the response rate being 40% by post and 75% via the web. The sample size was increased by 44%, compared with the October 2012 survey, due primarily to the fact that more surveys were sent out to callers.

A small number of surveys had missing data where some questions had not been answered and therefore, for the purpose of analysis, the missing data is excluded from the figures reported below.

Person living with Parkinson's

Table 1 shows that the majority (56%) of respondents were spouses, partners, other family and /or carers of people with Parkinson's, which highlights how well used the service is by this group.

Table 1: Type of respondents

I am:	Total	%
a person with Parkinson's	28	39%
a carer/friend/family member	40	56%
other condition	1	1%
suspects Parkinson's	1	1%
none of the above	2	3%
Totals	72	100%

People with Parkinson's made up 39% of respondents. However, this does not necessarily represent the usual breakdown of callers: for example, in 2012, 36% of callers were people with Parkinson's compared with 31% carer/family. We also had a response from someone who suspects they have Parkinson's and a person with dystonia.

Age

Table 2 shows the age group of those responding. The largest proportion was aged over 65 (54%), while 32% were between the ages of 45 and 64, and 9% were under the age of 44.

Table 2: Age group of respondents

Age group	Total	%
24 and under	1	1%
25-44	6	8%
45-64	23	32%
65-84	38	53%
>84	1	1%
totals	69	100%

(5% of respondents did not answer this question)

Time since diagnosis

Table 3 below shows how long callers with Parkinson's had been diagnosed for. In this survey, the majority (48%) of our sample had been diagnosed between 3-10 years.

Table 3: Time since diagnosis

Time since diagnosis	total	%
less than 2 years	10	34%
3-10 years	14	48%
11-20 years	5	17%
>20 years	0	0%
totals	29	100%

(Question only applies to pwp. 1% did not answer this question)

The helpline service is supporting people at varying stages of their Parkinson's journey and clients are likely to be experiencing a range of issues which require support. It's interesting that we did not capture any respondents who have lived with the condition for over 20 years, although these do make up the smallest proportion of person likely to be contacting us. This area may be worth considering in terms of helpline promotion – many people with Parkinson's will die before reaching 20 years of living with the condition. However where this is not the case, are they aware they can call us, are we reaching them? For example is Parkinson's UK and the helpline promoting itself sufficiently in care and residential settings?

Ethnicity

Table 4 shows that this question was not answered by 6% of the survey respondents. Of those responding, the majority (93%) defined themselves as white British and 3% as white other. 4% were from black and minority ethnic communities. Previous surveys have not been successful in capturing any responses from people not identifying as white British.

Table 4: Ethnicity of respondents

Age group	Total	%
Chinese	1	1%
mixed	2	3%
white other	2	3%
white British	63	93%
totals	68	100%

(6% of respondents did not answer this question)

It is positive that all non-white British respondents rated the service excellent (80%) or good (20%), and considered the information provided very adequate (80%) or quite adequate (20%) to their needs. 100% would recommend the service to other people.

Geographic area

Participants were asked to provide their postal code. 22% of respondents did not provide a post code. Table 5 shows that those in the southern regions of England (London, South, South East and West) outnumbered all other users, totalling 57% of respondents; the South West making up the highest number of respondents (23%), followed by London (16%). There were no respondents from the East Midlands or Northern Ireland.

Table 5: Where respondents are from

Breakdown of respondents by region			
Eastern England	14%	South of England	11%
East Midlands	0%	South East of England	7%
London	16%	South West of England	23%
North East of England	2%	Wales	4%
North West of England	4%	West Midlands	14%
Northern Ireland	0%	Yorkshire and Humber	2%
Scotland	4%		

(22% did not answer this question.)

This breakdown of respondents is not generally reflective of callers by region; for example based on year-to-date usage figures, although it does mirror the low usage in Northern Ireland and the North East, southern England areas make up a total of 30% of total helpline users, which is significantly lower than the 57% figure here.

Membership

Respondents were not asked about their membership status. Likewise, we did not enquire if they had called us before or if they had used any other support service provided by the charity.

Contacting the helpline

How did you find out about the helpline?

Table 6 shows how those responding found out about the helpline service. By far, most people heard about the service through the website or through a health professional (25% for both sources).

Table 6: How respondents found out about the service

How respondents found out about the helpline	Total	May 2013 %	2012 %
healthcare professional	18	25%	14%
friends/relatives	10	14%	13%
ISW	10	14%	18%
Parkinson's UK website	18	25%	34%
media	3	4%	3%
other (including <i>The Parkinson</i> , literature and branch meetings)	12	17%	18%
totals	71	100%	100%

Where respondents indicated they heard about us through their healthcare professional, we have no way of knowing if it was the actual helpline that was recommended to them or the charity as a whole. It is likely to have been the latter. Likewise, there is no breakdown of the *type* of healthcare professional who told the respondent about the helpline or the charity. Compared with the 2012 surveys, a significant increase (11%) is noted in the number of people finding out about the helpline through a healthcare professional.

Further breakdown of the above categories, especially 'professionals' and 'other', in future surveys would allow us to monitor those who, for example, hear about the helpline through posters left on hospital notice boards, and those who find out about us after attending a branch meeting.

As an organisation, and as a helpline service, we are aware that we do not reach everyone affected by Parkinson's. Yet further important work is being carried out in this area and we should notice the results of this in the near future. The following comment is positive, but at the same time says something about the work that is still to be done in terms of reaching people:

“This is a brilliant service, I'm really pleased with the level of detail you gave me. And all the links were for services local to my mum which would have taken me ages to track down. If I had known about this service sooner I would have used it more. My mum has had Parkinson's for 8 years and I've only just discovered this wonderful service.” – respondent 2.

Reasons for contacting the helpline service?

The current survey does not ask respondents why they called the helpline and this should be reviewed for future surveys to allow analysis of satisfaction rates at this level. From the comments made, it is clear that speaking to a nurse is common reason for calling and a valued part of the service. This mirrors general helpline usage.

Within the comments, it is clear that many callers are seeking, or at least feel they receive, reassurance of some kind, for example:

“This lady was very kind and answered all my questions, putting my mind at rest.” – respondent 36.

“She lived up to her description of 'helpline worker', listening carefully to what I said and made comments. She was very sympathetic.” – respondent 52.

“Good to know it is confidential - can speak freely knowing details won't be shared with own medical support people. Allows for me to ask all questions which concern me.” – respondent 60.

Problems getting through

As shown in the table 7 below, 94% of callers responding said they had ‘no problems’ contacting the helpline and getting through. 6% said they did.

Table 7: Problems contacting the helpline

Experiencing problems getting through to the helpline	May 2013 %	2012 %
no problems	94%	97%
experienced problems	6%	3%
totals	100%	100%

We can notice a slight drop in the number of people getting through first time compared with 2012. The helpline’s KPI for calls answered on first attempt is 80%; therefore, among the callers surveyed, we exceeded our target. 6% of callers stated they did have difficulty getting through but their accompanying comments suggested the issues were with the fact they had to wait for a further call-back from a nurse or specialist advisor. Only one respondent said they were unable to actually get through first time.

Comments included:

“Recorded message, no one was available.” – respondent 68.

“Left message and call was returned the next day. Extremely helpful nurse.” – respondent 42.

“I rung up on the Friday and didn’t get a call back until the following Wednesday” – respondent 4.

“I had to wait 2 days for someone to call me back.” – respondent 5.

A theme that emerges in some of the comments is the desire that calls should either be answered by a nurse, or at least be transferred to a nurse immediately.

“Have a nurse available when you call. I have phoned a few times before and I always have had to wait 2-3 days for a nurse to call me back, and don’t have people with no experience or knowledge of Parkinson's answering the phone.”
– respondent 5.

Clearly all advisors have experience of Parkinson’s, however, they are unable to answer medical questions and, for this caller, this does not seem reasonable. It is unlikely that it would be easy for the current helpline service to satisfy this particular caller’s needs.

Accessing information through other means

The helpline surveys currently cover phone calls received only – in the future, surveys for users on the email service could be considered.

Integrated information and support

The helpline service is part of Parkinson's UK’s wider information and support service, which includes the ISW service, telephone peer support service, local groups and branches as well as the website and the online discussion forum. The current survey does not ask respondents what other Parkinson’s UK information services they have used. This makes it difficult in most cases to ascertain how aware the respondents are of other sources of support and/or if they use them. This could be considered for future surveys and the question does feature in the ISW surveys.

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 supportive qualities

These important soft skills, whilst not necessarily essential to hard fact giving, normally allow users of a service such as a helpline to feel at ease to talk, and to perhaps open up more than they otherwise would. It is also important that callers feel supported in their call. Many experience ‘professional’ services, such as consultants, GPs, etc, as distanced and generally rushed.

Table 8 below shows that respondents (96%) found the advisor/nurse they spoke to ‘very friendly and supportive, with 4% rating them as ‘quite friendly and supportive’.

Table 8: Friendly and supportive

Was the helpline worker you spoke to friendly and supportive?		
	May 2013	2012
very	96%	93%
quite	4%	5%
average	0%	2%
not particularly	0%	0%
not at all	0%	0%

Comments include:

“She came across as being kind and caring”. - respondent 35

“She was helpful, considerate and kind.” – respondent 39

“She lived up to her description of ‘helpline worker’, listening carefully to what I said and made comments. She was very sympathetic.” – respondent 52

Clearly, the helpline advisors’ approach and tone is one that invites and encourages conversation, whilst showing support and care for the caller. There were no negative comments in this area.

Adequacy of information and advice

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

Table 9 shows 68% of those responding thought the information and advice provided was ‘very adequate’ to their needs, with 25% feeling it was ‘quite adequate’.

Table 9: Adequacy of information and advice provided

Did the helpline provide information and advice adequate to your needs?		
	May 2013	2012
very adequate	68%	74%
quite adequate	25%	20%
average	4%	4%
not particularly	3%	2%
not at all	0%	0%

(4% of callers did not answer this question)

Yet for 4% of respondents, the adequacy of information was just average.

Comments include:

“The nurse was very kind, comforting and helpful but couldn’t provide me with the answers I was looking for - but not her fault, I don’t think there is enough research available to answer my questions.” – respondent 5.

Because we do not ask what the nature of the query was or why the caller rang, it is impossible to know if there is anything the nurses could do to improve the information they provide about the caller’s question. . Based on the overall feedback about the nurses (and helpline advisors), it is safe to assume that the caller is right, and that perhaps the information is simply not ‘out there’. With more details we could perhaps consider if there is anything more that can be done in terms of managing callers’ expectations and also the possible frustration that underlies them.

Likewise, this respondent says:

“Not able to help as it is a health matter which nobody seems to know the answer. The nurse talked us through the problem and although she had limited experience of the problem she made some useful contacts.” – respondent 30.

Here we were provided with the caller details and uncovered that the issue was a fairly common one, but the nurse told the caller it was a notoriously hard one to treat. The nurse did advise the caller to speak to their PDNS in order to possibly change one of the drugs their husband takes, as this may ease the symptom. Again, the issue here is likely to be more about an underlying frustration, and understandable disappointment, that perhaps no one can fully resolve this issue.

One respondent (52), who rated the information provided as 'quite adequate', nonetheless said:

"Would it be possible to train helpline workers with greater knowledge of drugs? It seems finding the right drugs/dosage is very important."- respondent 52.

Similarly, another respondent, who rated the information provided as 'not particularly adequate', says:

"Parkinson's nurse been off ill at least 6-7 weeks, no replacement. Husband needed tablets reviewing can't do that over the phone. Doctor very helpful afterwards, seeing neurologist shortly. As helpful as talking over the phone but can't do anything practical." – respondent 62

Evidently, the callers here were unable to understand, accept, or were not clearly told, that helpline nurses can only provide guidance around medication, and that they are not in a position to make actual changes to medication. This highlights an area of frustration for people with Parkinson's and their families/cares: at times (and sadly for some users often or always), local practical medical support is unavailable. The helpline service unfortunately will never be in a position to replace the local medical services in full.

Besides these callers, by far the majority, rated the information provided as 'very adequate' or 'quite adequate' to their needs (89%). Comments include:

“The nurse to whom I spoke was very professional, clear in the information she provided and responsive to the special details of my query, not simply providing 'off the peg' responses. It was a very positive experience in every respect and a great reassurance for me in supporting my mother.” – respondent 10

“Could not have been better for what I required. Very helpful and sent factsheets by return post.” – respondent 34.

“This is a brilliant service, I'm really pleased with the level of detail you gave me.” – respondent 2

“Very good service. Provided information and seamless advice.” – respondent 8.

Recommending the service to others

A sign of a service being valued and considered useful is users recommending it to others. Table 10 below shows that, when asked if they would recommend the service, responses were very positive.

Table 10: Recommending the service

Would you recommend the service?			
	Yes	Not sure	No
May 2013	99%	1%	0%
2012	100%	0%	0%

The results from this survey (May 2013) are in line with those from 2012, where all users say they would recommend the service. Of interest is the one respondent who states they are unsure that they would recommend the service. It is unclear why this is as they rate the service highly in all other areas and give it an overall rating of 'good'. It is likely that they ticked the 'not sure' box by mistake.

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 have in mind. Table 11 shows that the service generally meets people's expectations and the vast majority of respondents are very positive about it overall.

Table 11: Rating the service overall

Overall did you find the service to be...					
	Excellent	Good	Satisfactory	Poor	Very poor
May 2013	67%	29%	3%	1%	0%
2012	74%	24%	1%	0%	0%

There was a slight lowering of ratings in comparison to surveys from 2012, where more people rated the service as 'excellent' and less as 'satisfactory' or 'poor'. However at this stage, there does not seem to be a shift that is indicative of a deterioration in the quality of the service. Yet, of course, it will be important to compare these results again once in the next survey.

The caller who rated the service as 'poor' in the 2013 survey, and who has been quoted here previously (respondent 62), felt that as the service could not offer anything practical, it was not useful. They were looking for changes to their spouse's medication and had nobody locally available to do this.

"Parkinson's nurse been off ill at least 6-7 weeks, no replacement. [...] needed tablets reviewing can't do that over the phone. Doctor very helpful afterwards, seeing neurologist shortly. As helpful as talking over the phone but can't do anything practical. See that Parkinson nurses have another person who can help not just talking when they are off ill for any length of time." – respondent 62.

Clearly this is a comment on NHS service provision, namely the availability of a PDNS, rather than a direct rating about the helpline service.

One of the respondents, who rated the service overall as 'satisfactory', says:

"I rung up on the Friday and didn't get a call back until the following Wednesday." – respondent 4.

However, this caller has rated the service highly in all other areas. It is unclear why they did not get a call back before Wednesday. Normally, calls are returned on the same day or within 24 hours, 48 hours at most. We have no way in this particular evaluation form to identify the respondent and follow this up to find out what occurred. It is possible it was due to it being a bank holiday weekend, staff sickness or other absence, but we can only speculate.

Listening ear

Although there is no question that directly asks about the quality of 'listening ear' calls, where the caller seeks reassurance or wishes to discuss issues such as depression, various comments were made that demonstrate helpline advisors' ability to show sensitivity and support callers during these types of calls:

"He was very patient as I was a bit emotional. He also made helpful and positive suggestions/advice on my relationship with my sister who was recently diagnosed. (...) it was very reassuring and helped me get things into a better perspective." – respondent 9.

"Put my mind at ease, very helpful. When I first rang I was at my worst. They explained that sometimes depression can be caused by Parkinson's and they sent me in the right way. Thank you." – respondent 14.

Other positive comments about the service

"Good to be able to speak to someone on a weekend." – respondent 41.

"Very helpful; asked enough questions to properly understand my problem and yet was not at all intrusive. It was a joy for the phone to be answered by a

real, live, person who immediately knew who best to transfer the call to. Both individuals were helpful and spoke in a calm manner that seemed genuinely friendly and helpful, with no hint of either the patronising tone that is often extended to someone who needs help, or of 'reading from a script' that is associated with call centres. Wonderful! Keep doing what you are doing.” – respondent 24.

“Very understanding and helpful and put me through to the correct specialist. Very good service. provided information and seamless advice.” – respondent 8.

“The lady I spoke to was a pleasure to talk to. She understood my problems, offered advice - which I have followed and I now feel much better about. I found the drugs booklet particularly helpful.” – respondent 21.

“Could not have been better for what I required. Very helpful and sent factsheets by return post.” – respondent 34.

Suggestions for improvements made by respondents

The main suggestion for improvement emerging from comments was to ensure that callers could speak to a nurse immediately when they called so they did not have to wait a few days for a call-back.

“Have a nurse available when you call. I have phoned a few times before and I always have had to wait 2-3 days for a nurse to call me back” – respondent 5.

“My only disappointment was the response time. I first rang Thursday afternoon and was called back Friday evening. However, I was told it would be at least a day before I'd be called back. I presume this is because of shortage of PD nurses.” – respondent 13.

“I rung up on the Friday and didn’t get a call back until the following Wednesday.” – respondent 4

However, most comments, where speaking to a nurse is mentioned, would indicate that people feel they speak to a nurse in a timely way and that the process is smooth and satisfactory.

“Left message and call was returned the next day. Extremely helpful nurse.” – respondent 42.

Conclusion

The results of the May 2013 helpline service user survey are again extremely positive, and clearly show the value that clients place on the service. 96% of survey respondents rated the service as ‘excellent’ or ‘good’ and 99% would recommend the helpline to others.

Also:

- Most callers have no problem in accessing the service.
- The helpline service reaches those from black and ethnic minorities and white non-British communities and, for the first time, a proportion of respondents to the survey were from one of these communities (7%). All rated the service very highly.

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

- Speaking to an advisor, or nurse, who is patient, friendly and supportive, and able to offer reassurance.
- The 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.

- 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.
- The ability to call on a Saturday.

The survey also highlighted that some callers find it frustrating that they are not able to speak to a nurse immediately and often will have to wait for a call-back within 24 to 48 hours. It is important to note that a large proportion of callers *do* hear back from a nurse on the same day or within 12 hours.

In some of the comments, it is clear that dissatisfaction is in fact with NHS services, such as the PDNS not being available.

Our responses generally mirror the findings of the Age UK July 2012 'Your call is valuable to us' report, where older people placed most value on helpline services that had 'human-beings' answering calls and within five to six rings, with opening hours that match our own. The most valued aspect of a service was advisors showing empathy and really listenening to a caller without rushing them. Our feedback confirms our callers generally feel this way and value this as well. Ideally, they prefer advisors that can answer all the questions and issues, although are happy to be transferred to 'specialists' if required. The full Age UK report can be accessed here from the Age UK website (www.ageuk.org.uk)