



Calls for urgent support for one in six people who live with a neurological condition to be included in the Autumn Budget.

Leading neurological charities have joined together to write a letter to Jeremy Hunt, Chancellor of the Exchequer about how the cost of living crisis is having a greater impact on those living with neurological conditions.

Neurological charities and members of the Neurological Alliance have all expressed grave concern about how the increase in energy bills and cost of living will affect their members.

The letter proposes three actions that will make a difference:

1. Uprate benefits in-line with inflation
2. Increase the levels of Disability Cost of Living Payments
3. Extend the Warm Homes Discount to disabled people

Cath Stanley, Chief Executive of the Huntington Disease Association, said,

"We have seen a worrying trend in the number of people getting in touch who are concerned about how they are going to keep their house warm this winter, people living with Huntington's disease already have increased energy needs. A recent survey found 93% of respondents say the symptoms of Huntington's disease mean you use higher levels of energy in your home. Many told us in the same survey they face homelessness and increased debt. They need support now."

Georgina Carr CEO of the Neurological Alliance said,

"Not only is it a struggle to access the right support, but living with the effects of a neurological condition often comes with a hefty price tag. A safe and comfortable home, the right specialist care and the right aids and adaptations, are all vitally important to staying in work as long as possible, socialising and retaining independence. That is why support to manage these extra costs is so important, but right now, the Government has not committed to meeting those costs. The new Chancellor has an opportunity to show his support for the one in six living with a neurological condition, starting with a recommitment to uprating benefits in line with inflation in the forthcoming Fiscal Plan."

This is the letter to Jeremy Hunt, Chancellor of the Exchequer:



Suite 24
Liverpool Science Park IC1
131 Mount Pleasant Liverpool
L3 5TF

HM Treasury
Unit 1, Horse Guards Road
Westminster
London
SW1A 2HQ
2 November 2022

Dear Chancellor of the Exchequer,

We are writing to you as representatives of charities supporting people affected by neurological conditions ahead of the Medium-Term Fiscal Plan, to highlight the challenges many people living with neurological conditions are facing in relation to the cost of living crisis.

One in six of us across the country live with a neurological condition. It is expensive to live with one. Extra costs associated with a neurological condition, including higher heating bills, buying specialised equipment, paying for taxis to get around or covering higher insurance premiums, are estimated to cost at least an additional £200 a week.

These higher costs come at a time when the general cost of living has risen exponentially. While the Energy Price Guarantee was both welcome and necessary, many deep concerns persist about affordability. Energy prices are still over 50% what they were this time last year and according to latest ONS figures inflation is at 10.1% with food prices up 14.5%. This is causing many to cut back on basics, increasing the risk of people getting into debt and homelessness – with the right support, this could be prevented.

Unfortunately, the support offered so far simply doesn't go far enough. What is more, those on benefits including those who are unable to take on more hours or



to work at all due to their neurological condition are seeing real term cuts to their income, as benefits are expected to fall at least 6% behind inflation this year. Without urgent action, this will push a further 600,000 to 1.3m people into poverty, including 150,000 to 500,000 children.

With that in mind, we urge you to offer additional support for those with disabilities, including people affected by neurological conditions. The best way to alleviate pressure on those at the sharpest end of this crisis would be to **urgently uprate benefits in-line with inflation**. This would go a long way for disabled people and those with long term conditions to be able to keep up with rising living costs.

Additionally, **increasing the levels of Disability Cost of Living Payments and extending the Warm Homes Discount to disabled people** would help to protect those living with neurological conditions from fuel poverty.

Many people affected by neurological conditions are facing the worst of the cost of living crisis. Additional costs and inadequate targeted support are putting people at greater risk of poverty as well as placing yet more pressures on already overstretched health and social care services. We urge you to provide additional support for the 1 in 6 of us living with a neurological condition as part of the Fiscal Plan.

Yours sincerely,

- Cath Stanley, CEO of the Huntington's Disease Association
- Georgina Carr, CEO of the Neurological Alliance England
- Kripen Dhrona, CEO of British Polio Fellowship
- Karen Cockburn, Charity Director of Nerve Tumours UK
- Sophie Muir, Chair and Founder of the Timothy Syndrome Alliance
- Sarah Gillett, Managing Director of the Neurology Academy
- Thomas Brayford, Policy and Public Affairs Officer of Brain Tumour Research
- Alex Massey, Head of Campaigning, Policy and Public Affairs for the Motor Neurone Disease Association
- Sara Hunt, CEO of Alex, The Leukodystrophy Charity
- Emma Williams MBE, CEO of Matthew's Friends Charity and Director of Matthew's Friends Clinics Ltd
- Sue Millman, CEO of Ataxia UK
- Philip Lee, CEO of Epilepsy Action
- Chloe Hayward, CEO of The United Kingdom Acquired Brain Injury Forum
- Dawn Golder, CEO of FND Hope UK
- Dan McLean, CEO of PANS PANDAS UK
- David Martin, CEO of the Multiple Sclerosis Trust



- Theresa Dauncey, CEO of the National Brain Appeal
- Angie Pullen, Programme Lead for Epilepsy Research UK
- Lesley Pope, Chair of INPA
- Joanne Griffiths, Vice Chair of Intractable Epilepsy
- Dr. Elizabeth Corcoran, Chair of Downs Syndrome Research Foundation UK, DSRF-UK
- Nick Moberly, CEO of MS Society
- Rebecca Packwood, CEO of PSPA
- Nanette Mellor, CEO of the Brain Charity
- Lorraine Stanley, CEO of SWAD
- Kamran Mallick, CEO of Disability Rights UK
- Darren Ely, MS Welfare Benefits Adviser for Disability Law Service
- Jane Hanna, CEO of SUDEP Action
- Brian Carlin, CEO of Aspire
- Lucy Bryne, CEO of Richmond Aid
- Amanda Batten, CEO at Contact, the charity for families with disabled children
- Dr Charles Shepherd, Medical Adviser for ME Association
- Una Farrell, Head of Communications for The Migraine Trust
- Kate Steele, CEO of Shine
- Hilary Boone, Founder and Trustee of Polio Survivors Network
- Catherine Woodhead, CEO, Muscular Dystrophy UK
- Sonya Chowdhury, CEO of Action for M.E.



You can find out more about the Huntington's Disease Association and the work they do [here](#).

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NOTES TO EDITORS

About Huntington's disease

Huntington's disease affects the body's nervous system – the network of nerve tissues in the brain and spinal cord that coordinate your body's activities. This leads to progressive deterioration – physically, cognitively, and mentally until the individual becomes dependent on the help of others. Symptoms include motor (movement), mental health (for example mood) and cognitive (for example learning and thinking) disturbances, which in the majority of cases appear in mid-adult life.¹

Huntington's disease affects around 8,000 people in the UK or 1 in 10,000 people.¹ Up to 32,000 people in the UK live at risk of developing the disease.⁴ It can start at any age, but symptoms usually first appear between ages 30 and 50. Symptoms gradually get worse over 10 to 25 years until the person dies. Every child conceived naturally to a parent who has the faulty Huntingtin gene that leads to Huntington's disease has a 50% chance of inheriting it.¹

About Huntington's Disease Association

The Huntington's Disease Association provides various services to people who are affected by Huntington's disease across England and Wales. These services include –

- Specialist advisory service
- Online support via social channels and website
- Funding of selected research studies and projects
- Local branches and support groups
- Events and activities for families and people affected by the disease
- Training and events for professionals

The Huntington's Disease Association relies almost entirely on voluntary donations and through the generosity of its supporters provides support to people across the whole of England and Wales.

The vision of the Huntington's Disease Association is to create a better life for anyone affected by Huntington's disease. The organisation wishes to enable everyone affected by Huntington's to live life to their full potential by:

¹Survey conducted by the Huntington Disease Association Sept/Oct 2022
One in six [research by Neurological Alliance](#)



- Improving care and support
- Educating families and the professionals who work with them
- Championing the needs of the Huntington's community and influencing decision-makers

Contacts

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You can view the Huntington's Disease Association's [privacy policy](#) and [website terms and conditions](#) here.