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

Parkinson’s local advisers evaluation report

November 2015

> “Our adviser helped us every step of the way. She’s the first person we turn to and she’s always at the end of the phone. She always goes the extra mile.”
>
> **November 2015 survey respondent**

Contents

1. Background

Parkinson's UK's local adviser service provides confidential one-to-one information and support to people affected by Parkinson's including family, friends and professionals.

Our trained local advisers can give tailored information and advice on all aspects of living with Parkinson's – such as symptoms, employment and benefits, health and social care, and emotional support.

Advisers can provide face-to-face information and support – at home or in the community – or by phone, email and/or letter.

Our local adviser service is part of the wider organisation's information and support offer and can be accessed anywhere in the UK.

This report presents results and feedback collected through the user survey conducted in November 2015.

The survey aims to gather user feedback about the local adviser service to ensure quality and, combined with the service's other monitoring mechanisms, to inform its development.

The survey was sent to more than 730 clients across the UK.

A total of 313 surveys were received back, which is a response rate of around 43%. Although the sample size is smaller than last year, mainly because of a change in how we distributed the survey, the response rate has stayed consistently high.

2. Who responded to the survey?

- The majority of responses (78%) were from people with Parkinson's, while 19% were from either a carer, partner or family member of someone with Parkinson's.
- 3% came from others, which included professionals working with a person with Parkinson's and carers who also have Parkinson's themselves.

What is your connection to Parkinson's?	Response percent	Response total
I have Parkinson's	78.32%	224
I am a carer, partner or family member of a person with Parkinson's	18.53%	53
Other – please specify	3.15%	9

- 69% of respondents were over 65 years of age, with 37% being over 75.

How old are you?	Response percent	Response total
Under 35	0%	0
35-44	1.1%	3
45-54	8.8%	25
55-64	21.4%	61
65-74	32.3%	92
75 and over	36.5%	104

- Slightly more men than women responded.

What is your gender?	Response percent	Response total
Female	45.96%	131
Male	54.04%	154
Other	0%	0
Prefer not to say	0%	0

- The ethnicity of respondents was mainly White British with 4% from ethnic groups, which is nearly double compared to last year.

What is your ethnicity?	Response percent	Response total
White – English, Welsh, Scottish, Northern Irish or British	93.66%	266
White – Irish	0.70%	2
White – Gypsy or Irish Traveller	0%	0
Any other White background – please specify	1.41%	4
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	1.06%	3
Asian or Asian British – Pakistani	1.06%	3
Asian or Asian British – Bangladeshi	0%	0
Asian or Asian British – Chinese	0%	0
Any other Asian background – please specify	1.06%	3
Black or Black British – African	0%	0
Black or Black British – Caribbean	0.35%	1
Any other Black, African or Caribbean background – please specify	0.35%	1
Other – Arab	0.35%	1
Any other ethnic group – please specify	0%	0

3. How did clients hear about the local adviser service?

- The majority of people (44%) heard about the local adviser service through a Parkinson's nurse or clinic.
- Other respondents heard about the helpline through a variety of other channels, including a Parkinson's UK branch or group (20%).

How did you hear about the Parkinson's local adviser service?	Response percent	Response total
Parkinson's UK website	5.65%	17
Parkinson's local helpline	1.99%	6
Parkinson's UK information event	2.33%	7
Parkinson's UK branch or group	19.60%	59
Parkinson's UK publications – please specify	2.66%	8
Friends or relatives	5.98%	18
Parkinson's nurse or clinic	44.19%	133
Consultant	8.31%	25
GP	2.33%	7
Other health care professional – please specify	1.33%	4
Social services	1.00%	3
Other voluntary organisation – please specify	0.33%	1
Other – please specify	4.32%	13

As in previous years, this shows the importance of Parkinson's nurses and branches as key stakeholders of the service.

4. Have clients contacted the local adviser service before?

- The majority of respondents had their first contact with the service between one and three months prior to completing the survey. This was followed by clients who contacted the service more than a year ago. Those whose first contact was more than a year ago may not have received a continuous service for that length of time. It is more likely that they are clients who, after having received a service before, have returned to their local adviser for further information and support.
- The majority of respondents (65%) had between two and five contacts with their local adviser. 13% had only had one contact with the local adviser, and 10% had contact with their local adviser more than 10 times.

When did you first have contact with your Parkinson's local adviser?	Response percent	Response total
In the last week	3.3%	10
Within the last month	12.3%	37
Less than 3 months ago	35.1%	106
Less than 1 year ago	20.2%	61
More than 1 year ago	29.1%	88

How many times have you had contact with your Parkinson's local adviser?	Response percent	Response total
Once	13.2%	40
2-5 times	64.6%	195
6-10 times	12.3%	37
More than 10 times	9.9%	30

5. Getting through to the service

As in previous years, a very large number of clients who responded to our survey (95%), said they had no problems getting through to the service. The main comments of those with few or many problems relate to not being able to get hold of their local adviser when needed. This will be mainly due to their local advisers working part-time, as well as local advisers often working away from the office in clients' homes.

The results highlight the importance of publicising the local adviser service as being part of an integrated information and support service, so that people affected by Parkinson's are aware of the various routes to information and support, including the helpline.

Did you have any problems making contact with your Parkinson's local adviser?	Response percent	Response total
No problems	94.74%	288
Few problems	4.93%	15
Lots of problems	0.33%	1

In what ways have you had contact with your Parkinson's local adviser? Please select all that apply.	Response percent	Response total
Telephone	81.31%	248
Email	34.75%	106
Letter	13.11%	40
Face-to-face	73.11%	223

In addition, 80% of respondents reported that they required a home visit. Of these, 87% received their home visit within two weeks, or 10 working days, as is our customer service pledge. 99% of respondents reported that they received a home visit within the timescale they needed.

6. Customer service and user satisfaction

- 97% of respondents felt the local adviser was very friendly and polite.

Was the adviser friendly and polite?	Response percent	Response total
Very	97.3%	290
Quite	2.0%	6
Average	0%	0
Not particularly	0.3%	1
Not at all	0.3%	1

Comments included:

“She really set me at ease. Was punctual and efficient. Rang me before she came around.”

“I found my local adviser to be extremely helpful and friendly. Access to information and sources was first class.”

“Down to earth, helpful and spoke to me in simple, understandable language without jargon.”

“Extremely professional and empathic without being patronising.”

“She is very warm, well-informed and gives encouraging, helpful responses. She also guides me to new info, but delicately, not thrusting things upon me.”

“His help and information instilled confidence and reassurance when they were needed most.”

- 99% felt they were treated fairly by their adviser.

Did you feel you were treated fairly?	Response percent	Response total
Yes	99.33%	296
Not sure	0.67%	2
No	0%	0

- 97.5% would recommend the service to others affected by Parkinson’s.

Would you recommend the service to other people affected by Parkinson’s?	Response percent	Response total
Yes	97.5%	274
Not sure	2.5%	7
No	0%	0

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

7. Reason for contact

Clients often have multiple reasons for contacting us.

- For 83% of respondents this included benefit advice and other financial issues.
- This was followed by emotional support or needing someone to talk to, being newly diagnosed, and looking for signposting including to local groups. Comments also suggest that information after being newly diagnosed was important to a significant number of respondents.

What sort of information or support did you contact us for? Please select all that apply.	Response percent	Response total
Medical advice	20.40%	61
Signposting or whom to contact	27.42%	82
Social care advice (eg nursing home, local authority home adjustments)	19.06%	57
Benefits advice and other financial issues	82.61%	247
Employment advice	6.02%	18
Emotional support or someone to talk to	28.76%	86
Creative or therapeutic activities (eg yoga, singing, tai chi)	10.70%	32
Newly diagnosed	27.76%	83
Respite care information	2.34%	7
Access to health services	13.71%	41
Carers' issues	18.39%	55
Housing issues	5.69%	17
Contact with local groups	29.43%	88
Daily living aids and equipment	26.76%	80
Holidays and travelling	3.01%	9
Other	9.03%	27

- 98% found the information they received either very easy or easy to understand.

How easy to understand was the information you received?	Response percent	Response total
Very easy	63.7%	184
Easy	34.6%	100
Not sure or can't say	1.7%	5
Quite difficult	0%	0
Very difficult	0%	0

- 96% said they completely or mostly received the information and advice they needed.

Did you get the information and advice you needed?	Response percent	Response total
Yes, completely	84.9%	253
Yes, mostly	11.4%	34
Not sure	2.0%	6
In part only	1.0%	3
Not at all	0%	0
Not yet – adviser is still supporting me	0.7%	2

Comments included:

"My local adviser has been a lifeline in terms of helping me get access to benefits, and helping me deal with my illness. She has been the only person outside the NHS to provide me with any help or support, and I do not know what I would have done without her."

"We were absolutely devastated when my husband was first diagnosed and our adviser helped us every step of the way. She's the first person we turn to and she's always at the end of the phone. She always goes the extra mile."

"We were shell shocked at the diagnosis. The adviser came to see us and talked us through the dos and don'ts. Very helpful and caring."

8. What aspects of living with Parkinson's did the local adviser service help with?

The survey asked people to give more detail about the areas where they felt their local adviser 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.

- Of the respondents who answered this question, 81% felt the service helped, helped a bit, or helped a lot in terms of improving their emotional wellbeing. Although a number of people did not answer this question, a total of 52% of all respondents who completed the survey felt this way. It is interesting to note that only 29% of respondents indicated they specifically contacted us for emotional support or someone to talk to. This indicates that although people may not contact us for emotional support, they often feel emotionally supported as a result of being a beneficiary of our service.

Improving emotional wellbeing	Response percent	Response total
Helped a lot	39.0%	87
Helped	30%	67
Helped a bit	11.7%	26
Didn't help	1.3%	3
N/A	17.9%	40

Improving understanding and management of Parkinson’s (treatments, symptoms etc.)	Response percent	Response total
Helped a lot	37.1%	83
Helped	33.9%	76
Helped a bit	10.3%	23
Didn’t help	2.2%	3
N/A	16.5%	40

Better understanding of benefit entitlement	Response percent	Response total
Helped a lot	71.7%	185
Helped	17.4%	45
Helped a bit	1.9%	5
Didn’t help	0.8%	2
N/A	8.1%	21

Better understanding of employment rights	Response percent	Response total
Helped a lot	13.7%	24
Helped	10.9%	19
Helped a bit	1.7%	3
Didn’t help	2.3%	4
N/A	71.4%	125

Better understanding of social care	Response percent	Response total
Helped a lot	22.3%	43
Helped	24.9%	48
Helped a bit	7.8%	15
Didn’t help	3.1%	6
N/A	42.0%	81

Information about further sources of support (nurses, support groups etc.)	Response percent	Response total
Helped a lot	47.0%	111
Helped	33.1%	78
Helped a bit	7.2%	17
Didn’t help	3.0%	7
N/A	9.7%	23

9. Impact of information

- 61% reported that the information and support helped them better manage their Parkinson's day-to-day.

Has the information and support helped you better manage your Parkinson's day-to-day?	Response percent	Response total
Yes	61.35%	173
Not sure	19.86%	56
Not applicable to me	19.15%	54

Comments included:

"Reduces my stress levels by being able to access services and by getting more aids or equipment to help with my daily living activities."

"The feeling that there is a network of support with the capacity to help deal with problems."

"Financial benefit allows us to get the occasional taxi and anything else needed to improve day-to-day living."

"I realise the importance of taking the medication at the proper time and the importance of regular exercise."

"It enabled me to cope with the shock of the diagnosis in the first place and then to get things into a bit of perspective by linking with the local scene and thus learning better how to help myself and how to be positive about the future."

"The information has reduced my stress around being unable to work and managing home finances. He helped me to get some small adaptations to my home to help me to manage better."

"Knowing there is someone to call on helps to remove some of the stress or anxiety that can come from living with Parkinson's."

However, some people who had only been in contact once were still waiting for the impact of the support.

Comments included:

"Not sure as it's early days."

"Still in the process of following up some of the options."

- 90% reported that the information and support helped them either a lot or a little to make choices that improved their lives in some way.

Did the information or support provided help you make any choices that improved your life in some way?	Response percent	Response total
It helped a lot	76.1%	216
It helped a little	13.7%	39
No change or can't say	9.9%	28
It didn't help	0.4%	1
It made things worse	0%	0

Comments included:

"Made me aware of sessions available, range of appropriate aids and equipment available, and the best ways of accessing these."

"I was put in touch with a number of healthcare professionals and as a result (as a carer) I was able, with the help of carers, to continue with some of my interests."

"Asking for professional help and communication with my family, starting counselling."

"Unravelled some of the mysteries of rights and entitlements, which help when applying for assisted living."

"Advice helped to gain access to services such as speech therapy and physiotherapy."

"The information helped a great deal. My husband was nervous and unsure what to expect and what to do. His symptoms were confusing and he didn't know how to cope with them. We read the brochures together and began to understand the disease and what to do. They also helped me to care for him better and to try and understand what he was feeling and how to treat him."

"On getting my blue badge, I now can get back my independence when driving as I know I can get parked conveniently in town."

Again, some people who had only been in contact once were still waiting for the impact of the support.

Comments included:

"Can't say yet, still waiting for a reply from the local authority."

"Still awaiting full outcome."

"Still awaiting a response for one issue."

- 87% reported that the information and/or support received made them feel either much more or somewhat more positive about their current situation.

Did the information and/or support you received make you feel more positive about your current situation?	Response percent	Response total
Yes, it made me feel much more positive	51.75%	148
Yes, it made me feel somewhat more positive	34.97%	100
No change or can't say	12.59%	36
It made me feel somewhat worse	0.70%	2
It made me feel a lot worse	0%	0

Comments included:

"It enabled me to begin to be more realistic and come to terms with my situation."

"I felt more positive because I wasn't dealing with it alone."

"Made me feel less anxious. She put me in touch with the local benefits adviser who gave me some very good advice and guidance."

"She has helped me look at alternative ways of handling some situations and focus on turning negative into positive where possible."

"She brought me out of my feeling of isolation and showed me that I was not alone, that there were people who cared and were willing to help me."

"It gave me perspective and guided me towards making positive choices to help myself."

"The generous amount of help and support offered by my Parkinson's UK local adviser has made a huge difference to my becoming personally involved with the local Parkinson's community and with Parkinson's UK research. I am certain that this support has had a positive influence upon my overall health and the self-management of my condition."

10. Recommendations for service improvement

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

Comments included:

"The help and advice we have received from our Parkinson's local adviser has been invaluable, especially in these early stages of diagnosis."

"I am very happy with the service provided and I would not wish to change it."

"You just need more of them!"

Other feedback highlighted areas that could be addressed, including finding out about the service at the time of diagnosis.

"My wife was diagnosed five years ago but I only heard about this service this year."

"It would be helpful if the Parkinson's nurse had a leaflet with contact details for the local adviser and if the local adviser had the same leaflet."

"I was diagnosed with Parkinson's in 2008 and it took seven years before I became aware of the local adviser service. It would have been good to have known of the advisers' existence when first diagnosed."

"It would help if new people were told about the service – we waited seven years."

"Make sure consultant or GP give out the contact number."

This confirms the importance for people affected by Parkinson's of finding out at point of diagnosis about the support and information that is available to them. We recognise that there is room for improvement in this area and we are continually working to invest in relationships with local health and social care providers. Additionally, work around improving the experience of diagnosis and the information people have access to at that point is being taken forward by the UK Parkinson's Excellence Network and the Personalised Relationships project.

We also received the following comment about contacting local advisers:

"It is so important to be able to contact the local adviser when needed and ours always gets back as soon as she can. However the service is only part-time."

This highlights the need to manage the clients' expectations and communicate clearly with clients about how the local adviser service works, signposting them to the most appropriate service.

For example if a client is looking for immediate information and support it might be more helpful for them to contact the helpline, especially if they did not get through to the local adviser in the first instance. Local advisers provide clients with the helpline phone number and how to access it in their email and phone out of office messages, but we can review if we could make these clearer.

11. Conclusion

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

- 97% felt the adviser was very friendly and polite.
- 97.5% would recommend the service to others affected by Parkinson's.
- 90% of respondents said that the information or support provided helped them a lot or a little to make choices that improved their life in some way.

- Clients generally have no problem in accessing the service.

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

- Having access to an approachable, friendly and polite local adviser who understands Parkinson’s.
- Having access to local advisers who can provide reassurance, know what help and support is available, and can help clients to access this.
- Local advisers being able to provide practical and emotional support helping people affected by Parkinson's to make choices to improve their lives and feel more positive about their current situation.

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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