

PARKINSON'S^{UK}



NOWHERE NEAR ENOUGH

What the government must do so that people with Parkinson's can survive the cost of living crisis

Contents

Key findings.....	03
About Parkinson's.....	04
Economic context.....	05
Parkinson's UK cost of living survey 2022.....	06
Cost of Living Payments and Energy Bills Support Scheme.....	09
Flawed system.....	10
Conclusion and recommendations	12
References.....	13

Key findings

To better understand how the cost of living was impacting our community, we ran a survey in September and October of 2022 and received over 400 responses from people with Parkinson's and those who support them.

- Almost **two thirds** (61%) of survey respondents with Parkinson's said they are **struggling to cover costs** in general.
- Over **three quarters** (77%) said they expected they would **turn on their heating less** frequently, come the winter **to save on fuel costs**.
- **A quarter** (25%) said they are having **fewer meals in order to save money**.
- Well over **two thirds** (70%) felt **more socially isolated** than they did at the start of 2022.
- **Two in five** (40%) say their **symptoms have been made worse** by their financial situation.
- **Gas bills, electricity bills and food** were the costs that survey respondents with Parkinson's said are most difficult to manage.

We call on the UK government to urgently boost the UK Energy Bills Support Scheme for people with Parkinson's by an extra £1,200 to cover costs incurred in winter 2022/23, and to repeat this payment in 2023/24.



About Parkinson's

There are over 40 symptoms of Parkinson's and these can include freezing, tremor, painful muscle cramps, difficulties speaking and swallowing, anxiety, depression, dementia and hallucinations.

145,000 people in the UK are living with Parkinson's.¹ It is the fastest growing neurological condition in the world.² With population growth and ageing, we estimate this will increase by nearly a fifth to 172,000 by 2030. Parkinson's not only affects those with the condition but also has a significant impact on family, friends and carers.

While the majority of people develop symptoms after the age of 65, thousands of working age people are also affected.³

About Parkinson's UK

Every hour, two more people are told they have Parkinson's. A neurological condition that gets worse over time. There is no cure. Yet.

Parkinson's UK is here for everyone affected by Parkinson's. Fighting for fair treatment and better services. Making everyone see its real impact.

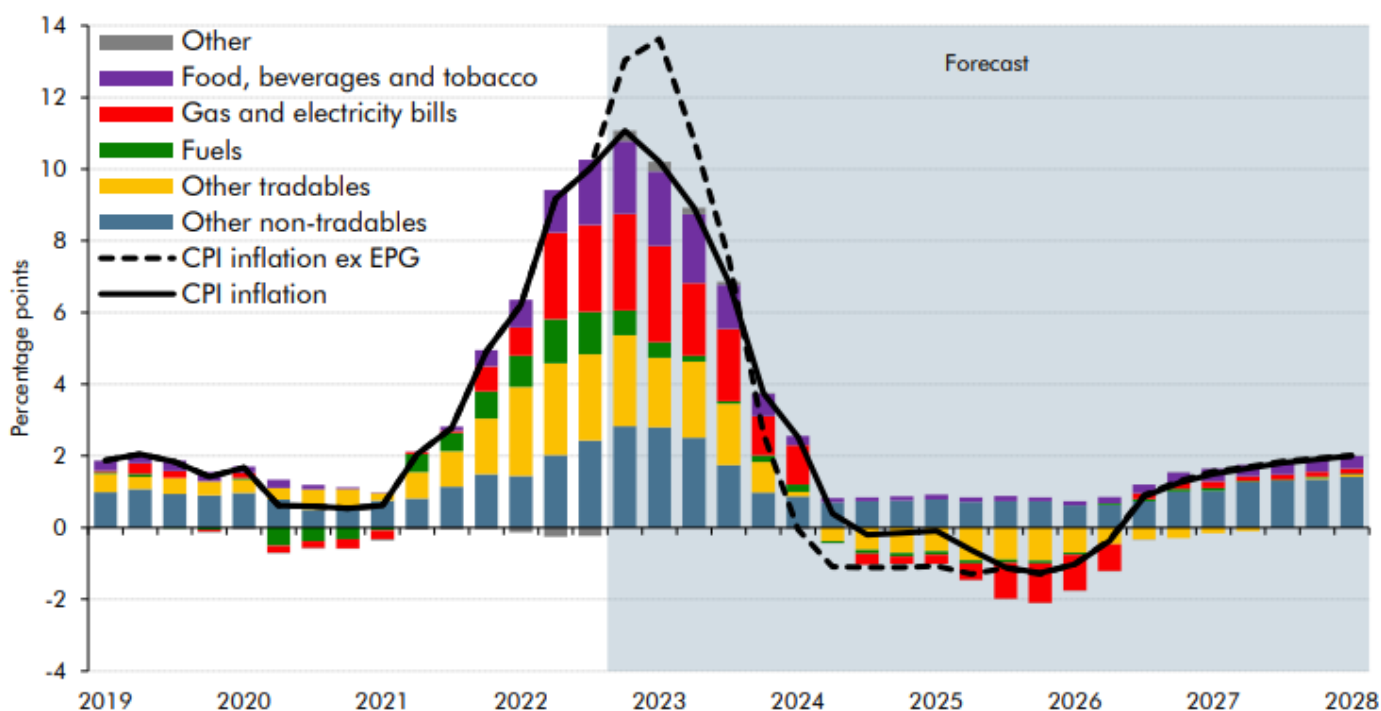
People with Parkinson's, scientists and supporters, fundraisers and families, carers and clinicians, all working side by side. Impatient for change, we're taking a stand, speaking out, chipping in, and playing our part.



Economic context

The UK has been experiencing a cost of living crisis since late 2021.⁴ From early 2022, household fuel and food were the costs that rose most significantly (see chart one below).

Chart one: Contributions to CPI inflation



Source: ONS, OBR

While the whole UK population experienced these spiralling costs, people with Parkinson's were hit harder than most.

Parkinson's affects the nervous system, which controls body temperature, so people with the condition can be more sensitive to heat and cold. If someone with Parkinson's is unable to keep warm, they can experience debilitating chronic limb pain, which can also negatively affect their mental health.^{6,7}

This greater need for warmth costs a household that includes someone with Parkinson's more each year. In 2017, the extra annual average household energy cost that people with Parkinson's had to pay was calculated

by Sheffield Hallam University⁸ to be £571. As a result of an overall increase in household energy specific consumer price index (CPI) since 2017, that cost escalated to £632 in 2021.⁹ In 2022, this figure increased by a further 89% to £1,196.¹⁰

According to energy market analysts Cornwall Insight, household fuel bills are not expected to return to pre-pandemic levels before the end of the decade.¹¹

Parkinson's UK cost of living survey 2022

“ I earn £1,350 per month (I can't continue to work 31 hours each week). My husband earns between £100 and £400 per month; this is all we have to live on. Everyday I am facing anxiety trying to juggle money to pay bills.”

Person with Parkinson's

“ My wife with Parkinson's is just starting with mobility issues affecting her daily life. Not everyday, she does work 3 days but luckily can work from home. My biggest fear at the moment is that we won't be able to manage financially.”

Person who supports someone with Parkinson's

Over a third (34%) of the people with Parkinson's who responded to our survey reported not having enough money to get by, with energy bills and food being the most difficult costs to manage. Just short of two thirds (61%) of people with Parkinson's are struggling to cover these costs.

Unaffordability of household fuel costs

“ I am often cold because we are trying to keep costs down. While the temperature looks ok, I cannot move, we are in the house all day so it is difficult keeping warm”

Person with Parkinson's

“ Due to constant sweats and dyskinesias (involuntary movements), especially during meal times, I have to change my clothes frequently due to making a mess with meals and drinks. The cost of washing and using water is far greater for me because of this.”

Person with Parkinson's

“ As we are not using our central heating yet, I tend to seize up and my falls are increasing as a result.”

Person with Parkinson's

Three quarters (77%) of people with Parkinson's said they expected to turn on their heating less during the winter of 2022-23, in order to save on fuel costs. This contrasts with the less than two thirds (57%) of the general UK population who are finding it harder to afford utility payments than in May 2022.¹²

Being cold has the effect of causing pain in those living with Parkinson's, and leads to difficulty walking or standing.¹³ So, not only is increased pain difficult to manage, it also means people with Parkinson's are less able to manage their symptoms through exercise.

Unaffordability of food and impact on the condition

“ I'm already trying to have the heating on less and cut down to one cooked meal per day.”

Person with Parkinson's

“ My main concern is heating and food costs. Food costs are also of concern, in particular, where specific dietary requirements are needed.”

Person who supports someone with Parkinson's

“ Keeping within a food budget is a real challenge now. We don't buy as much fruit and veg as we used to because we rely on online shopping and the cheaper produce is often out of stock, so they only offer the more expensive items which we just cannot afford to buy at such ridiculous prices.”

Person who supports someone with Parkinson's

Our survey found that a quarter (25%) of people with Parkinson's are having fewer meals in order to save money. A quarter (25%) of respondents also said they were eating less healthy food in order to save money. This is very worrying given that it's important that a person with Parkinson's gets all the nutrients they need, as this can help reduce symptoms including constipation, muscle weakness and fatigue.^{14 15}

And common symptoms such as muscle rigidity and dyskinesia (involuntary movement) can burn a lot of energy,¹⁶ which necessitates a high calorie intake.

People with Parkinson's are also at risk of oxidative stress, which causes cell and tissue damage. A good diet – specifically the daily consumption of five portions of a variety of fruit and vegetable – is critical to minimising this risk.¹⁷

Additionally, those with the condition are at increased risk of poorer bone health and are often diagnosed with osteoporosis. This is compounded by the fact that the absorption of protective nutrients like calcium is reduced in people with Parkinson's. And loss of balance and falling also affects many people with Parkinson's. All of this means that consuming enough vitamin D and calcium is crucial¹⁸ for people with Parkinson's.

Cheaper foods, such as canned vegetables and fried food, are associated with more rapid progression of Parkinson's.¹⁹

As well as negatively affecting Parkinson's symptoms directly, a poorer diet can also make medication less effective. Diet discipline, such as following a protein redistribution diet, where protein intake is concentrated at certain times of the day, can make medications like levodopa more effective and control side effects.²⁰

Unaffordability of travel, less social interaction, less exercise

“I don't see my friends and family as much as I used to do. My home is colder due to fuel costs, and these things have impacted on my mental health which in

turn has made my Parkinson's symptoms worse.”

Person with Parkinson's

“Right now I have to travel by taxi when attending any appointment which might improve my health. Sometimes I have to cancel my appointment because I can't afford to pay.”

Person with Parkinson's

“I can't afford visiting the person as often as before so she's spending more time by herself, getting less active physically.”

Person who supports someone with Parkinson's

Nearly half of the people with Parkinson's who responded to our survey (48%) reported socialising less frequently due to their financial situation. Well over two thirds (70%) of people with Parkinson's said they felt more socially isolated than they did at the beginning of 2022. The vast majority (88%) of people who support someone with Parkinson's say that person has become more socially isolated since the beginning of 2022.

Both isolation and loneliness are well known to be highly damaging to both physical and mental health.²¹

“Less access to wellbeing facilities equals less movement.”

Person with Parkinson's

“I am having to cut back on a lot of activities such as exercise classes and gym membership and I am not as active as I was. I know I could exercise without attending classes but the motivation is much more difficult.”

Person with Parkinson's

Almost a quarter (22%) of people with Parkinson's who responded to our survey said their financial situation has meant that they attend physical activity sessions less frequently. And according to Sport England, almost half of the people (48%) they surveyed think the cost of living is likely to have a negative impact on their ability to be physically active in the future. Sport England also found that people from lower socioeconomic backgrounds, those living in the most deprived places and people with a disability or long-term health condition, are most likely to agree the cost of living is having a significant impact on their ability to be physically active.²²

This matters for people with Parkinson's, as being active for 2.5 hours a week can help manage Parkinson's symptoms and has a positive impact both physically and mentally.²³

“Physical exercise can help with managing both motor and non motor symptoms. In the winter months many people with Parkinson's have to rely on online exercise classes. However, fuel poverty means that many people with Parkinson's cannot afford to heat their homes to a reasonable temperature, this not only restricts movement but importantly limits their ability to stay active which adversely impacts on their health and causes deconditioning.”

Dr David Dexter, Parkinson's UK Director of Research

Impact on symptoms

“Medication takes longer to activate when I am stressed. I shake more and my coordination is worse.”

Person with Parkinson's

“I'm struggling with my mental health as I have PTSD from military service. I have also noticed that my hands and head tremors become more intense and frequent when I think about my current financial status.”

Person with Parkinson's

Well over a third (40%) of people with Parkinson's told us that their symptoms are being made worse by their financial situation. When people's physical symptoms are worsened, their mental health is affected too. At any given time 40%²⁴ of people with Parkinson's will have depression and up to 31%²⁵ will experience anxiety. Just as worsening physical symptoms has a negative impact on mental health, compromised mental health has a detrimental effect on physical symptoms as well as on the effectiveness of medication.

Worsening symptoms leave people with Parkinson's feeling isolated, as both mobility and motivation are affected. As mentioned above, the negative consequences of isolation and loneliness are very well documented.²⁶

“I worry that I won't be able to afford heating and food. Worrying that I can't afford heating, so I'm not moving around because I'm already using a fleece blanket. My movements are getting slower, this is not good for me”

Person with Parkinson's

“Worry, stress and anxiety make my Parkinson's symptoms worse. My tremor is worse, my balance and ability to walk. I feel anxious and stressed all the time worrying what the future might bring.”

Person with Parkinson's

Cost of Living Payments and Energy Bills Support Scheme

In response to increasing household fuel costs, in May 2022 the then Chancellor announced the Cost of Living Payment package, which provided the following support:²⁷

- **£650 for those receiving means-tested benefits** such as, amongst others, Universal Credit and Pension Credit.
- **£150 for those receiving disability benefits**, such as Personal Independence Payment and Attendance Allowance.²⁸
- **£300 for pensioner households.**
- **£400 Energy Bills Support Scheme**,²⁹ payment for all UK households were granted a rebate on their electricity bill.³⁰

Those who qualified for all of these payments and rebates gained £1,500 between May 2022 and March 2023. Yet only one of these payments was targeted at disabled people specifically - the £150 Disability Cost of Living Payment. That payment was only made to people who were receiving a disability benefit. And even if a person with Parkinson's received all the Cost of Living Payments available in 2022/23, it would have left them with just £300 once they had paid for their extra household fuel costs. That £300 would need to stretch to cover the escalating cost of other essentials such as food and transport, for a year.

But this is nowhere near enough. Over half (51%) of the people with Parkinson's who responded to our survey said their benefits are not enough to live on and pay for disability related costs. Less than half (43%) agree that the UK government's Cost of Living Payments are enough to meet all daily living costs.

In January 2023, the Government announced another series of Cost of Living Payments to be paid from April 2023:

- **£900 for those receiving means-tested benefits** such as, amongst others, Universal Credit and Pension Credit.
- **£150 for those receiving disability benefits**, such as Personal Independence Payment and Attendance Allowance.
- **£300 for pensioner households.**³¹

By Spring 2024, those eligible for two years' worth of Cost of Living Payments will have received £2,850. With the Office for National Statistics reporting UK food prices rising at the fastest rate in over 40 years and motor fuel prices and rail fares still rising, this is woefully adequate.

Flawed system

“ I have Parkinson’s but wouldn’t qualify for PIP as I am ok for most of the time due to medication, but do have several hours a day which are less good. I am surviving on my small work pension as at 61 won’t get a state pension for a long time. I wouldn’t be fit enough to work and get tired easily. Most of my very limited disposable income is spent on exercise classes online with a physiotherapist specialist in Parkinson’s. I get no financial support or any other help from anywhere.”

Person with Parkinson’s

Even if the Disability Cost of Living Payment truly reflected the extra cost of living with Parkinson’s in a cost of living crisis, not everyone in need will have benefited from the payment. This is because not everyone will have been getting a qualifying disability benefit.³²

When we spoke to people with Parkinson’s in 2021, half (50%) of people with Parkinson’s with experience of benefits and employment support, said the person assessing how Parkinson’s affects daily living, didn’t have a good knowledge of the condition.³³

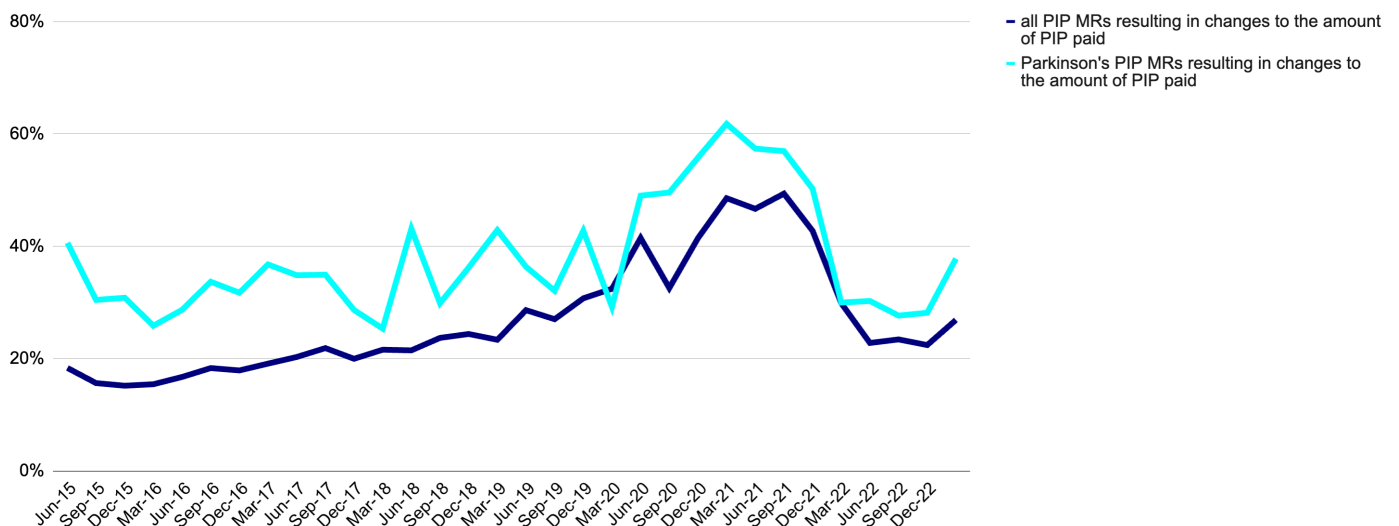
In our most recent research, we found that:

- Less than two in five (38%) of working age people living with Parkinson’s are getting Personal Independence Payment (PIP), Disability Living Allowance (DLA) or Adult Disability Payment (ADP).
- Less than a quarter (22%) of people with Parkinson’s of state pension age and over, get Attendance Allowance (AA).

Over a third (38%) of PIP claims made by people with Parkinson’s since quarter end June 2015 were initially assessed incorrectly. These cases were revised following mandatory reconsideration of the decision and the amount awarded to the claimant changed.

This figure is, on average, 10% higher than that for the general PIP claimant population (see chart two).³⁴

Chart two: PIP mandatory reconsiderations resulting in a change of amount of benefit



Source: DWP

Many people with Parkinson's who are incorrectly assessed as being ineligible for PIP will accept that decision, unless they receive advice from an expert, such as a Parkinson's UK adviser.

If those who do not challenge DWP's initial assessment of their PIP claim are factored in, the proportion of people with Parkinson's who do not get the benefit they are entitled to, first time, will exceed a third of applicants by a large margin.

For too many people with Parkinson's, the benefits system isn't working. This means there are very real limitations to relying on the benefit system to identify those most in need of cost of living support, due to their disability.

The government has suggested that those who did not receive Cost of Living Payments should seek support from their local authority Household Support Fund (HSF). Yet, with HSF eligibility criteria set locally, there is no guarantee that people with Parkinson's in need, will be supported.

Tried and tested alternative

We believe that there is an alternative. During the height of the Covid pandemic, the Summary Care Records (SCR) database (and devolved equivalents) was used to identify those most at risk of serious illness if infected. We believe the UK government should use SCR to identify those diagnosed with Parkinson's and provide them with additional support for their extra household fuel costs via the same mechanism used to provide UK households with the £400 fuel rebate.

Conclusion and recommendations

While we welcome the support offered to people with Parkinson's, we know it is nowhere near enough. Not only are the amounts offered inadequate, too many people with Parkinson's simply have not qualified for any of the Cost of Living Payments.

The cost of living crisis and the government's inadequate support for people with Parkinson's is damaging the health of our community. Without adequate support, people with Parkinson's are experiencing worsening physical and mental health.

Not only do worsening symptoms damage the quality of life experienced by people with Parkinson's, it costs the health service in increased treatment costs. And it costs the government in lost income tax revenue, as people with Parkinson's become less able to work.

People with Parkinson's are living in fear of how they will manage the cost of living and their condition. The government must take urgent action to address this.

We call on the UK Government to:

- identify people with Parkinson's via the SCR and devolved equivalents
- boost financial support provided to people with Parkinson's by £1,200 for the years 2022/23 and 2023/24, using the Energy Bills Support Scheme mechanism.

“ At the moment because I'm still working we can manage these bills. I do now start to wonder how we will, as my symptoms worsen, and I know I will have to stop working.”

Person with Parkinson's

Parkinson's UK
April 2023

References

- ¹ The incidence and prevalence of Parkinson's in the UK. Parkinson's UK. 2018. Available at <https://bit.ly/3ntTYJK>,
- ² Bloem B R. Okun M S. Klein C. Parkinson's disease. *The Lancet*. 2021. Available at [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00218-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00218-X/fulltext)
- ³ Pringsheim T. Jette N. Frolkis A. Steeves T D L. The prevalence of Parkinson's disease: a systematic review and meta-analysis. *Movement Disorders*. 2014. Available at <https://pubmed.ncbi.nlm.nih.gov/24976103/>
- ⁴ Hourston P. Cost of living crisis. Institute for Government. 2022. Available at <https://www.instituteforgovernment.org.uk/explainer/cost-living-crisis>
- ⁵ Inflation measured by consumer price index (CPI) is defined as the change in the prices of a basket of goods and services that are typically purchased by specific groups of households Definition. Available at <https://data.oecd.org/price/inflation-cpi.htm>
- ⁶ Kataoka H. Ueno A. Severe Cold Lower Limbs in Patients with Parkinson's Disease During the Summer. *Neurology International*. 2016. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5136751/>
- ⁷ Turk D C. Fillingim R B. Ohrbach R. Kushang V. Patel K V. Assessment of Psychosocial and Functional Impact of Chronic Pain. *The Journal of Pain*. 2016. Available at <https://www.sciencedirect.com/science/article/abs/pii/S152659001600523X>
- ⁸ Gumber A. Economic, Social and Financial Cost of Parkinson's on Individuals, Carers and their Families in the UK. Sheffield Hallam University. 2017. Available at <https://shura.shu.ac.uk/15930/12/Gumber%20Economic%20Social%20and%20Financial%20Cost%20of%20Parkinsons%20.pdf>
- ⁹ Inflation and price indices. ONS. Available at <https://www.ons.gov.uk/economy/inflationandpriceindices>
- ¹⁰ Inflation and price indices. ONS. Available at <https://www.ons.gov.uk/economy/inflationandpriceindices>
- ¹¹ Bagge B. Offshore wind crucial to stabilising the UK energy market. Cornwall Insight. 2022. Available at <https://www.cornwall-insight.com/press/offshore-wind-crucial-to-stabilising-the-uk-energy-market/>
- ¹² YouGov's Cost of Living research (Sample Size: 1719 adults in UK Fieldwork: 10th - 11th November 2022)
- ¹³ Kataoka H. Ueno A. Severe Cold Lower Limbs in Patients with Parkinson's Disease During the Summer. *Neurology International*. 2016. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5136751/>
- ¹⁴ Knight E. Geetha T. Burnett D. Babu J R. 2022. The Role of Diet and Dietary Patterns in Parkinson's Disease. *Nutrients*. 2022. Available at <https://www.mdpi.com/2072-6643/14/21/4472>
- ¹⁵ Gałtarek P. Kałużna-Czaplińska J. 2021. Nutritional aspects in Parkinson's disease. *Critical Reviews in Food Science and Nutrition*. 2021. Available at <https://www.tandfonline.com/doi/abs/10.1080/10408398.2021.1902261>
- ¹⁶ Barichella M. Emanuele Cereda E. Pezzoli G. Major nutritional issues in the management of Parkinson's Disease. *Movement Disorders*. 2009. Available at <https://movementdisorders.onlinelibrary.wiley.com/doi/abs/10.1002/mds.22705>
- ¹⁷ Ciulla M. Marinelli L. Cacciatore I. Di Stefano A. Role of Dietary Supplements in the Management of Parkinson's Disease. *Biomolecules*. 2019. Available at <https://www.mdpi.com/2218-273X/9/7/271>

References

- ¹⁸Barichella M. Cereda E. Cassani E. Pinelli G. Lorio L. Ferri V. Privitera G. Pasqua M. Valentino A. Fatemeh Monajemi F. Caronni S. Lignola C. Pusani C. Bolliri C. Samanta A. Faierman S A. Lubisco A. Frazzitta G. Petroni M L. Pezzoli G. Dietary habits and neurological features of Parkinson's disease patients: Implications for practice. *Clinical Nutrition*. 2017. Available at <https://www.sciencedirect.com/science/article/abs/pii/S0261561416301558>
- ¹⁹Lange K W. Nakamura Y. Chen N. Guo J. Kanaya S. M. Lange K M. Li S. Diet and medical foods in Parkinson's disease. *Food Science and Human Wellness*. 2019. Available at <https://www.sciencedirect.com/science/article/pii/S2213453019300230>
- ²⁰Boelens Keun J T. Ac Arnoldussen I. Vriend C. van de Rest O. Dietary Approaches to Improve Efficacy and Control Side Effects of Levodopa Therapy in Parkinson's Disease: A Systematic Review. *Advances in Nutrition*. 2021. Available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8634393/>
- ²¹Leigh-Hunt N. Bagguley D. Bash K. Turner V. Turnbull S. Valtorta N. Caan W. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*. 2017. Available at <https://www.sciencedirect.com/science/article/abs/pii/S0033350617302731>
- ²²Activity Check-in: Focus on - the impact of cost of living. Sport England. 2022. Available at <https://sportengland-production-files.s3.eu-west-2.amazonaws.com/s3fs-public/2022-11/Activity%20Check-in%20-%20cost%20of%20living.pdf?VersionId=FJVVDlzUMbL8vmVrrsrzRLrVKISnhme4>
- ²³Fayyaz M. Jaffery S S. Anwer F. Zil-E-Ali A. Anjum I. The Effects of Physical Activity in Parkinson's Disease: A Mini-Review. *PMC*. 2018. Available at <https://pubmed.ncbi.nlm.nih.gov/30245949/>
- ²⁴Dag Aarsland D. Pålhlagen S. Ballard C G. Ehrt U. Svenningsson P. Depression in Parkinson's disease – epidemiology, mechanisms and management. *Nature Reviews Neurology*. 2012. Available at <https://www.nature.com/articles/nrneurol.2011.189>
- ²⁵Broen M P G. Nadia E Narayen N E. Kuijff M L. Nadeeka N W. Dissanayaka N N W. Albert F G. Leentjens A F G. Prevalence of anxiety in Parkinson's disease: a systematic review and metaanalysis. *Movement Disorders*. 2016. Available at <https://pubmed.ncbi.nlm.nih.gov/27125963/>
- ²⁶Leigh-Hunt N. Bagguley D. Bash K. Turner V. Turnbull S. Valtorta N. Caan W. An overview of systematic reviews on the public health consequences of social isolation and loneliness. *Public Health*. 2017. Available at <https://www.sciencedirect.com/science/article/abs/pii/S0033350617302731>
- ²⁷Cost of Living Payment 2022. 2022. Available at <https://www.gov.uk/guidance/cost-of-living-payment>
- ²⁸Personal Independence Payment (PIP), its predecessor, Disability Living Allowance (DLA) and its Scottish equivalent, Adult Disability Payment (ADP) are paid to people of working age assessed as having compromised ability to carry out day to day activities, including getting around. Attendance Allowance (AA) is paid to people of state pension age and over who are assessed as having compromised ability to carry out day to day activities
- ²⁹Help with your energy bills. 2022. Available at <https://www.gov.uk/get-help-energy-bills/getting-discount-energy-bill>
- ³⁰This does not include heat network customers who will not receive additional support

³¹Millions of low-income households to get new Cost of Living Payments from Spring 2023. 2023. Available at <https://www.gov.uk/government/news/millions-of-low-income-households-to-get-new-cost-of-living-payments-from-spring-2023>

³²Personal Independence Payment (PIP), its predecessor, Disability Living Allowance (DLA) and its Scottish equivalent, Adult Disability Payment (ADP) are paid to people of working age assessed as having compromised ability to carry out day to day activities, including getting around. Attendance Allowance (AA) is paid to people of state pension age and over who are assessed as having compromised ability to carry out day to day activities

³³Survey of people with Parkinson's experience of benefits and employment support carried out by Parkinson's UK during August and September 2021

³⁴DWP. Available at <https://stat-xplore.dwp.gov.uk>

We are Parkinson's UK.
Powered by people.
Funded by you.
Improving life for everyone
affected by Parkinson's.
Together we'll find a cure.

PARKINSON'S^{UK}

Free confidential helpline **0808 800 0303**
Monday to Friday 9am to 6pm, Saturday 10am to 2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk

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

