

PARKINSON'S<sup>UK</sup> CHANGE ATTITUDES. FIND A CURE. JOIN US.



## Parkinson's local adviser evaluation report 2017

“The support provided helped me regain my confidence, which I seemed to have lost. Very inspiring.”

“It is very reassuring to know that help is available when one’s future is uncertain.”

“The information provided helped me feel that you’re not on your own – there is a good support network out there.”

## 2017 survey respondents

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## 1. Background

Our Parkinson's UK's local adviser service provides confidential one-to-one information and support to people affected by Parkinson's including family, friends, carers 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 from anywhere in the UK.

This report presents results and feedback collected through the user survey conducted in autumn 2017. The survey aimed to gather user feedback about the local adviser service to ensure quality and inform its further development, combined with the service's other monitoring mechanisms.

The survey was sent to 757 clients across the UK by post and email. A total of 273 surveys were received back, which is a response rate of 36%. This is slightly higher than last year.

## 2. Who responded to the survey?

	2017		2016	2015
What is your connection to Parkinson's?	Response total	Response percentage	Response percentage	Response percentage
I have Parkinson's	200	81.9%	80%	78.3%
I am a carer, partner or family member of a person with Parkinson's	42	17.2%	18.1%	18.5%
Other – please specify	2	0.8%	1.9%	3.2%

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

- 82% of responses were from individuals with Parkinson's while 17% were from either a carer, partner or family member of someone with Parkinson's.
- A further 1% came from others – which included a carer of a person whose diagnosis changed from Parkinson's to progressive supranuclear palsy.

	2017		2016	2015
How old are you?	Response total	Response percentage	Response percentage	Response percentage
Under 35	0	0%	0%	0%
35-44	3	1.2%	1.1%	1.1%
45-54	23	9.5%	8.7%	8.8%
55-64	49	20.2%	18.2%	21.4%
65-74	92	37.9%	36.7%	32.3%
75 and over	76	31.3%	35.2%	36.5%



	2017		2016	2015
What is your gender?	Response total	Response percentage	Response percentage	Response percentage
Female	113	46.5%	46.4%	46%
Male	130	53.5%	53.6%	54%
Other	0	0%	0%	0%

	2017		2016	2015
What is your ethnicity?	Response total	Response percentage	Response percentage	Response percentage
White – English/Welsh/Scottish/ Northern Irish/British	227	93%	92.6%	93.7%
White – Irish	3	1.2%	1.9%	0.7%
White – Gypsy or Irish Traveller	0	0%	0.39%	0%
Any other white background – specify below	3	1.2%	1.2%	1.4%
Mixed or multiple ethnic groups – white and black Caribbean	0	0%	0.39%	0%
Mixed/multiple ethnic groups – white and black African	0%	0%	0%	0%
Mixed/multiple ethnic groups – white and Asian	0	0%	0%	0%
Any other mixed/multiple ethnic background – specify below	0	0%	0%	0%
Asian/Asian British – Indian	3	1.2%	0.8%	1.1%
Asian/Asian British – Pakistani	2	0.8%	0.4%	1.1%
Asian/Asian British – Bangladeshi	0	0%	0%	0%
Asian/Asian British – Chinese	0	0%	0.4%	0%
Any other Asian background – specify below	3	1.2%	0.8%	1.1%
Black/black British – African	1	0.4%	0.8%	0.4%
Black/black British – Caribbean	1	0.4%	0.78%	0.35%
Any other black/African/Caribbean background – specify below	0	0%	0%	0.4%
Other – Arab	0	0%	0%	0.4%
Any other ethnic group – specify below	1	0.4%	0%	0%

Of these:

- 69% of respondents were over 65 years old – 31% were over 75.
- Slightly more men than women responded.
- The ethnicity of respondents was mainly white British with 4.5% from ethnic groups, which is consistent with the previous year.

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

	2017		2016	2015
How did you hear about the Parkinson's local adviser service?	Response total	Response percentage	Response percentage	Response percentage
Parkinson's UK website	21	8.6%	9.8%	5.7%
Parkinson's UK helpline	9	3.7%	6.7%	2.0%
Parkinson's UK information event	3	1.2%	1.6%	2.3%
Parkinson's UK branch or group	44	18%	18.9%	19.6%
Parkinson's UK publications – specify below	6	2.5%	2.4%	2.7%
Friends or relatives	16	6.6%	5.1%	6%
Parkinson's nurse or clinic	105	43%	36.6%	44.2%
Consultant	12	4.9%	5.9%	8.3%
GP	6	2.5%	4.3%	2.3%
Other healthcare professional – specify below	7	2.9%	3.5%	1.3%
Social services	1	0.4%	0.4%	1%
Other voluntary organisation – specify below	1	0.4%	0.8%	0.3%
Other – please specify	13	5.3%	3.9%	4.3%

As in previous years, the main source for finding out about the service was through a Parkinson's nurse or clinic (43%), followed by a Parkinson's UK branch or group (18%). This indicates the importance of Parkinson's nurses and branches as key stakeholders of the service.

### 4. Have clients contacted the local adviser service before?

	2017		2016	2015
When did you first have contact with your Parkinson's local adviser?	Response total	Response percentage	Response percentage	Response percentage
In the last week	6	2.4%	2.6%	3.3%
Within the last month	14	5.6%	7.1%	12.3%
Less than 3 months ago	49	19.8%	28.7%	35.1%
Less than 1 year ago	99	39.9%	27.2%	20.2%
More than 1 year ago	80	32.3%	34.3%	29.1%

This year, the largest group of respondents had their first contact with the service between 3 months and a year ago (40%), which is an increase on the previous years. This group was followed closely by clients who contacted the service over a year ago (32%).

Clients from both groups 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.

	2017		2016	2015
How many times have you had contact with your Parkinson's local adviser?	Response total	Response percentage	Response percentage	Response percentage
Once	28	11.3%	94.8%	94.7%
2-5 times	157	63.3%	5.2%	4.9%
6-10 times	29	11.7%	0%	0.3%
More than 10 times	34	13.7%	14.2%	9.9%

The majority of respondents had between two and five contacts with their local adviser (63%). A total of 11% had only had one contact with the local adviser and 14% had contact more than 10 times.

## 5. Getting through to the service

As in previous years, a large number of clients who responded to our survey (94%) said they had no problems getting through to the service.

The main comments of those with few problems (7%) 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 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 part of an integrated information and support service.

People affected by Parkinson's need to be made aware of all the routes to information and support, including via our helpline, and how these can be used alongside one another.

	2017		2016	2015
Did you have any problems making contact with your Parkinson's local adviser?	Response total	Response percentage	Response percentage	Response percentage
No problems	230	93.5%	94.8%	94.7%
Few problems	16	6.5%	5.2%	4.9%
Lots of problems	0	0%	0%	0.3%

	2017		2016	2015
In what ways have you had contact with your Parkinson's local adviser? Please select all that apply.	Response total	Response percentage	Response percentage	Response percentage
Telephone	206	83.4%	82.8%	81.3%
Email	82	33.2%	29.5%	34.8%
Letter	42	17%	14.2%	13.1%
Face to	193	78.1%	83.6%	73.1%

As many as 78% of respondents had face-to-face contact with their local adviser, and 83% had telephone contact.

A total of 80% of respondents reported they required a home visit. Of these, 93% received their home visit within two weeks, or 10 working days, as is our customer service pledge. A complete 100% of respondents reported that they received a home visit within the timescale they needed.

## 6. Customer service and user satisfaction

	2017		2016	2015
Was the adviser friendly and polite?	Response total	Response percentage	Response percentage	Response percentage
Very	239	98.4%	97%	97.3%
Quite	3	1.2%	2.2%	2%
Average	1	0.4%	0.7%	0%
Not particularly	0	0%	0%	0.3%
Not at all	0	0%	0%	0.3%

	2017		2016	2015
Did you feel you were treated fairly?	Response total	Response percentage	Response percentage	Response percentage
Yes	240	99.2%	98.1%	99.3%
Not Sure	2	0.8%	1.9%	0.7%
No	0	0%	0%	0%

	2017		2016	2015
Would you recommend the service to other people affected by Parkinson's?	Response total	Response percentage	Response percentage	Response percentage
Yes	237	97.1%	97.7%	97.5%
Not Sure	5	2%	1.5%	2.5%
No	2	0.8%	0.8%	0%

A total of 98% of respondents said the adviser was very friendly and polite while 99% said they were treated fairly by their adviser. As many as 97% would recommend the service to others affected by Parkinson's. 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.

Comments included:

"Was very approachable, reassuring and became a valuable person in our lives for giving support and information."

"My adviser was extremely approachable and supportive."

"Very knowledgeable, understanding and sympathetic to information and help required."

"Very accommodating and helpful."

"The adviser was very friendly, cooperative and professional."

"Very knowledgeable and extremely helpful and friendly."

"The best person I have seen so far. Very honest, polite and friendly."

## 7. Reason for contact

	2017		2016	2015
What sort of information or support did you contact us for? Please select all that apply.	Response total	Response percentage	Response percentage	Response percentage
Medical advice	65	26.3%	24.9%	20.4%
Signposting: who to contact	63	25.5%	29.7%	27.4%
Social care advice (eg care home, local authority home adjustments)	38	15.4%	20.1%	19.1%
Benefits advice and other financial issues	183	74.1%	70.6%	82.6%
Employment advice	17	6.9%	4.5%	6.0%
Emotional support or someone to talk to	57	23.1%	31.6%	28.8%
Creative or therapeutic activities (eg yoga, singing, tai chi)	33	13.4%	12.6%	10.7%
Newly diagnosed	58	23.5%	33.5%	27.8%
Respite care information	6	2.4%	5.2%	2.3%
Access to health services	33	13.4%	17.5%	13.7%
Carers' issues	37	15%	20.1%	18.4%
Housing issues	15	6.1%	4.5%	5.7%
Contact with local groups	70	28.3%	29.7%	29.4%
Daily living aids and equipment	55	22.3%	28.3%	26.8%
Holidays and travelling	11	4.5%	4.8%	3%
Other	21	8.5%	8.2%	9%

Clients often contact our service for multiple reasons:

- 74% of respondents contacted the service for information on benefits advice and other financial issues
- This was followed by contact with local group (28%), medical advice and signposting: who to contact (both 26%), being newly diagnosed and emotional support (both 23%) and daily living aids and adaptations (22%).

	2017		2016	2015
How easy to understand was the information you received?	Response total	Response percentage	Response percentage	Response percentage
Very easy	148	60.4%	63.7%	63.7%
Easy	78	31.8%	32.6%	34.6%
Not sure/can't say	11	4.5%	1.9%	1.7%
Quite difficult	8	3.3%	1.5%	0%
Very difficult	0	0%	0.4%	0%



92% said the information they received was either very easy or easy to understand.

The number of respondents telling us that they were either not sure, couldn't say or found it quite difficult to understand has gone up slightly compared to the last few years. However, of these respondents 79% said they did completely or mostly receive the information and advice needed. It is possible that this shift in how easy the information was to understand has something to do with the complexities of the benefits system.

	2017		2016	2015
Did you get the information and advice you needed?	Response total	Response percentage	Response percentage	Response percentage
Yes, completely	205	83%	82.1%	63.7%
Yes, mostly	32	13%	15.2%	34.6%
Not sure	4	1.6%	1.5%	1.7%
In part only	5	2%	0.4%	0%
Not at all	0	0%	0.8%	0%
Not yet – adviser is still supporting me	1	0.4%	2.7%	0%

As many as 96% said they completely or mostly received the information they needed.

Comments included:

"If I didn't have the support, I may not have had my Disability Living Allowance after it was changed to Personal Independence Payment (PIP)

"My husband and I were at crisis point having struggled on our own for three very difficult weeks. Our adviser arranged for my husband to be admitted into hospital."

"It gave me better understanding of Parkinson's. Due to very clear and good information in a very courteous manner, I felt much better after speaking to you and know what wonderful care and advice is out there for Parkinson's."

"I know that without her valuable input and amazing support we would not have reached the fantastic outcome today. We secured the grant and works are due to start in early September."

"I value her views and support. I know she gives 110% in every part of her role and know she is a valuable credit to your charity."

"It has made such a difference to me and the way I deal with my diagnosis."

"With her encouragement and support, I have been given the opportunity to join in the running of a Parkinson's café. It's bringing me newfound confidence, which I hope will lead to further volunteer roles with Parkinson's UK."

"I would like to say a very big thank you to my local adviser for her amazing support and hard work, dedication to me and my family throughout your time at Parkinson's UK. I feel so blessed to have the pleasure in meeting and working with you."

## 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.

	2017		2016	2015
Improving emotional wellbeing	Response total	Response percentage	Response percentage	Response percentage
Helped a lot	67	35.3%	38.3%	39%
Helped	66	34.7%	32.5%	30%
Helped a bit	17	8.9%	11.5%	11.7%
Didn't help	10	5.3%	1.9%	1.3%
N/A	30	15.8%	15.8%	17.9%

A total of 79% 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 23% of respondents indicated they specifically contacted us for emotional support/someone to talk to (see section 7). This suggests many clients experience an improvement in their emotional wellbeing as an added benefit of contacting our service.

	2017		2016	2015
Improving understanding and management of Parkinson's (treatments, symptoms etc)	Response total	Response percentage	Response percentage	Response percentage
Helped a lot	64	34.6%	36.7%	37.1%
Helped	53	28.6%	32.4%	33.9%
Helped a bit	24	13%	11.4%	10.3%
Didn't help	12	6.5%	1.9%	2.2%
N/A	32	17.3%	17.6%	16.5%

	2017		2016	2015
Information about further sources of support (nurses, support groups etc)	Response total	Response percentage	Response percentage	Response percentage
Helped a lot	90	44.1%	50.9%	47.0%
Helped	76	37.3%	29.2%	33.1%
Helped a bit	14	6.9%	5.2%	7.2%
Didn't help	8	3.9%	1.4%	3%
N/A	16	7.8%	13.2%	9.7%

	2017		2016	2015
Better understanding of benefit entitlement	Response total	Response percentage	Response percentage	Response percentage
Helped a lot	151	69.9%	66.4%	71.7%
Helped	36	16.7%	20.2%	17.4%
Helped a bit	7	3.2%	4%	1.9%
Didn't help	4	1.9%	2.2%	0.8%
N/A	18	8.3%	7.2%	8.1%

	2017		2016	2015
Better understanding of employment rights	Response total	Response percentage	Response percentage	Response percentage
Helped a lot	34	21.7%	14.6%	13.7%
Helped	18	11.5%	7%	10.9%
Helped a bit	6	3.8%	5.1%	1.7%
Didn't help	5	3.2%	2.5%	2.3%
N/A	94	59.9%	70.9%	71.4%

A total of 37% of respondents said the service helped give them a better understanding of employment rights. However, only 7% specifically contacted us for information and support on employment advice (see section 7).

	2017		2016	2015
Better understanding of social care	Response total	Response percentage	Response percentage	Response percentage
Helped a lot	43	25.4%	27.1%	22.3%
Helped	43	25.4%	22.7%	24.9%
Helped a bit	13	7.7%	8.8%	7.8%
Didn't help	8	4.7%	3.9%	3.1%
N/A	62	36.7%	36.7%	42%

A total of 59% of respondents said the service helped give them a better understanding of social care. Again, it is interesting to note that only 15% of respondents indicated they contacted us specifically for information and support about social care advice (see section 7).

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

## 9. Impact of the service

	2017		2016	2015
Has the information and support helped you better manage your Parkinson's day to day?	Response total	Response percentage	Response percentage	Response percentage
Yes	145	70%	63.9%	61.4%
Not Sure	62	30%	22.0%	19.9%

70% of respondents said that the information and support helped them better manage their Parkinson's day to day.

Comments covered the practical, emotional to continuing in work. They included:

"Feeling more confident in day-to-day situations."

"Attendance allowance has enabled me to get some help looking after our home, as my husband works. Also, the blue badge is a tremendous help."

"I can now complete forms and speak to other agencies on behalf of my partner."

"It has enabled me to make decisions regarding equipment and use to make life more comfortable and bearable."

"She took a hard situation and made it more easily manageable and, with her help, I received financial help."

"With Personal Independence Payment, I am now able to afford to get acupuncture physio, which helps my mobility."

"Hand rails on staircase. Grab rails on door entrance in shower. Bed rails to assist getting up and down from bed."

"More able to cope and accept the situation."

"Now able to continue doing a job I love as adaptations were recommended and made to enable this."

"It helped me to understand why I am slow and many other things about my illness which helped me to deal with my problem."

	2017		2016	2015
Did the information or support provided help you make any choices that improved your life in some way?	Response total	Response percentage	Response percentage	Response percentage
It helped a lot	171	71%	71.9%	76.1%
It helped a little	50	20.7%	19.1%	13.7%
No change/can't say	18	7.5%	8.2%	9.9%
It didn't help	2	0.8%	0.8%	0.4%
It made things worse	0	0.0%	0%	0%

Consistently high with previous years, 92% of respondents said the information or support helped them either a lot or a little to make choices that improved their lives in some way.

Comments included:

"The support provided helped me regain my confidence, which I seemed to have lost. Very inspiring."

"It helped psychologically."

“Knowing that I had someone that could back me up when I encountered prejudice means a lot to me.”

“Signposting, giving empowerment.”

“Finding out about local pilates classes for Parkinson’s sufferers.”

“Told me that I was probably available for a free bus pass!”

“Eating and sleeping well. Exercising. Effective management of medication.”

“It gave me the confidence to try new projects.”

Many talk about the impact of financial assistance on their lives and ability to make choices:

“After advice given I was able to reduce a day a week in work, so helping my condition and tiredness.”

“Help receiving care allowance means I can pay for care at home.”

“Helping the claim attendance allowance helped my wife to cut down doing overtime and 12 hours. This gives her more time to be at home and look after me.”

“The presence and support of the local adviser has given my wife the confidence to make applications for grants and allowances that she would not otherwise have pursued. In so doing, her quality of life has improved – eg more beneficial car parking facilities and financial assistance for her to get everyday activities that she can no longer comfortably manage herself done by a third party.”

	2017		2016	2015
Did the information and/or support you received make you feel more positive about your current situation?	Response total	Response percentage	Response percentage	Response percentage
Yes, it made me feel much more positive	120	49.8%	48.7%	51.8%
Yes, it made me feel somewhat more positive	76	31.5%	35.2%	35%
No change/can't say	44	18.3%	14.2%	12.6%
It made me feel somewhat worse	1	0.4%	1.9%	0.7%
It made me feel a lot worse	0	0%	0%	0%

81% of respondents said the information and or support they received made them feel much more or somewhat more positive about their current situation. Looking at the comments, much of this is attributed to feeling like you don't have to face Parkinson's alone. Knowing there is someone who understands Parkinson's there to turn to for help when needed.

Comments included:

“Knowing that someone understood what I’m going through and if I encounter any problems I can call her and she willingly helps me.”

“It is very reassuring to know that help is available when one’s future is uncertain.”



“More confidence to deal with challenges ahead.”

“Without the help I got I don’t know what I would have done.”

“Did not feel so isolated and, knowing I could talk to her about practical or emotional situations, at any time and get support really helped.”

“I felt I wasn’t alone and that there is support available. I am less worried about financial concerns.”

“The information provided helped me feel that you’re not on your own –there is a good support network out there.”

“It is very reassuring to know that help is available when one’s future is uncertain.”

“It made us feel we were being listened to instead of being fobbed off with throwaway statements and remarks.”

“Been feeling lonely with my Parkinson’s, felt more positive after talking about it and what help is out there. Adviser also followed up with a phone call.”

“It made me stronger and more able to fight for my Personal Independence Payment entitlement. It made me more able to understand the situation and accept it.”

## 10. Recommendations for service improvement

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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.

### Finding out about the service at diagnosis

Comments included:

“I feel that all the services Parkinson’s UK offer should be better advertised, as we only found out about the advisory service after my wife spoke to someone at Lewisham Hospital on a different matter. Maybe a directory of some kind that people can request.”

“Be better linked to the NHS. The NHS teams are the weak link and where it all falls down – they have no obvious information and you have to go searching for it. Parkinson’s UK is much more helpful and organised.”

“More advice at the earlier stages of Parkinson’s. We just learned as it progressed.”

“Attend more clinics, write to those who receive diagnosis explaining services offered.”

“Increase more Parkinson’s advisers and more Parkinson’s specialists.”

Parkinson’s UK has taken this feedback, which has been a theme for some time, to heart and is currently carrying out work to reach out to people who are newly diagnosed. We’re doing this by holding introduction days for the newly diagnosed and linking with clinicians to make sure people find out about our service at point of diagnosis. This is so we can provide people with a tailored proactive support offer.

### Have more local advisers and more ongoing support

Comments included:

“The most obvious I guess would perhaps have more advisers as they cover such a large area.”

“Not our current local adviser – she’s superb. However, nationally, I would suggest funds be made available to increase the number of local advisers appointed – to reduce the pressure of workload on existing resources.”

“Extra staff required due to the heavy workload.”

“More face to face opportunities?”

“More regular contact to check if other services needed or to check progress.”

“It would be appreciated if our adviser were able to keep closer contact. We only meet when I have an issue.”

Our specialist local adviser service focuses on supporting those with the highest and most complex needs. The support provided is issues based, which means we don’t provide ongoing support but rather come in when the need is most pressing. Local advisers signpost and refer to organisations and groups, including Parkinson’s UK local groups, for more long-term support where needed.

There has been a drop in the frequency of feedback on having more local advisers and ongoing support over the 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 clients to the most appropriate services.

## 11. Conclusion

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The results of the 2017 local adviser service user survey are again very positive, and clearly show the value that clients place on the service.

- 98% felt the adviser was very friendly and polite.
- 97% would recommend the service to others affected by Parkinson’s
- 92% 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:

- They have access to an approachable, friendly and polite local adviser who understands Parkinson’s.
- They have 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 are able to provide both practical and emotional support – 79% of respondents said the service helped a bit, helped or helped a lot in improving their emotional wellbeing.

We will continue to review and improve how we communicate what the local adviser service offers, as well as how we signpost and refer to relevant organisations and groups.

We are committed to reaching out to and developing our offer for newly diagnosed people. That way, they are able to connect with Parkinson’s UK in a meaningful way from an early stage in their journey.

Every hour, two people in the UK are 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.**

Parkinson's UK  
215 Vauxhall Bridge Road  
London SW1V 1EJ

Free confidential helpline **0808 800 0303**  
(Monday to Friday 9am–7pm,  
Saturday 10am–2pm). Interpreting available.  
NGT Relay **18001 0808 800 0303**  
(for textphone users only)

**hello@parkinsons.org.uk**  
**parkinsons.org.uk**