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

Parkinson's local advisers evaluation report

November 2016

“The information given has made a total difference to how we now live. It is difficult to think straight when faced with being diagnosed and we were under a lot of stress. The local advisers were so knowledgeable it filled me with confidence for the future.”

“I don't feel that I am on my own and I don't feel that any question I ask is silly or stupid. I know that I am an individual and that Parkinson's is unique in the way it affects our lives, but with consideration and adaptation I can live as independently as possible.”

2016 survey respondents

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.

The local adviser service forms part of the organisation's wider information and support services and can be accessed anywhere in the UK.

This report presents results and feedback collected through the user survey conducted in autumn 2016. The survey aimed to gather user feedback about the local adviser service to ensure quality and, combined with the service's other monitoring mechanisms, to inform its further development.

The survey was sent to 868 clients across the UK by post and email. A total of 285 surveys were received back, which is a response rate of 33%. Although still a good response rate, this is lower than in previous years, mainly due to some distribution issues early on in sending the surveys out.

2. Who responded to the survey?

We received responses mainly from people with Parkinson's, carers and family members.

- 80% of responses were from individuals with Parkinson's and 18% were from either a carer, partner or family member of someone with Parkinson's.
- A further 2% came from others – which included individuals whose diagnosis changed from Parkinson's to Multiple System Atrophy (MSA).

What is your connection to Parkinson's?

	2016		2015
	Response percent	Response total	Response percent
I have Parkinson's	80.0%	212	78.3%
I am a carer, partner or family member of a person with Parkinson's	18.1%	48	18.5%
Other - please specify:	1.9%	5	3.2%

72% of respondents were over 65 years, with 35% being over 75.

How old are you?			
	2016		2015
	Response percent	Response total	Response percent
Under 35	0.0%	0	0.0%
35-44	1.1%	3	1.1%
45-54	8.7%	23	8.8%
55-64	18.2%	48	21.4%
65-74	36.7%	97	32.3%
75 and over	35.2%	93	36.5%

Slightly more men than women responded.

What is your gender?			
	2016		2015
	Response percent	Response total	Response percent
Female	46.4%	123	46.0%
Male	53.6%	142	54.0%
Other	0.0%	0	0.0%
Prefer not to say	0.0%	0	0.0%

The ethnicity of respondents was mainly White British with 3.9% from ethnic groups, which is consistent with the previous year.

What is your ethnicity?			
	2016		2015
	Response percent	Response total	Response percent
White – English, Welsh, Scottish, Northern Irish or British	92.6%	239	93.7%
White – Irish	1.9%	5	0.7%
White – Gypsy or Irish Traveller	0.4%	1	0.0%
Any other White background – please specify	1.2%	3	1.4%
Mixed or multiple ethnic groups – White and Black Caribbean	0.4%	1	0.0%
Mixed or multiple ethnic groups – White and Black African	0.00%	0	0.0%
Mixed or multiple ethnic groups – White and Asian	0.00%	0	0.0%
Any other Mixed or multiple ethnic background – please specify	0.00%	0	0.0%
Asian or Asian British – Indian	0.8%	2	1.1%
Asian or Asian British – Pakistani	0.4%	1	1.1%
Asian or Asian British – Bangladeshi	0.00%	0	0.0%
Asian or Asian British – Chinese	0.4%	1	0.0%
Any other Asian background – please specify	0.8%	2	1.1%
Black or Black British – African	0.4%	1	0.0%
Black or Black British – Caribbean	0.8%	2	0.3%
Any other Black, African or Caribbean background – please specify	0.0%	0	0.3%
Other – Arab	0.0%	0	0.3%
Any other ethnic group – please specify	0.0%	0	0.0%

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

- Many respondents (37%) heard about the local adviser service through a Parkinson's nurse or clinic.
- Other respondents heard about the service through a variety of other channels, including a Parkinson's UK branch or group (19%).

How did you hear about the Parkinson's local adviser service?			
	2016		2015
	Response percent	Response total	Response percent
Parkinson's UK website	46.4%	123	46.0%
Parkinson's UK helpline	53.6%	142	54.0%
Parkinson's UK information event	0.0%	0	0.0%
Parkinson's UK branch or group	18.9%	48	19.6%
Parkinson's UK publications – please specify below	2.4%	6	2.7%
Friends/relatives	5.1%	13	5.9%
Parkinson's nurse or clinic	36.6%	93	44.2%
Consultant	5.9%	15	8.3%
GP	4.3%	11	2.3%
Other healthcare professional – please specify below	3.5%	9	1.3%
Social Services	0.4%	1	1.0%
Other voluntary organisation – please specify below	0.8%	2	0.3%
Other – please specify below	3.9%	10	4.3%

As in previous years the results show the importance of Parkinson's nurses and branches as key stakeholders of the service. The number of respondents who found us via their Parkinson's nurse and consultant has dropped slightly compared to last year. However, four respondents added nurse and consultant as an additional source in the comment box.

There has been an increase in respondents finding our service through our website and through the helpline, as well as other healthcare professionals like physiotherapists and speech therapists.

4. Have clients contacted the local adviser service before?

- The largest group of respondents had their first contact with the service more than a year ago (34%). This was followed closely by clients who contacted the service between one and three months ago (29%).
- Those whose first contact was over 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.

When did you first have contact with your Parkinson's local adviser?

	2016		2015
	Response percent	Response total	Response percent
In the last week	2.6%	7	3.3%
Within the last month	7.1%	19	12.3%
Less than 3 months ago	28.7%	77	35.1%
Less than 1 year ago	27.2%	73	20.2%
More than 1 year ago	34.3%	92	29.1%

The majority of respondents had between two and five contacts with their local adviser (56%). 13% had only had one contact with the local adviser and 14% had contact more than 10 times.

How many times have you had contact with your Parkinson's local adviser?

	2016		2015
	Response percent	Response total	Response percent
Once	13.1%	35	13.2%
2-5 times	56.0%	150	64.6%
6-10 times	16.8%	45	12.3%
More than 10 times	14.2%	38	9.9%

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 problems (5%) relate to not being able to get hold of their local adviser as quickly as expected. This will be mainly due to their local advisers working part-time as well as the job entailing local advisers working away from the office in clients' homes for a significant part of their working week.

The results highlight the importance of managing clients' expectations and 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 all the routes to information and support, including our helpline.

Did you have any problems making contact with your Parkinson's local adviser?

	2016		2015
	Response percent	Response total	Response percent
No problems	94.8%	255	94.7%
Few problems	5.2%	14	4.9%
Lots of problems	0.0%	0	0.3%

84% of respondents had face-to-face contact with their local adviser, and 83% had telephone contact.

In what ways have you had contact with your Parkinson's local adviser? Please select all that apply.

	2016		2015
	Response percent	Response total	Response percent
Telephone	82.8%	222	81.3%
Email	29.5%	79	34.7%
Letter	14.9%	38	13.1%
Face to face	83.6%	224	73.1%

85% of respondents reported they required a home visit. Of these, 90% received their home visit within two weeks, or 10 working days, as is our customer service pledge. 98% 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.
- These figures are consistently high year on year and highlight the empathy and professionalism of the local advisers, which is essential for the delivery of a high quality service.

Was the adviser friendly and polite?			
	2016		**2015**
	Response percent	Response total	Response percent
Very	97.0%	261	97.3%
Quite	2.2%	6	2.0%
Average	0.7%	2	0.0%
Not particularly	0.0%	0	0.3%
Not at all	0.0%	0	0.3%

Comments included:

"She is fantastic at what she does. She shows empathy, listens carefully and is very pro-active in her approach. She is in short an absolute credit to your organisation."

"As far as I am concerned it is an excellent service. Our local adviser is professional, friendly and well informed."

"I feel that she offered everything I needed at that point in time and left me feeling confident to contact her again whenever I needed."

"I find the service excellent – the adviser is very reliable, easy to contact. Her response to queries is very quick."

98% said they were treated fairly by their adviser.

Was the adviser friendly and polite?			
	2016		**2015**
	Response percent	Response total	Response percent
Yes	98.1%	264	99.3%
Not sure	1.9%	5	0.7%
No	0.0%	0	0.0%

98% would recommend the service to others affected by Parkinson's.

Would you recommend the service to other people affected by Parkinson's?			
	2016		2015
	Response percent	Response total	Response percent
Yes	97.7%	254	97.5%
Not sure	1.5%	4	2.5%
No	0.8%	2	0.0%

7. Reason for contact

Clients often have multiple reasons for contacting the local adviser service.

- 71% of respondents contacted the service for information and advice on benefits and other financial issues.
- This was followed by being newly diagnosed (33%), emotional support/needing someone to talk to (32%), and looking for signposting including to local groups (30%).

What sort of information or support did you contact us for? Please select all that apply.			
	2016		2015
	Response percent	Response total	Response percent
Medical advice	24.9%	67	20.4%
Signposting: Who to contact	29.7%	80	27.4%
Social care advice (eg nursing home, local authority home adjustments)	20.1%	54	19.1%
Benefits advice and other financial issues	70.6%	190	82.6%
Employment advice	4.5%	12	6.0%
Emotional support / someone to talk to	31.6%	85	28.8%
Creative or therapeutic activities (eg yoga, singing, tai chi)	12.6%	34	10.7%
Newly diagnosed	33.5%	90	27.8%
Respite care information	5.2%	14	2.3%
Access to health services	17.5%	47	13.7%
Carer's issues	20.1%	54	18.4%
Housing issues	4.5%	12	5.7%
Contact with local groups	29.7%	80	29.4%
Daily living aids and equipment	28.2%	76	26.8%
Holidays and travelling	4.8%	13	3.0%
Other (please specify):	8.2%	22	9.0%

96% said the information they received was either very easy or easy to understand.

How easy to understand was the information you received?			
	2016		2015
	Response percent	Response total	Response percent
Very easy	63.7%	170	63.7%
Easy	32.6%	87	34.6%
Not sure/can't say	1.9%	5	1.7%
Quite difficult	1.5%	4	0.0%
Very difficult	0.4%	1	0.0%

97% said they completely or mostly received the information they needed.

Did you get the information and advice you needed?			
	2016		2015
	Response percent	Response total	Response percent
Yes, completely	82.1%	216	63.7%
Yes, mostly	15.2%	40	34.6%
Not sure	1.5%	4	1.7%
In part only	0.4%	1	0.0%
Not at all	0.8%	2	0.0%
Not yet – adviser is still supporting me	2.7%	7	0.7%

Comments included:

“The service I received and continue to receive from my support worker has been excellent. I could not have got through these stressful times without her.”

“Overwhelmed by assistance. Necessitated two home visits, completed with promptness and good grace.”

“All of the advice that has been offered has been relevant and appreciated. It seems a minefield of information to deal with when first diagnosed but the adviser offers a roadmap through it all.”

“We benefited from the adviser's comprehensive knowledge. We had not been aware of the help that is currently available and have already benefited greatly from aspects set up by the adviser. We are grateful for her suggestions and her kindness and patience at this worrying time.”

“The information given has made a total difference to how we now live. It is difficult to think straight when faced with being diagnosed and we were under a lot of stress. The local advisers were so knowledgeable it filled me with confidence for the future.”

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.

81% of respondents said the service helped a bit, helped, or helped a lot to improve their emotional wellbeing. It is interesting to note that only 32% of respondents indicated they specifically contacted us for emotional support/someone to talk to (see section 7).

Improving emotional wellbeing

	2016		2015
	Response percent	Response total	Response percent
Helped a lot	38.3%	80	39.0%
Helped	32.5%	68	30.0%
Helped a bit	11.5%	24	11.7%
Didn't help	1.9%	4	1.3%
N/A	15.8%	33	17.9%

Improving understanding and management of Parkinson's (treatments, symptoms etc)

	2016		2015
	Response percent	Response total	Response percent
Helped a lot	36.7%	77	37.1%
Helped	32.4%	68	33.9%
Helped a bit	11.4%	24	10.3%
Didn't help	1.9%	4	2.2%
N/A	17.6%	37	16.5%

Information about further sources of support (nurses, support groups etc)

	2016		2015
	Response percent	Response total	Response percent
Helped a lot	50.9%	108	47.0%
Helped	29.2%	62	33.1%
Helped a bit	5.2%	11	7.2%
Didn't help	1.4%	3	3.0%
N/A	13.2%	28	9.7%

Better understanding of benefit entitlement

	2016		2015
	Response percent	Response total	Response percent
Helped a lot	66.4%	148	71.7%
Helped	20.2%	45	17.4%
Helped a bit	4.0%	9	1.9%
Didn't help	2.2%	5	0.8%
N/A	7.2%	16	8.1%

27% of respondents said the service helped give them a better understanding of employment rights. However, only 4% specifically contacted us for information and support on employment advice (see section 7).

Better understanding of employment rights

	2016		2015
	Response percent	Response total	Response percent
Helped a lot	14.6%	23	13.7%
Helped	7.0%	11	10.9%
Helped a bit	5.1%	8	1.7%
Didn't help	2.5%	4	2.3%
N/A	70.9%	112	71.4%

59% of respondents said the service helped give them a better understanding of social care. Again it is interesting to note that only 20% of respondents indicated they contacted us specifically for information and support about social care advice (see section 7).

Better understanding of social care			
	2016		2015
	Response percent	Response total	Response percent
Helped a lot	27.1%	49	22.3%
Helped	22.7%	41	24.9%
Helped a bit	8.8%	16	7.8%
Didn't help	3.9%	7	3.1%
N/A	37.6%	68	42.0%

When we look at the information and support that respondents contacted us for, compared to the areas they felt their local adviser had made an impact, we find that many individuals experience added benefits from the service, often receiving information and support in areas over and above the ones they initially contacted us for. This indicates the importance of our expert local advisers in helping clients to uncover what they don't know and what they would benefit from knowing in their current situation.

Our new client preparation resource aims to further enable our local advisers to support clients to think about what matters most to them, what works well and not so well for them in their life with Parkinson's, and in what areas they need more information and support to make positive changes.

9. Impact of information

64% of respondents said 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?			
	2016		2015
	Response percent	Response total	Response percent
Yes	63.9%	163	61.3%
Not sure	22.0%	56	19.9%
Not applicable to me	14.1%	36	19.1%

Comments included:

"I don't feel that I am on my own and I don't feel that any question I ask is silly or stupid. I know that I am an individual and that Parkinson's is unique in the way it affects our lives, but with consideration and adaptation I can live as independently as possible."

"It made me have not as many panic attacks as I live on my own."

"It has increased my knowledge of the condition and what I can do to get help if I need it."

"Today's visit to the local hospital was far less stressful than of late. We were able to utilise a disabled person's bay and found this benefited both of us when attending an appointment."

"As a result of the intervention we now have equipment that has made an incredible amount of difference on a daily basis. We now don't know how we managed without!"

"Helped get my mobility car back!"

"The information I have received means I know what is out there, and I have choices to join in with groups if I choose."

"Helped me come to terms with diagnosis."

"It's helped make it possible for things to be achieved that were too difficult before."

"I am a committee member of a Parkinson's branch and it has helped me to be able to take it on."

"The extra money has enabled me to join an exercise class and a hydrotherapy class which I find extremely helpful."

91% of respondents said that the information or support helped them either a lot or a little to make choices that improved their lives in some way.

Has the information and support helped you better manage your Parkinson's day-to-day?

	2016		**2015**
	Response percent	Response total	Response percent
It helped a lot	71.9%	184	76.1%
It helped a little	19.1%	49	13.7%
No change/can't say	8.2%	21	9.9%
It didn't help	0.8%	2	0.4%
It made things worse	0.0%	0	0.0%

Comments included:

"I was encouraged to apply for Disability Living Allowance and given some guidance about Personal Independence Payment. I would not have applied for either if it had not been for my local adviser."

"Applied to DWP for Attendance Allowance for my bedridden wife, which was later received."

"Applied to social care department of local council for a needs assessment and received various aids to help with safety around the house."

"Making the right choices with regard to getting help, both financial and physical."

"Day to day choices in how I could manage the condition, such as pacing myself, asking for help, accepting assistance to enable me to travel for work – all of these help to reduce my stress level, which has a positive effect on my health."

"With having the correct information I was able to be raised from working group in Employment and Support Allowance to the support group. Also a number of years ago with her help I received full amounts of Disability Living Allowance when I had only been getting minimum amounts."

"It gave me the confidence to apply for Personal Independence Payment, which I was subsequently awarded at enhanced rate for both daily living and mobility."

"Literature made me better informed for discussions with the Parkinson's nurse."

"More confident about the availability of support as and when required."

84% of respondents said that the information and/or support they 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?

	2016		2015
	Response percent	Response total	Response percent
Yes, it made me feel much more positive	48.7%	130	51.7%
Yes, it made me feel somewhat more positive	35.2%	94	35.0%
No change/can't say	14.2%	38	12.6%
It made me feel somewhat worse	1.9%	5	0.7%
It made me feel a lot worse	0.0%	0	0.0%

Comments included:

“It was the first time that a lot of information had been made available to me and I suppose, before that, I was a little naïve. Yes initially it did have an adverse effect on me. Once I had all the relevant facts, I am more able to come to terms with, and manage, the condition better.”

“Not the same feeling of isolation and it also helped me to talk with my family and friends about Parkinson's much better.”

“It helped to put things in perspective and prioritise certain aspects of my life. The support I have from my local adviser goes far beyond what I expected. To say she goes the extra mile would be an understatement. I'm NEVER made to feel a nuisance. She always returns my calls, makes me feel secure that someone is there.”

“It made me feel it is not the end of the world, life can go on.”

“Travel and parking less stressful, hence social contact greater, since obtaining Blue Badge.”

“I now meet with other young people monthly thanks to my advisers and it’s so helpful talking to others in my situation and knowing I am not alone.”

“It made me feel I was not alone and that there is a caring community willing and able to help.”

“I could stop worrying about all the changes to my life. Just knowing that someone is there for me if I need advice makes me more positive.”

“It has helped a lot to be able to talk things through with someone who understands.”

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:

“I feel they are doing a great job and I am very happy with the support.”

“Very happy with the support we get. Always friendly and accessible.”

“I found the service excellent and can't think how it could be improved.”

“I think they are doing a fantastic job and would not be without them. They are always quick to reply and are well known in our area now.”

Other feedback did highlight areas that could be addressed, including contacting local advisers.

Comments included:

“An out of hours contact service would be helpful.”

"Overlapping of part-time people so that we have business hours coverage not just abandoned when they are off duty."

There has been a drop in the frequency of this sort of feedback compared to other years. For several years we have worked to improve the way we communicate with clients about how the local adviser service works and the best ways of signposting them to the most appropriate service. For example, local advisers indicate their normal working days and hours on their email signature and voicemail, and direct people to the helpline service on their out of office emails and voicemails. However, the fact that we do still receive this feedback suggests we need to review this to see if there is more we can do.

11. Conclusion

The results of the 2016 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.
- 98% would recommend the service to others affected by Parkinson's.
- 91% of respondents said that the information or support provided helped them either 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 clients generally 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 and know what help and support is available and can help clients to access this.
- Local advisers being able to provide both practical and emotional support – 81% of respondents said that the service helped a bit, helped or helped a lot in improving their emotional wellbeing.

One action that has come out of the results is the need to review how we communicate our service offer and how best to access it.

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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