PARKINSON'S UK

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CARING ABOUT PARKINSON'S

How local authority social care services are working for people with Parkinson's and carers in England

Contents

Foreword

Although people with Parkinson's are able to live independently, or are cared for by friends and loved ones, there will often come a time when additional support is necessary. In these situations, timely access to high quality social care is vital for people with advanced Parkinson's, in order to help them remain in control of their situation and avoid families reaching crisis point.

This report examines how the social care system is working for people with Parkinson's and their carers in England.

It's disappointing that so few people with Parkinson's and their carers are aware of the information and support that local authorities are required to provide, or how to request an assessment. Still fewer of the people who responded to our survey were being offered assessments of their needs.

We empower people with Parkinson's and their carers to access support through our network of local advisers and our helpline. We work hard to improve knowledge and understanding of the condition among social care professionals through the UK Parkinson's Excellence Network.

> "It's disappointing that so few people with Parkinson's and their carers are aware of the information and support that local authorities are required to provide, or how to request an assessment."

However, we cannot do this alone. The report and its findings demonstrate that local authorities in England and the Department of Health have more work to do to ensure that social care support is available for people with Parkinson's and their carers and that both groups find the care system easy to understand and access.

Steve Ford
Chief Executive
Parkinson's UK

Acknowledgements

We would like to thank Phil Reynolds and Liam Collins for writing this report. We would also like to thank those people with Parkinson's, their carers and Parkinson's local advisers who participated in our surveys.

Social care for people with Parkinson's in England 2016

Parkinson's is a complex neurological condition that affects around 127,000 people in the UK. There is currently no cure. There are over 40 motor and non-motor symptoms, including pain, fatigue, freezing, tremors, stiffness, confusion, dementia, slurred speech and problems swallowing. These symptoms fluctuate unpredictably. Parkinson's is also degenerative. In many cases, as the condition progresses, people with the condition and their carers require social care support to maintain their independence for as long as possible.

To better understand how social care is working for people with Parkinson's and their carers in England since the Care Act came in to force in April 2015, we conducted a survey of 354 people with Parkinson's and their carers, 35 locally based Parkinson's local advisers in England, and submitted 148 Freedom of Information (FOI) requests to local authorities responsible for social care provision in England.

Key findings

Confusion and lack of knowledge about accessing information and requesting an assessment

- Over half (51%) of respondents with Parkinson's and 76% of carers who answered the question "have you ever been offered an assessment of your own needs?" had never received an assessment.
- 74% of respondents with Parkinson's and 59% of carers were unaware of their local authority's social care information service and many people with Parkinson's and carers did not know how to request a social care assessment.

Social care assessors' mixed knowledge of Parkinson's and quality of assessments

- Around a third of Parkinson's local advisers that responded to the survey disagreed that "assessments in my area have been conducted with a good understanding of Parkinson's" or asked about how a person's condition fluctuates.
- No carer in our survey reported receiving access to preventative support, despite Care Act guidance which emphasises the value of this support for carers.

In some cases, people with Parkinson's are losing access to support they desperately need

- Of the 82 respondents who revealed the outcome of their social care assessment, almost a third were denied access to support because they were above the earnings threshold and a quarter gained access to additional support.
- 63% of local authorities who responded to FOI requests were unable to provide any of the requested information. In the majority of cases, this was because to the local authority did not collect data by condition.
- Around 10% of the Parkinson's population identified across the 21 local authorities that did collect this data have seen reductions in their social care support, upon reassessment.

Recommendations

Recommendations for the Department of Health (DH)

We recommend that the DH's current research to evaluate the implementation of the Care Act on prevention and support for carers should also include:

- Involving people with Parkinson's and their carers in this research, in order to fully understand their experiences and improve the availability of support for people with degenerative conditions.
- Examining local authorities' compliance with the quality and format of social care assessments to ensure that councils are fulfilling these key requirements.
- Benchmarking local authorities' social care assessment outcomes, to examine whether councils are adhering to criteria that are the equivalent of "substantial" under Fair Access to Care Services.

Recommendations for local authorities

We recommend that individual local authorities across England:

- Collate information about accessing social care in their area and make it easily accessible online.
- Proactively engage with local Parkinson's UK groups to share information about social care and also consider meeting with groups in their areas to better understand and address barriers to social care for people with the condition and their carers.
- Encourage social care staff to engage and collaborate with Parkinson's UK by joining the UK Parkinson's Excellence Network so they can improve assessors' knowledge and understanding of Parkinson's to avoid situations such as people with the condition losing vital access to support.
- Ensure that when people with Parkinson's and carers are identified by local authorities, they are offered annual reassessments of their needs, to ensure that social care support is increasing in step with their condition.
- Collect information on named conditions such as Parkinson's, as recommended by the Health and Social Care Information Centre. This will enable them to meet their obligations in the Care Act statutory guidance.

Recommendation for the HSCIC

- We recommend that the HSCIC reissues the Equalities and Classifications Framework guidance to local authorities, and urges them to collect data on people with Parkinson's who access social care.

To read the full report, please visit
parkinsons.org.uk/caringaboutparkinsons

About us

Imagine not being able to move, sleep or smile. Feeling anxious or depressed and struggling to think or remember. Your body not feeling like your own. This is what Parkinson's can feel like. 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.

The UK Parkinson's Excellence Network brings professionals together to transform care for people affected by Parkinson's. The Network offers resources to support service improvement, as well as comprehensive information about education and training and collaboration opportunities. 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.

About Parkinson's

Parkinson's is a progressive and incurable neurological condition that affects around 127,000 people in the UK, or one person in every 500, and is commonly misunderstood. There are over 40 physical and non-physical symptoms. Symptoms vary from person to person and fluctuate unpredictably. The way the condition progresses also varies greatly between individuals.

For people with Parkinson's, daily life has its own challenges. Whether that's trouble crossing the street, exercising, or the loss of smell and taste.

Given that Parkinson's is always degenerative, people with advanced Parkinson's often require additional help to overcome these barriers and maintain their independence.

Social care and Parkinson's

Social care supports people with Parkinson's in a variety of ways, such as personal care at home, daily living aids to help with tasks such as showering and dressing, or sometimes residential care if people have more advanced needs. Social care can be given in a variety of ways for example by agencies, care providers and loved ones.

Despite social care playing an important role in assuring that people with Parkinson's have the support they need, our research shows that people with the condition are often unaware of social care and how it can help them. In particular, a recent study reveals that, in many cases, people with Parkinson's only encounter social care at crisis point – when unpaid carers can no longer provide support[1] which can lead to increased social care costs.

The research also found that the benefits of social care were interrelated. Improvements to the quality of life of a person with Parkinson's may also reduce the burden on carers, or help to avoid wider costs to the state such as residential care or hospital admissions.

Social care is vital to making sure people with Parkinson's can live well, take control and have choices in how they live day-to-day. Social care that is person-centred, regularly assessed and encourages social inclusion is the key to maintaining wellbeing.

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[1] Tod, Angela Mary et al (2016) *Good-quality social care for people with Parkinson's disease: a qualitative study*, BMJ Open 2016;6:2, available at: doi:10.1136/bmjopen-2014-006813

Care Act 2014

When the Care Act received Royal Assent in 2014, it was the most significant change to social care law for 60 years as it merged other acts and built on a number of different pieces of existing law. The Care Act came in to force in April 2015, with the exception of the cap on care costs, which has been deferred until 2020.

The legislation provides the framework for ensuring that people's care and support requirements are met by local authorities and sets out a number of new responsibilities on them.

Local authorities must now provide residents with information and advice in an accessible way relating to care and support for adults and their carers. This information includes independent financial advice, carers' services and benefits, eligibility, how to apply for disability benefits, how to understand care charges and ways to pay for care.

Local authorities are also required to offer people with Parkinson's and their carers an assessment, where an individual appears to need care and support. Assessments aim to understand an individual's physical, mental and emotional wellbeing – seeking to establish the extent of their needs before considering eligibility for support.

How the assessment is conducted varies, but the Care Act specifies that it must be in a format that will help the person who is being assessed. Whether in person, over the phone or online. Local authorities must also think about whether the individual's current level of need my change in the future and to what degree the condition could change. The fluctuation of a person's condition should be incorporated into their care plan.

One of the most significant reforms is a standard eligibility criteria for carers and people with care needs across all local authorities in England. However, this has now been set to the equivalent of substantial needs under the previous Fair Access to Care Services criteria[2] – which required that a person had to demonstrate "an inability to carry out the majority of personal care or domestic routines" and that "the majority of social support systems and relationships cannot or will not be sustained" among other criteria[3].

Local authority social care funding

National funding for social care has reduced significantly in recent years. Adult social care budgets accounted for 40% of local authorities' total savings between 2013-14 and 2014-15. This compared with only 15% from 2010-11 to 2011-12, according to the National Audit Office[4].

In addition to these significant spending reductions, the Government announced in the 2015 Comprehensive Spending Review its intention to enable local authorities to increase council tax by up to 2% per financial year. However, the Care and Support Alliance estimates that even if every council introduced the maximum 2% precept allowed, this would still lead to a £1.4billion gap in social care funding from April 2016 rising to £1.6billion in April 2017.

Taken together, this demonstrates that local authorities are being forced to ration and target social care support to those who need it most. Given the progressive nature of Parkinson's, there is a risk that only people in the advanced stages of the condition may be eligible for support.

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[2] www.scie.org.uk/publications/guides/guide33

[3] www.scie.org.uk/publications/guides/guide33/changing-scene/eligibility-criteria.asp

[4] National Audit Office, '*The impact of funding reductions on local authorities*' available at: www.nao.org.uk/wp-content/uploads/2014/11/Impact-of-funding-reductions-on-local-authorities.pdf

Methodology

In order to understand how social care services are operating for people with Parkinson's and their carers since the introduction of the Care Act, we used the following methods:

Survey of carers, people with Parkinson's and Parkinson's local advisers

We undertook a survey aimed at carers and people with Parkinson's that asked for their views on how the provisions of the Care Act affected them. In particular, we asked about the information and support provided by local authorities, assessments and advocacy.

Our survey ran from 15 April to 16 May. It was promoted to our members and supporters through social media, e-campaigns networks and local advisers. We received 354 responses.

Another survey was circulated among our UK-wide network of Parkinson's local advisers. They give one-to-one support to people with the condition and their families when applying for welfare and social care support. This survey got 35 responses from 90 local advisers in England.

Freedom of Information (FOI) requests

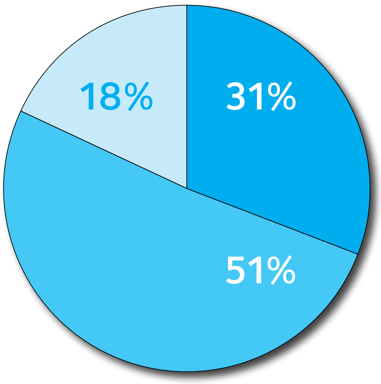
We also submitted a FOI to 148 local authorities in England with responsibility for providing social care. This included all 32 London boroughs, all county councils and unitary authorities. We got 45 responses.

1. RESPONDENTS

Of the 354 respondents, over half (180) had Parkinson's. The remaining respondents were made up of unpaid carers, friends or family members (167). Only a small minority were paid carers (7). Paid and unpaid carers' experiences will be counted together.

Of the respondents who described themselves as "unpaid carers, friends or family members" or "paid carers" 37% (64) described themselves as responding "on behalf of a person with Parkinson's" and so are treated as a person with Parkinson's in these analyses[5]. This brought the total of respondents with Parkinson's to 244 and carers to 110.

Breakdown of survey respondents (N=355)



◀ People with Parkinson's

◀ Carers responding on behalf of someone with Parkinson's

◀ Carers responding on their own behalf

2. INFORMATION AND SUPPORT

It is worrying that 74% of respondents with Parkinson's (180) and 59% of carers (66) were unaware of their local authority's social care information service. This contrasts with 26% of people with Parkinson's (64) and 40% of carers who were aware. Of those who answered (37 carers and 51 people with Parkinson's) the majority reported that their local authority provided information on a range of issues. The exception was access to independent financial advice, of which fewer than 10% of respondents were aware. Respondents to the Parkinson's local advisers' survey agree that social care information is available. However, the extent this information is of use to people with Parkinson's and their families is questionable. 69% of respondents (22) said that clients did not find the information sufficient to meet their needs.

(continued on the next page)

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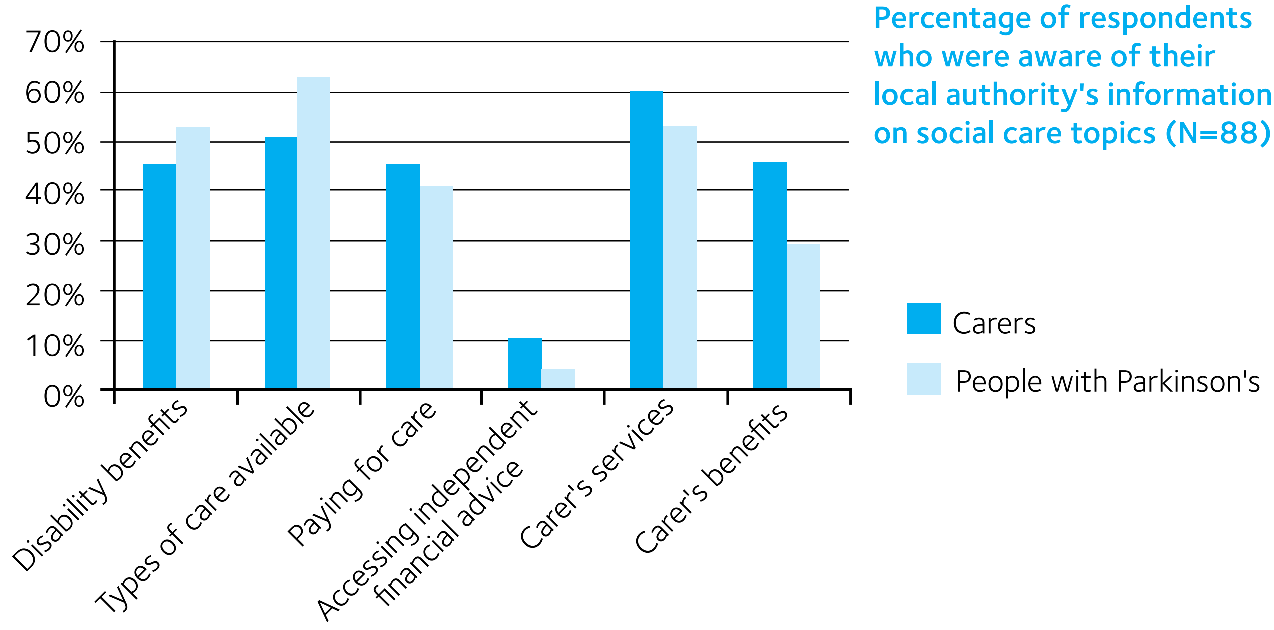
[5] One additional response to this question was received, where a person counted themselves as both a carer and as a person with Parkinson's. This was treated as anomalous.

2. INFORMATION AND SUPPORT (CONTINUED)

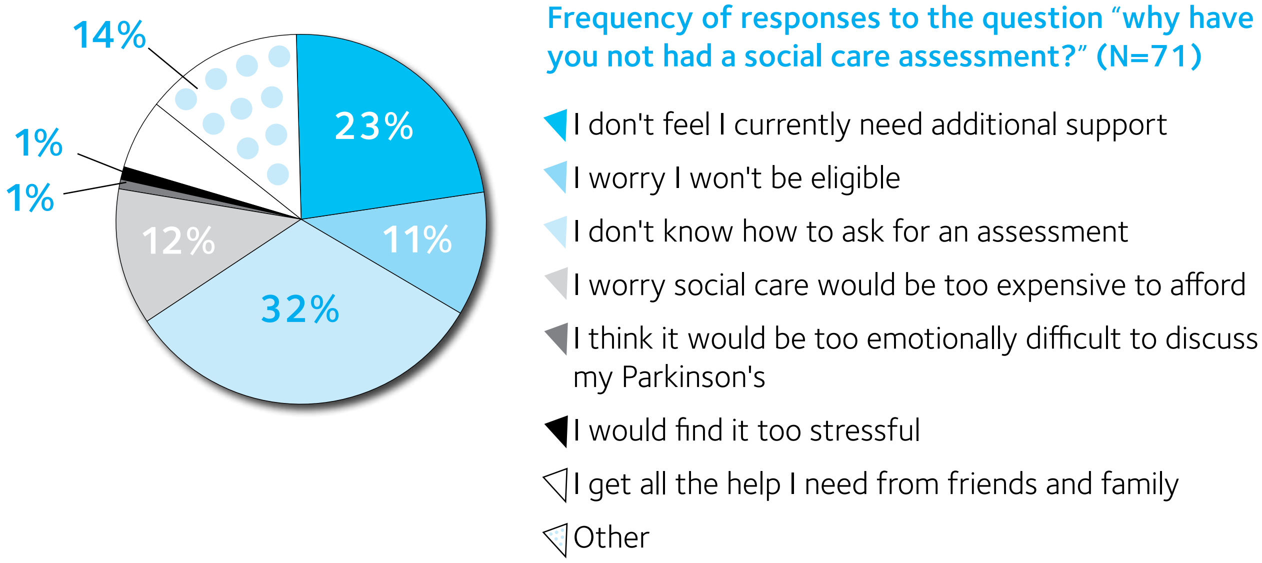


Percentage of respondents who were aware of their local authority's information on social care topics (N=88)

3. NUMBERS OF SOCIAL CARE ASSESSMENTS UNDERTAKEN

The majority of respondents had never received a social care assessment. Analysis found that 51% of respondents with Parkinson's (125) had never been assessed for their social care needs. Of those who had an assessment (75), 48% (36) were assessed after 1 April 2015 – the date the Care Act came into force in England. Over half (39) were assessed before 1 April 2015. Of those carers (71) who answered the question "as a carer, have you ever been offered an assessment of your own needs?", 76% (54 people) had never received an assessment of their needs. Of the 24% of carers (21) who responded, six had been assessed since the Care Act came into force. An additional question looking at why respondents had not received an assessment was added during data-collection[6]. We found that the majority of the 65 respondents were unaware of how to request one.

Frequency of responses to the question "why have you not had a social care assessment?" (N=71)



This supports the findings of previous research that found people were frequently unaware of social care support until they were at crisis point.

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[6] Because the question was added subsequently, it wasn't possible to segment this by carer or person with Parkinson's

Assessment quality

Around a third of Parkinson's local advisers (11) disagreed that "assessments in my area have been conducted with a good understanding of Parkinson's" while almost half neither agreed nor disagreed.

The advisers' survey gives a mixed picture about whether assessors asked about how a person's condition fluctuates. Around 28% (9) of respondents disagreed and 28% (9) neither agreed nor disagreed.

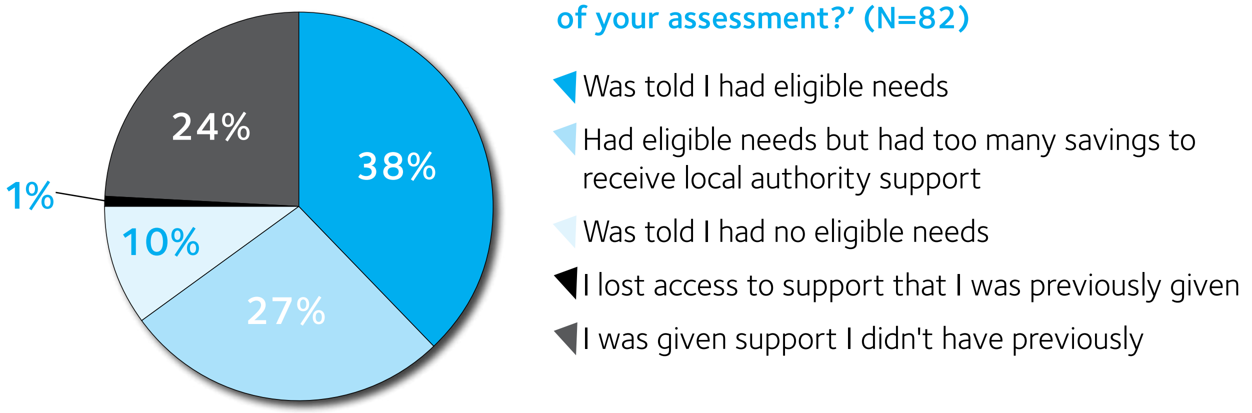
A Parkinson's local adviser explains:

> "My local authority has appointed experienced Carer Practitioners to support staff who conduct carer's assessments. They are keen to understand about Parkinson's. The problem comes when Parkinsons is not fully understood and the motor and non-motor symptoms not fully explored or explained. People tend to be very stoical and underplay needs."

Assessment outcomes

Of the 96 respondents who had an assessment, 82 answered the question "what was the outcome of your social care assessment?" Of these, 13 were carers and 69 were people with Parkinson's.

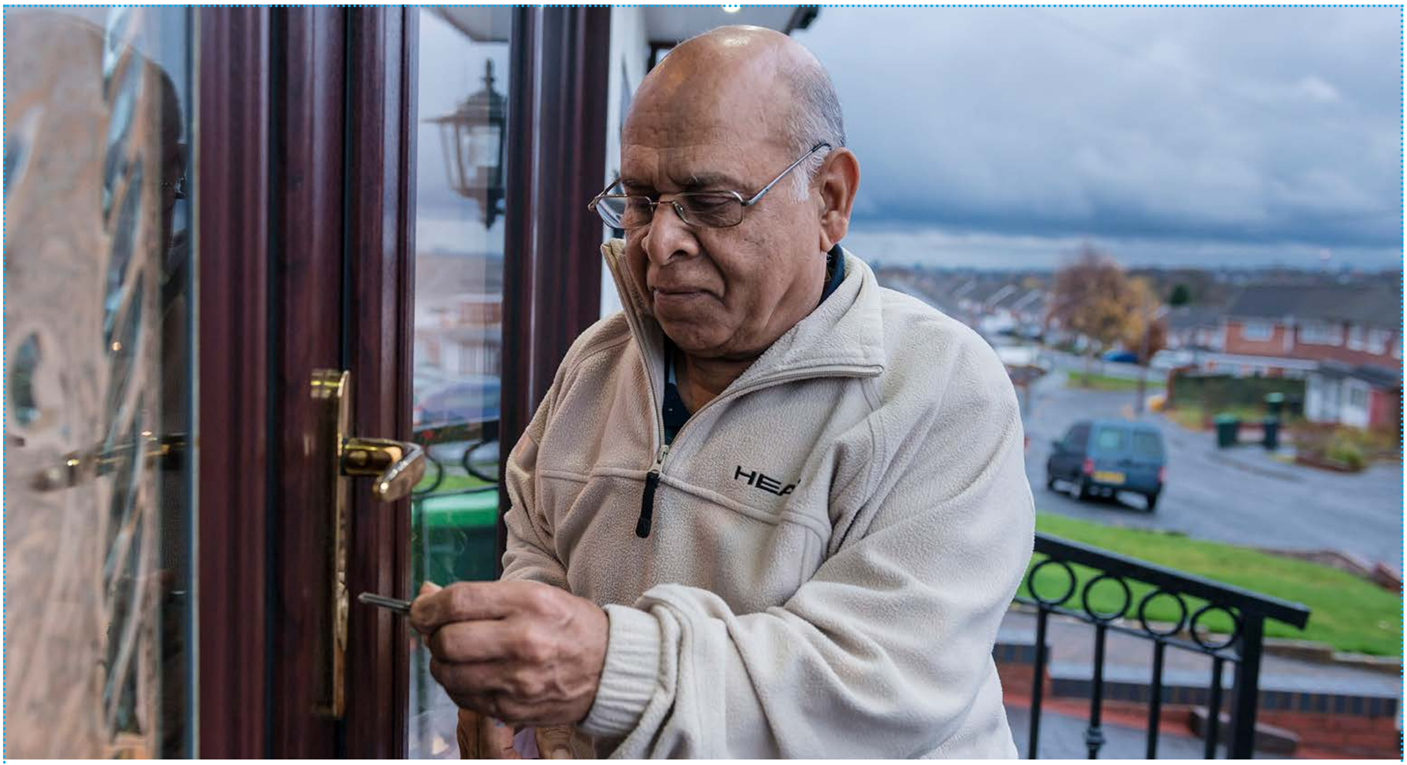
Responses to the question 'what was the outcome of your assessment?' (N=82)



It is positive that around a quarter of respondents (23) said they gained access to additional support. Only one respondent lost access to social care support. Despite this, almost a third (25) were denied access because they were above the earnings threshold.

However, Parkinson's local advisers' responses note a lack of confidence in the changes to the eligibility criteria, as introduced in the Care Act. For example, half of respondents (15) agreed with the statement "People with Parkinson's are generally less likely to receive access to appropriate local authority social care support than previously, because of the Care Act eligibility criteria (which are set to the equivalent of 'substantial' need)".

Around 40% of respondents (13) also agreed that "Carers are generally less likely to receive access to local authority social care support than previously, because of the Care Act eligibility criteria". However, 24% (8) neither agreed nor disagreed.



Of those who were offered additional support to help meet their eligible needs, or were told they had eligible needs (50 people with Parkinson's and nine carers), 74% of respondents (26) were offered aids and adaptations (of whom 22 were people with Parkinson's). Almost a third of respondents (10) received home care, including three carers.

Carers' experiences

No carer reported receiving access to preventative support. This is concerning because the Care Act guidance for local authorities[7] highlight the potential value of preventative support for carers. It states that this support 'can range from wide-scale whole-population measures aimed at promoting health, to more targeted, individual interventions aimed at improving skills or functioning for one person or a particular group or lessening the impact of caring on a carer's health and wellbeing'.

Responses from Parkinson's local advisers demonstrate difficulties in arranging respite care for people with Parkinson's in their local areas. Around 39% of respondents (13) disagreed that "respite care is easy to arrange in my area" while 28% (9) strongly disagreed.

Local advisers explain:

> "Respite is a particular problem because there is nowhere suitable for people to go to. I have a client who uses a wheelchair who wants to go to somewhere where he can socialise – this will also give his wife a break. At the moment he is coming to the end of 12 weeks of this type of activity at the local hospice. It has been fabulous for his and his wife's emotional wellbeing. So far the local authority can find him nothing suitable. His wife had 100 hours of respite vouchers and has used 10 hours. She said this is because she can only use them to get people to sit in with her husband and what he really needs is to get out."

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[6] www.gov.uk/guidance/care-and-support-statutory-guidance

> “It is virtually impossible to get respite care for more than a few hours a week in the areas I cover. Though the take a break scheme does give a few hours a week.”

Respondents reported the significant and beneficial impact these improvements had on their lives. 61% of respondents to the question “what impact has additional support had on your life?” (48) felt the changes helped manage their lives better. 37% of respondents (17) reported that it took pressure off family and carers. However, for those respondents who did not gain additional support they felt they needed (28), 53% (15) said this would put pressure on family finances, while 35% said the stress would make their lives worse.

Respondents explain:

> “Puts more pressure on the carer, who provides 24/7 care, but isn’t entitled to her own support, as she has an old age pension. Parkinson’s is such a variable illness that very few people understand the changes throughout the day, which makes it difficult to get appropriate cover to give the carer a break.”

> “We have since moved to a bungalow, and had to down size. I lost my job shortly before my diagnosis, because of excessive time off work, we have considerably less income, but manage now we have moved to a bungalow, and hope to make adaptions for progression in the future.”

> “My wife leads a very lonely limited life, I have to work we have a mortgage I worry she will fall she suffers depression and rarely sees anyone she is not fit to leave the house.”

4. FREEDOM OF INFORMATION (FOI) REQUESTS

Out of the 148 FOI's sent to local authorities 56 responded, of which 63% (35) were unable to provide any of the requested information. In the majority of cases, this was because the local authority did not collect the data. Several councils explained that they were not obligated to collect Parkinson’s specific data and only reported on mandatory conditions such as Autism and Asperger Syndrome as required by the Health and Social Care Information Centre’s Equalities and Classifications Framework (EQ-CL)[8]. However, the EQ-CL notes that “The Framework is not entirely prescriptive as each local authority will still be able to collect much locally specified data in local formats” and counts Parkinson’s among a list of “items are recommended to be recorded” since 2013.

This is at odds with Care and Support Statutory guidance, which states that local authorities “should have in place robust methods to collect, analyse and extrapolate this information about care and support needs, including as appropriate information about specific conditions (for example, neurological conditions such as stroke, Parkinson’s, and Motor Neurone Disease), and multiple and complex needs”[9]. Of those 21 local authorities that provided statistical information, Parkinson’s populations in local authorities ranged from three in Poole, to 292 in Bromley. The Parkinson’s population identified across the local authorities was 1,717 people.

The 21 local authorities reported that 1,091 reassessments had been conducted in the last year. This suggests 64% of the identified Parkinson's population across the local authorities were reassessed in 2014-15.

However, some local authorities emphasised that in some cases these were reassessments of the same individual, so care must be taken when drawing conclusions from this finding.

As a result of these reassessments, the local authorities identified 388 people with Parkinson's who got increased support over the previous year, a total of 35% of cases saw an increase.

However, 10% of reassessments led to a reduction in the level of available local authority social care support. This means that 112 people with Parkinson's had their support reduced even though the condition is degenerative.

Lastly, 591 assessments were offered to carers of people with Parkinson's across the 21 local authorities that returned data, of which 66% (391) assessments were conducted.

Among those assessments, 54% (214) led to support and 20% (80) led to reductions in support.

In most cases, local authorities did not specify the outcomes for the remaining 97 carers who received a social care assessment as identified in Q5b. It is likely their level of support was unchanged.

Freedom of Information request response analysis

	How many people with Parkinson's have had their social care needs assessed by the local authority in 2015?	Do you collect condition specific data on people applying for social care?	How many social care reassessments of people with Parkinson's have been undertaken since 1 April 2015?	4. How many of reassessments of people with Parkinson's undertaken since 1 April have led to	
				a) increased social care support?	b) decreased social care support?
Total	1,717	21	1,091	388	112

	5. How many carers' assessments has the local authority		6. Please provide the number of carers of people with Parkinson's who	
	a) offered to carers of people with Parkinson's, in 2015?	b) undertaken for carers of people with Parkinson's, in 2015?	a) qualified for local authority support following assessment, in 2015	b) did not qualify for local authority support following assessment, in 2015
Total	591	391	214	80

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[8] www.hscic.gov.uk/media/12019/Guidance-for-EQ-CL/pdf/EQ-CL_2014-15_Framework_v1.5.pdf

[9] www.gov.uk/guidance/care-and-support-statutory-guidance/general-responsibilities-and-universal-services

Social care is an essential source of support for people with advanced Parkinson's and their carers, which can help them maintain their independence for as long as possible. However, this can only happen when social care is well understood and easy to arrange.

Confusion and lack of knowledge about accessing information and requesting an assessment

Our research has found a great deal of confusion among people with Parkinson's and their carers – the majority of whom did not receive social care – about finding information about their local authority's social care support and how to request a social care assessment.

Around 74% of respondents with Parkinson's and 59% of carers were unaware of their local authority's social care information service. Many people with Parkinson's and carers did not know how to request a social care assessment.

It is therefore vital that information about social care is easily accessible, in order to ensure people with Parkinson's and carers get access to the support they need before they reach crisis point.

Social care assessors' knowledge of Parkinson's and quality of assessments.

Our findings indicate that where people with Parkinson's and carers are being assessed, much more needs to be done to ensure the Care Act delivers on its promise of making social care more accessible.

The research identified real concerns among the charity's Parkinson's local advisers around the degree to which social care assessments are conducted with a good understanding of the condition and examine whether a person's condition fluctuates.

Around a third of Parkinson's local advisers that responded to the survey disagreed that "assessments in my area have been conducted with a good understanding of Parkinson's" or asked about how a person's condition fluctuates.

These are clear warnings that the knowledge and understanding of Parkinson's among assessors already requires significant further improvement, in order to ensure that local authority social care services can deliver the support required by people with Parkinson's and carers.

There are indications that people with Parkinson's are losing access to support they desperately need and carers are struggling to get help when they need it.

Most concerning, is the finding that around 10% of people with Parkinson's identified by local authorities have had social care support reduced upon reassessment, despite the fact that the condition is always degenerative.

This supports the views of Parkinson's local advisers, who have questioned whether the Care Act's introduction of a uniform eligibility criteria will mean that more people with Parkinson's and their carers receive access to the vital social care support when they need it.

Advisers also warned of significant difficulties in arranging respite care, to enable carers to get a break from their vital caring responsibilities. It is also of great concern that no carer had been offered preventative support to help them cope, or improve their skills.

Recommendations

Recommendations for the Department of Health (DH)

We recommend that the DH's current research to evaluate the implementation of the Care Act on prevention and support for carers should also include:

- involving people with Parkinson's and their carers in this research, in order to fully understand their experiences and improve the availability of support for people with degenerative conditions
- examining local authorities' compliance with the quality and format of social care assessments to ensure that councils are fulfilling these key requirements
- benchmarking local authorities' social care assessment outcomes, to examine whether councils are adhering to criteria that are the equivalent of "substantial" under Fair Access to Care Services

Recommendations for local authorities

We recommend that individual local authorities across England:

- Collate information about accessing social care in their area and make it easily accessible online
- Proactively engage with local Parkinson's UK groups to share information about social care and also consider meeting with groups in their areas to better understand and address barriers to social care for people with the condition and their carers
- Encourage social care staff to engage and collaborate with Parkinson's UK by joining the UK Parkinson's Excellence Network so they can improve assessors' knowledge and understanding of Parkinson's to avoid situations people with the condition losing vital access to support
- Ensure that when people with Parkinson's and carers are identified by local authorities, they are offered annual reassessments of their needs, to ensure that social care support is increasing in-step with their condition.
- Collect information on named conditions such as Parkinson's, as recommended by the Health and Social Care Information Centre. This will enable them to meet their obligations in the Care Act statutory guidance.

Recommendation for the HSCIC

- We recommend that the HSCIC reissues the Equalities and Classifications Framework guidance to local authorities, and urges them to collect data on people with Parkinson's who access social care.

Appendix 1: Parkinson's and carers' survey questions

1. Which local authority or council area do you live in?

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2. When did you, or the person you care for, get diagnosed with Parkinson's?

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3. Which of the following best describes you? (please tick one)

☐ A person with Parkinson's
☐ A paid carer of a person with Parkinson's
☐ An unpaid carer, friend or family member of a person with Parkinson's

4. If you are a carer, are you responding on your own behalf or on behalf of a person with Parkinson's? (please tick one)

☐ On my own behalf
☐ On behalf of someone with Parkinson's

Information and support

Local authorities are legally required to provide information and support around social care, helping people understand the types of services on offer, how much it might cost, how to pay for it and how to access support

5. Are you aware of your local authority or council's social care information service? (If 'no' please skip to question eight)

☐ Yes ☐ No

6. On a scale of 1-10 (one being lowest, 10 highest) how would you rate the quality of the information provided by the local authority? (please circle one)

1 2 3 4 5 6 7 8 9 10

7. Was information provided on the following services? (please tick all that apply)

☐ Disability benefits
☐ Types of care available
☐ Paying for care
☐ Accessing independent financial advice
☐ Carer's services
☐ Carer's benefits

Assessments

8. When did you last have an assessment of your care needs? (please tick one)

☐ Before 1 April 2015
☐ After 1 April 2015
☐ Not sure
☐ Never been assessed before (please skip to question 36)
☐ I am a carer of a person with Parkinson's

9. Why have you not had an assessment? (please tick all that apply)

☐ I worry I wouldn't be eligible
☐ I don't know how to ask for an assessment
☐ I worry social care would be too expensive for me to afford
☐ I think it would be too emotionally difficult to discuss my Parkinson's
☐ I would find it too stressful
☐ I get all the help I need from friends and family
☐ I don't feel I currently need additional support
☐ Other (please specify)

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10. Despite not having had an assessment, are you currently unable to manage any of the following activities? (please tick all that apply. Please skip to question 36 after answering this question)

☐ Cooking and eating
☐ Going to the toilet
☐ Being able to make use of your home safely
☐ Washing and cleaning yourself
☐ Dressing yourself
☐ Keeping your home clean and tidy
☐ Building and maintaining relationships with friends and family
☐ Accessing and staying in work, training, education or volunteering
☐ Making use of facilities or services in your local community including public transport and recreational facilities or services
☐ Other (please specify)

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11. As a carer, have you ever been offered an assessment of your needs? (please tick one)

☐ Yes ☐ No (please skip to question 30)

12. When was your carer's assessment? (please tick one)
☐ Before 1 April 2015 ☐ Since 1 April 2015

13. Were you offered an assessment in a variety of formats (face-to-face, over the phone)? (please tick one)
☐ Yes ☐ No

14. What format was your assessment?
☐ Phone ☐ Face-to-face ☐ Home-based

15. How long were you waiting between being offered an assessment and receiving one?
☐ 0-1 weeks ☐ 2-3 weeks ☐ 4-5 weeks ☐ 5-6 weeks ☐ 7 or more weeks

16. During your assessment, did the assessor ask about the way your condition, or the way the condition of the person you care for, changes over time?
☐ Yes ☐ No

17. To what extent do you agree with the following statements? (please select one response per row)

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
The assessor gave me the opportunity to explain how my impairment or health condition impacts on my day-to-day life					
The assessor clearly explained to me what information they had recorded					
The assessor gathered an accurate picture of me and how Parkinson's affects day-to-day life					
The assessor had a good understanding of Parkinson's					
I found the assessment a stressful experience					
I found that the assessment had a negative impact on my mental health					

18. Please use the space below to tell us anything you want us to know about the assessment

Assessment outcomes

19. What was the outcome of your assessment? (please tick all that apply)
☐ Was told I had eligible needs (please skip to question 20)
☐ Had eligible needs but had too many savings to receive local authority support
☐ Was told I had no eligible needs
☐ I lost access to support that I was previously given
☐ I was given support I didn't have previously (please skip to question 20)

20. If you have lost (or not gained extra support that you were hoping for) what impact has this had on your life? (please tick all that apply)
☐ The stress has made my life worse
☐ Put pressure on family finances
☐ Less independent
☐ Preventative services have been taken away
☐ Respite care has been cancelled
☐ Had to give up work
☐ Moved into residential care
☐ Entered a care home
☐ Emergency hospital admission
☐ Other

Please tell us more

21. If you have received additional support, what were you offered to meet your eligible needs? (please tick all that apply)
☐ Preventative services (emotional support, access to carers groups, I.T. training, respite care)
☐ Aids and adaptations (grab rails to prevent falls, wheelchairs, sticks and canes)
☐ Home care (a person visiting your home to help you manage things like washing and dressing)
☐ A place in a care home
☐ Other (please specify)

22. What impact has this additional support had on your life? (please tick all that apply)

☐ Regained or retained independence
☐ Enabled me to have a social life
☐ Saved me money
☐ Taken pressure off family and loved ones
☐ Helped manage my needs better

23. Was this sufficient to meet your needs? (please tick one)

☐ Yes ☐ No

24. Sometimes, when receiving social care, your council will provide things to help you or someone you care for move around the home, like rails, walking sticks, or frames. If you or the person you care for receives these have you or they been charged for them since April 2015?

☐ Yes ☐ No

25. If so, approximately how much were you charged?

Personal budgets

26. Were you offered a personal budget – an amount of money paid to you directly, so you can pay for care and support services as you need them?

☐ Yes ☐ No

27. If you were offered a personal budget, was this enough to meet your needs?

☐ Yes ☐ No

28. Approximately how much were you offered?

Care and support planning

Since April 2015, local authorities are supposed to provide you with a "care and support plan" after your assessment, which sets out your needs, whether the local authority will meet them, what you wish to achieve and information on what can be done to reduce your needs.

29. Were you given a care and support plan?

☐ Yes ☐ No

Independent advocacy

30. Would you, or the person you support, have benefited from having an independent advocate, (for example during your assessment) who could represent people with mental capacity issues?

☐ Yes ☐ No

31. Were you offered this?

☐ Yes ☐ No

Paying for care

The Care Act introduced a national deferred payment scheme, which means people with care needs will be able to defer social care costs and pay them at a later date.

32. Were you offered a deferred payment to help you pay for care?

☐ Yes ☐ No

33. Local authorities are able to charge for certain services, such as preventative care. Have you been charged for local authority social care services?

☐ Yes ☐ No ☐ Don't remember

34. Approximately how much were you charged?

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35. Did you feel the amount you were charged was fair?

☐ Yes ☐ Not sure or can't say ☐ No

36. What impact have charges had on your ability to pay for your care?

Appendix 2: Parkinson’s local advisers’ survey questions

1. Are you aware of the local authorites’ social care information service?
☐ Yes ☐ No

2. If yes, was this information available online and in physical form?
☐ Online and physical form ☐ Online only ☐ Physical format only

3. If yes, was information provided on the following services (please tick all that apply)
☐ Disability benefits
☐ Accessing independent financial advice
☐ Types of care available
☐ Carers’ services
☐ Paying for care
☐ Carers’ benefits

4. If yes, does the local authority signpost on to sources of independent financial advice?
☐ Yes ☐ No

5. If yes to question five, was this advice free or charged for?
☐ Free ☐ Charged for

6. If yes to question one, was the information sufficient to meet the needs of your clients?
☐ Yes ☐ No

7. If yes to question one, on a scale of 1-10 (one being lowest, 10 highest) how would you rate the information provided by the local authority? (please circle one)
1 2 3 4 5 6 7 8 9 10

Assessments

8. Based on your experiences supporting people with Parkinson’s and their carers, to what extent do you agree with the following statements? (please select one response per row)

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
Assessments in my area have been conducted with a good understanding of Parkinson’s						
Assessors have asked about how a person’s condition fluctuates						
Assessments build a complete picture of a person’s condition						
Assessments are being offered in a format that best suits the person’s needs (face-to-face, over the phone, online)						
People with Parkinson’s that lack capacity are receiving access to independent advocates when they need them						
People with Parkinson’s are receiving free access to aids and adaptations (such as grab rails in the home, walking sticks or wheelchairs) under the value of £1,000						
People with Parkinson’s are well supported with preventative services to help them slow the progress of their condition (psychological and emotional support)						

9. Based on your experiences of supporting carers of people with Parkinson's, to what extent do you agree with the following statements? (Please select one response per row)

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
Carers are being offered assessments of their needs						
Carers are being well supported with preventative services (such as emotional support, I.T. training) to help them continue their caring role						

9. continued...

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
Carer's assessments have been conducted with a good understanding of the challenges facing a carer of a person with Parkinson's						
Assessments are being offered in a format that best suits the person's needs (face-to-face, over the phone, online)						
Respite care is easy to arrange in my area						

10. Of the assessment outcomes (if any) you have seen, to what extent do you agree with the following statements? (please select one response per row)

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
Assessors are generally making the right decision according to the Care Act assessment criteria for people with Parkinson's						
Assessors are generally making the right decision according to the Care Act assessment criteria for carers of people with Parkinson's						
That decisions on social care eligibility are consistent when you compare claimants of similar needs						
That the eligibility criteria are being applied fairly						
Local authorities are rationing social care because of funding constraints, causing people with Parkinson's to lose out						
Local authorities are rationing social care because of funding constraints, causing carers of people with Parkinson's to lose out						

11. Based on your experiences, to what extent do you agree with the following statements? (please select one response per row)

Statements	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
People with Parkinson's are generally less likely to receive access to appropriate local authority social care support than previously, because of the Care Act eligibility criteria (which are set to the equivalent of "substantial" need)						
Carers are generally less likely to receive access to local authority social care support than previously, because of the Care Act eligibility criteria						
People with Parkinson's are losing access to social care support when being reassessed under the Care Act eligibility criteria						
Carers of people with Parkinson's are losing access to social care support when being reassessed under the Care Act eligibility criteria						

12. Are there any outstanding comments not covered above you would like to make about the Care Act, its implementation by local authorities and its effect on those affected by Parkinson's?

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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Free confidential helpline **0808 800 0303**
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Saturday 10am–2pm). Interpreting available.
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