PARKINSON'S UK

CHANGE ATTITUDES. FIND A CURE. JOIN US.

Making social care fair in your area:

A guide to campaigning

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About this toolkit

In many cases people living with Parkinson's will need extra support. In these situations, social care is a vital method of keeping people with Parkinson's independent and in control, and stopping families from reaching crisis point.

Our research shows that people living with Parkinson's are often unaware of the support local authorities in England offer and don't know how to ask for an assessment. This campaign is specifically about improving access to support in England, as the situation is different in Scotland, Wales and Northern Ireland.

There are some simple ways councils could better ensure people with Parkinson's get support before they reach crisis point, and better provide information about the support they offer and how to apply for care.

We're asking you, as local campaigners, to reach out to your council and encourage them to take action. This toolkit includes all the information you need to meet with your local councillors and gives you a clear idea of the steps they need to take.

Taking part in this campaign could do so much to improve the lives of those who are affected by Parkinson's. Good quality social care can help people living with Parkinson's to better manage their condition. It can also provide more help and respite for those supporting people living with Parkinson's.

If you need any support or have any questions please contact the Campaigns team on **campaigns@parkinsons.org.uk** or **020 7963 9349**.

HOW YOU CAN HELP

- If you have five minutes, you could send a letter to your local council about our social care campaign.
- If you have an hour, you could meet your councillor and ask them to do more to support people with Parkinson's.
- If you have a day or more, you could launch a local campaign to make social care more accessible in the area.

Why is social care so important for people with Parkinson's and their families?

There are around 127,000 people with Parkinson's in the UK. They experience a mix of over 40 symptoms including tremor, stiffness, slowness of movement, pain, fatigue, slurred speech, problems swallowing, depression, anxiety, dementia, confusion and constipation. Many people with Parkinson's and their carers could benefit from the different forms of social care, such as aids and adaptations in the home, personal care at home and residential care.

Targeted early care can improve quality of life in people with Parkinson's, reduce the strain on carers and help to avoid associated costs to the state such as hospital admissions or the need for residential care.

As Parkinson's gets worse over time, the level of social care and support that people with the condition need to maintain their independence is likely to increase.

The nature of Parkinson's has implications for both the assessment and provision of social care, so a good knowledge of the condition among social care professionals is vital. As Parkinson's is **progressive**, regular reassessments are needed to ensure that support increases in step with an individual's condition.

As Parkinson's is **fluctuating**, assessments must take account of the fact that needs can change dramatically from day to day, and will worsen as Parkinson's drugs wear off during a day. And as each individual with Parkinson's experiences a **unique combination of symptoms**, assessments must be truly person-centred.

What should people with Parkinson's expect from social care in England?

Legislation

From April 2015, the provisions of the Care Act 2014 replaced most existing laws regarding adults with care needs and carers in England.

The Care Act governs what information local authorities are required to provide about social care, who is eligible, how assessments must be carried out, and when and how local authorities can charge for community or residential care. For the first time, standard eligibility criteria for carers and people with care needs apply across all local authorities in England.

However, the level set for eligibility is equivalent to 'substantial needs' under the previous criteria, meaning social care may be harder to access than previously in some areas.

Key changes under the Care Act 2014

The Care Act places local authorities under a general obligation to **promote an individual's wellbeing** (including control over their own day-to-day lives), and obliges them to start from the assumption that an individual is best placed to judge their own wellbeing.

It also obliges them to plan care services **to prevent or delay the development of needs** for care, rather than just responding when people reach a crisis point.

Under the legislation and guidance local authorities are also now obliged to:

- **Provide residents with information and advice relating to care and support for adults and their carers.** This includes information on how to access independent financial advice, carers' services and benefits, disability benefits, understanding care charges and ways to pay.
- **An assessment for any adult who appears to have any level of care needs,** irrespective of the individual's financial situation or whether they think the individual has eligible needs.
- **Conduct person-centred assessments,** aimed at establishing an individual's needs and desired outcomes and involving any person the individual wants to be involved.
- **Consider whether an individual's needs may fluctuate, and factor fluctuating needs into the care plan.** As part of this, they must consider the individual's care and support history over a suitable period of time, and may consider what fluctuations can reasonably be expected based on others with a similar condition.
- **Collect information on care and support needs for named conditions including Parkinson's.** Up to date records on when people with conditions like Parkinson's request support can help shape their planning.

What's going wrong with social care?

Funding for social care has reduced significantly in recent years, forcing local authorities to ration services, which in turn increases the risk that people with progressive conditions such as Parkinson's will only be deemed eligible in the advanced stages of the condition.

Research conducted by Parkinson's UK in July 2016 found that a high proportion of people with Parkinson's (and their carers) were not benefiting from most of the Care Act's reforms.

Our *Caring About Parkinson's* report examined the findings of a survey of almost 350 people with the condition and carers, Parkinson's local advisers, as well as responses to Freedom of Information (FOI) requests to local councils responsible for providing social care in England. The report found that:

- Almost three-quarters (74%) of our respondents are **not aware of what social care is available to them or how to access it**. This means that they may not be receiving assessments or support to which they are entitled.
- Furthermore, our research found that 51% of respondents with Parkinson's and 76% of carers are not being offered social care assessments, despite changes to legislation that mean assessments should always be offered to anyone who appears to have needs. This means they **may not receive social care until they reach crisis point** – a situation that often results in people needing expensive social care.
- Around a third of Parkinson's local advisers (who provide local advice and support to people applying for social care) disagreed that **social assessments are carried out by people with a good understanding of Parkinson's**. There's therefore a risk that they will not fully explore all of the motor and non-

motor symptoms. In addition, some assessors **fail to ask about how a person's condition fluctuates**.

- Most concerning of all, our research found that around 10% of people with Parkinson's in 21 local authority areas **have had their support reduced upon reassessment**. Despite the fact that Parkinson's is degenerative. This may be due to their budget constraints, or because of the tougher eligibility criteria introduced by the Care Act.
- Around two thirds of councils who responded to our FOI requests were unable to provide any of the information we asked for. In the majority of cases, this was because to the local authority did not collect data by condition.

Research commissioned by Parkinson's UK in 2014 emphasised the importance of an 'anticipatory approach' to social care, which increases in step with a person's growing needs. This can stop families reaching crisis point, when informal carers are no longer able to cope and a significant amount of expensive social care is needed.

What we're asking local councils to do

Our *Caring About Parkinson's* report recommended a number of simple things local councils could do to make social care easier to access and Parkinson's friendly.

Our campaign is asking councils to:

- make social care easier to access in their area by putting information in one place on their website and making it available in public places
- keep in touch with local Parkinson's UK groups in the area to share information about social care. They could perhaps meet with groups in their areas to better understand and address barriers to social care for people with the condition and their carers, and also to explain what is available.
- encourage their social care staff to join the UK Parkinson's Excellence Network – the major professional network for people involved in Parkinson's care. This would improve assessors'

WHAT YOU CAN DO?

Our research set out a number of recommendations for councils in England, to help make social care more accessible and visible for people with Parkinson's and their families.

We need as many people as possible to meet their councillor in order to make sure these recommendations are taken up.

Here's a suggested plan of action for your campaign:

1. Gather evidence or case studies
2. Identify your councillor using the details in this toolkit.
3. Write to them with your concerns.
    - Follow the letter up four weeks later if you haven't heard anything.
    - If your councillor still doesn't respond, write a letter to the editor of your local newspaper outlining your concerns.
4. Prepare to meet with the councillor if they agree. Thank them by letter or email after your meeting, and use this to summarise what they agreed to do to help you.
5. Two weeks after your meeting, follow up any actions your councillor has agreed to undertake for you by letter or email.
6. Invite your councillors to a local group meeting. This can help build a relationship that you can use to encourage them to take action.
7. Complete the feedback form on pages 11–12 to let the Policy and Campaigns team know how you got on.
8. Keep in touch with your councillor – invite them to group events and activities in the future.

If you'd like further information or advice on any of these, please contact us on **campaigns@parkinsons.org.uk or 020 7963 9349** 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 your council, they are offered annual reassessments of their needs, to ensure that social care support is increasing in step with their condition
- collect information on conditions such as Parkinson's, as recommended by NHS Digital. This will enable them to meet their obligations in the Care Act statutory guidance.

BOB'S STORY

Bob has been caring for his wife Pauline since she was diagnosed with Parkinson's over 24 years ago and was struggling to cope.

Bob was interviewed on a local radio station, where his story was heard by his local councillor. As a result, she contacted him to talk about his concerns and how to help improve services for carers in the area.

She also agreed to support Bob's case for NHS funded care so the couple would no longer have to contribute to care costs out of their own savings.

> "I thought it was really important to speak up and let people know how hard it is for carers to get the right services. I was so pleased when our councillor contacted us and said she was coming over for a cup of tea. We are now getting some of the financial help we need, and our case is being used by the council to highlight the suffering caused by social care and health not working together."

Gathering evidence and case studies

To persuade people to support your campaign or convince decision makers that something needs to change, you need to prove your issue is a problem (not a one-off difficulty) and show how it can be fixed. To do this you need evidence. Evidence can be facts, figures and real-life stories. It must be 100% accurate and stories must be true.

Case studies

You may already know people who would benefit from social care but don't have any support. But don't be afraid to ask other people for their personal experiences – chances are they'll be glad to help if you explain how it will boost your campaign.

Two real-life stories will really help build your case. Local groups are a good place to find people who might be willing to tell their story. You may be able to build a group of people affected by the issue who will help you with your campaign.

Facts and figures

This toolkit sets out many of the existing legal requirements councils should be meeting. See 'What should people with Parkinson's expect from social care in England?' on page 3 for information on current legislation.

To get more specific local evidence, you could also ask other people connected to your issue such as your Parkinson's nurse or consultant.

If you still can't find the evidence you need, you could get it by:

- starting a petition and asking people who sign to share their experiences
- carrying out a questionnaire in patient or support groups (an example questionnaire is available in the appendix)
- carrying out a survey – either on paper or using an online survey tool such as Survey Monkey (you can replicate the questions in our example questionnaire)

Who should I contact?

In England, many areas have different types of council – district, borough or city councils that are known as 'lower tier' and county councils that are known as 'upper tier'. Some areas have just one level of council, which provides all services. These are called 'unitary authorities' in areas that also have a county council. London boroughs or metropolitan boroughs are also unitary authorities. County councils, unitary authorities, London boroughs or metropolitan boroughs are responsible for social care provision.

Your local councillor(s) is a good way of making contact with the council as they have a duty to you as one of their constituents. However, there may be specific decision makers you want to target such as the Council Leader or a councillor with a responsibility for social care. You can use **www.writetothem.com** to find out who your local councillor(s) is, which council is responsible for social care in your area or contact the Campaigns team on **campaigns@parkinsons.org.uk** or **020 7963 9349** to check.

HOW DO I LOBBY MY COUNCIL?

You can lobby your councillors in one of these three ways::

- By letter – please see the template letter on page 9 which you can personalise and send off. Making the letter your own will make it more likely that your councillor will respond.
- By arranging a meeting.
- By going to their surgery – you can find details of the council's surgery times and dates on your local council website.

Meeting your councillor

Meetings with decision makers give you the opportunity to put your message across directly. As decision makers are often very busy, you are likely to only have a short time with them, so make it count! Talking person-to-person gives you the opportunity to explain your

Top tips for successful meetings

Before the meeting

✓ Think carefully about what you want to say and write down the key points to take with you.

✓ Get all your evidence together.

✓ Send information to everyone who will be there (the attendees). This should be a list of the attendees and an agenda or short summary of the issues you want to talk about.

✓ Decide what you are going to ask the decision maker to do.

✓ Prepare a short written briefing to leave with the councillor with your main points, evidence, solutions and your contact details.

During the meeting

✓ Make notes during the meeting or just afterwards to record what was said and who said it.

✓ Make sure you give your councillor the briefing you have prepared.

✓ Take a photo of you meeting with your councillor – you can use this in your branch newsletter.

After the meeting

✓ Write to the people you have met afterwards, thanking them for coming to the meeting. An email is fine.

✓ Include a summary of what was discussed and a list of actions that people agreed to take.

✓ If you don't hear back, get back in touch about four weeks later to find out what's happening.

✓ If you haven't heard back after four weeks you could write a letter to the editor of your local newspaper (please see page 10) outlining your concerns about access to social care for people with Parkinson's in the area. Most local papers will have a letters page with instructions on how to send in letters, and similar information will be on their website.

concerns and possible solutions. It also means that the decision maker has to answer your points.

Remember our goals for this campaign include the following:

- Making information about social care easily accessible.
- Better monitoring of how many people with Parkinson's are requesting support.
- Encouraging councils to work with Parkinson's UK and access our specialist support and training.
- Making sure people with Parkinson's get reassessed for their social care needs and offered more support when they need it.

Thank you

Thank you for taking the time to look through this toolkit. We hope you've found it a useful guide on how to start campaigning for better social care in your area.

We'd love to hear from you once you get your campaign off the ground. Do use the feedback form at the end of this guide to let us know about any meetings you've had with your local councillors.

If you do need any more support or advice please email us at **campaigns@parkinsons.org.uk** or call **020 7963 9349**.

Resources

You can read more about our research on social care and the gaps for those affected by Parkinsons, *Caring about Parkinson's*, at **parkinsons.org.uk/caringaboutparkinsons**

You can read more about the research Parkinson's UK conducted in partnership with researchers from Sheffield Hallam on social care at **parkinsons.org.uk/sites/default/files/socialcareresearchsummary.pdf**

The full Parkinson's UK campaigns toolkit is available at **parkinsons.org.uk/campaignstoolkit**

The UK Parkinson's Excellence Network brings together health and social care professionals to transform care for people affected by Parkinson's. You can access their materials and resources at **parkinsons.org.uk/professionals**

Campaign checklist

☐ Gather evidence or case studies.

☐ Identify your councillor using the details in this toolkit (page 7).

☐ Write to them with your concerns (page 9).

☐ Follow the letter up four weeks later if you haven't heard anything.

☐ If your councillor still doesn't respond, write a letter to the editor of your local newspaper outlining your concerns (page 10).

☐ Prepare to meet with councillor if they agree. Thank them by letter or email after your meeting, use this to summarise what they agreed to do to help you.

☐ Two weeks after your meeting, follow up any actions your councillor agreed to undertake for you by letter or email.

☐ Invite your councillors to a local branch meeting. This can help build a relationship that you can use to encourage them to take action.

☐ Complete the feedback form (page 11) to let the Policy and Campaigns team know how you got on.

TEMPLATE LETTER TO COUNCILLOR

[Insert your name & address]

[Insert councillor name]
[Add councillor address]
Postcode

Date

Dear [Insert councillor Name]

RE: Improving social care in [Insert your city/town/village]

As your constituent, I am writing to express my concern that people with Parkinson's are not able to access social care when they need it most. I need to ask for your help in making care more accessible in the area.

You may know that Parkinson's is an incurable neurological condition with symptoms such as freezing, tremor, confusion, slurred speech, pain, fatigue and dementia.

Parkinson's is degenerative. This means that some people with the condition and their loved ones find the support that social care provides absolutely invaluable when it can be accessed in a timely way.

However, research conducted by Parkinson's UK in 2016 found that:

- Over half of respondents with Parkinson's and three quarters of carers had never received an assessment.
- Almost three quarters of respondents with Parkinson's and two thirds 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 an assessment.

I am pleased to say there are a number of simple things the council could do to address these issues and make social care more accessible for people with Parkinson's and their families.

For example, the council could consider making information about social care more prominent on the website and accessible offline, or keeping in touch with your nearest Parkinson's UK group to share information with them about accessing social care.

I would welcome the opportunity to further discuss this issue with you, if you have some time in the near future.

Yours sincerely,

[Add your name]

TEMPLATE LETTER TO NEWSPAPER EDITOR

[Insert your name & address]

[Add editor name]
[Add newspaper title]
[Add address}
Postcode

Date

Dear [Insert Editor Name]

RE: Improving social care in [Insert your city/town/village]

I write to express my concern that people with Parkinson's are not able to access social care in **[Insert your city/town/village]**, when they need it most.

Parkinson's is an incurable condition that gets worse over time. It includes symptoms such as freezing, tremor, confusion, pain and dementia. This means that some people with Parkinson's and their families find social care invaluable when it can be accessed.

However, research conducted by Parkinson's UK in 2016 found that almost three quarters of respondents with Parkinson's and two thirds of carers were unaware of their local authority's social care information. Many people also did not know how to request an assessment.

There are some simple things the council could do to address these issues, like making information about social care easy to find on the website, making information accessible offline, or offering assessments more proactively.

These small changes will make social care more accessible for people with Parkinson's and their families.

Yours sincerely,

[Add your name]

FEEDBACK FORM

If you've used this guide to contact your councillor to ask for improvements in access to social care, please let us know what discussions you've had and what the outcome was.

Name .... **Group** ....

Address ....

Telephone ....

Email ....

Local authority ....

Name of Councillor contacted ....

What did you discuss?

Please add details below in comments box.

What did your councillor agree to do?

Please add details below in comments box.

Please add any other comments

Please add details below in comments box.

How will you be keeping in touch with the current councillors?

Please add details below in comments box.

Which local paper did you contact and what was their response?

Please add details below in comments box.

Please return this form in the post to: **Policy and Campaigns team, Freepost RLUB-RSHA-KSET, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**

You can find the full Parkinson's UK Campaigns toolkit at **parkinsons.org.uk/content/campaign-resources**

SOCIAL CARE SURVEY QUESTIONS

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

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

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

3. Are you aware of your local authority or council's social care information service?

☐ Yes ☐ No

4. 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

Assessments

5. When did you (or the person you support) last have an assessment of your care needs? (please tick one)

☐ Before 1 April 2015
☐ After 1 April 2015
☐ Never been assessed before
☐ I am a carer of a person with Parkinson's
☐ Not sure

IF YOU (OR THE PERSON YOU SUPPORT) HAVE NOT HAD AN ASSESSMENT COMPLETE THE TWO QUESTIONS BELOW

6. Why have you (or the person you support) 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):

7. Despite not having had an assessment, are you (or the person you support) currently unable to manage any of the following activities?

☐ Cooking and eating

☐ Washing and cleaning yourself

☐ Going to the toilet

☐ Being able to make use of your home safely

☐ 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

☐ Dressing yourself

☐ Keeping your home clean and tidy

☐ Other (please specify):

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.

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.
Text Relay **18001 0808 800 0303**
(for textphone users only)

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