

# Caring about Parkinson's: How local authority social care services are working for people with Parkinson's and carers in England – Executive summary

**PARKINSON'S<sup>UK</sup>**  
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## 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 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](https://parkinsons.org.uk/caringaboutparkinsons)