



**THE
NEUROLOGICAL
ALLIANCE**

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Secretary of State for Health and Care, Rt Hon Stephen Barclay
Department of Health and Social Care
39 Victoria Street
London
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Major Conditions Strategy – Improving treatment, care and support for people affected by neurological conditions

22 March 2023

Dear Secretary of State,

At least one in six of us live with a neurological condition such as epilepsy, multiple sclerosis (MS), dystonia, functional neurological disorder (FND), motor neurone disease (MND), headache or stroke. Yet too many cannot access the right care and treatment at the right time – there is significant unwarranted variation in service provision throughout England. We are writing to you to ask for a meeting to discuss how neurological conditions will be addressed in the new ‘Major Conditions Strategy’.

As a coalition of over 90 organisations and professional bodies working to improve services for people affected by neurological conditions, we welcome commitments to publish the long-term workforce strategy shortly and actions set out in the England Rare Disease Action Plan to improve support for people with rare conditions, including rare neurological conditions. However, we are concerned that, at present, the proposed ‘Major Conditions Strategy’ omits many neurological

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conditions. This is a significant omission as these conditions affect millions of people in England and have a significant impact on quality of life, personal independence and our economy.

In your statement to the House of Commons regarding the proposed strategy you said, “Our approach will be rooted in the best understanding of the evidence to tackle the major conditions which contribute to the burden of disease in England, namely: cancers; cardiovascular diseases, including stroke and diabetes; chronic respiratory diseases; dementia; mental ill health; and musculoskeletal disorders.” Neurological conditions intersect across these themes.

Research shows that:

- The likelihood of having a co-morbid mental health condition is high for people living with a neurological condition, and mental, emotional and cognitive health problems are often caused by physical damage to the brain or atypical biological characteristics within the brain.¹
- Brain tumours are the biggest cancer killer of children and adults under 40²
- Women with the neurological condition neurofibromatosis type 1 have an increased risk of breast cancer.³
- Around three in 10 people with Parkinson's have Parkinson's-related dementia at any one time.⁴

In addition:

- **Neurological conditions are a leading cause of disability and mortality:** Neurological conditions are the leading cause of disability worldwide⁵ and the second leading cause of death globally, accounting for approximately 9 million deaths per year⁶. The global toll of neurological conditions now exceeds that of all other diseases, such as cardiovascular diseases. As global populations continue to grow and age, the impact is set to increase.

¹ The Neurological Alliance (2017), Parity of Esteem for People affected by Neurological Conditions. [Online] Available here: <https://www.neural.org.uk/assets/pdfs/2017-07-parity-of-esteem.pdf> Accessed: March 2023

² Brain Tumour Research (2016) Addressing the historic underfunding of brain tumour research. [Online] <https://www.braintumourresearch.org/docs/default-source/default-document-library/public-affairs-and-campaigning-documents/brain-tumour-research---report-on-national-research-funding---2016.pdf> Accessed: March 2023

³ NHS (2021) Neurofibromatosis type 1 <https://www.nhs.uk/conditions/neurofibromatosis-type-1/#:~:text=NF%20and%20breast%20cancer,they're%2040%20years%20old>. Accessed: March 2023

⁴ Parkinson's UK (2022) Improving care for people with Parkinson's-related dementia. [Online]. <https://www.parkinsons.org.uk/get-involved/improving-care-people-parkinsons-related-dementia#:~:text=Around%203%20in%2010%20people,compared%20to%20the%20general%20population>. Accessed: March 2023

⁵ World Health Organization. Brain Health. [Online]. Available at: https://www.who.int/health-topics/brain-health#tab=tab_2 Last accessed: March 2023

⁶ Global, regional, and national burden of neurological disorders, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6459001/> Last accessed: March 2023

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- **They have a significant economic impact:** In 2020, the total cost of neurological disorders in Europe was \$1.06 trillion, equivalent to the cost of heart diseases, cancer and diabetes combined.⁷ The World Health Organization estimates that half of the worldwide economic impact of disability will be due specifically to brain-related conditions by 2030 if we do not change this trajectory.⁸
- **There are opportunities to improve treatment, care and support:** In 2020/21, 6 out of 10 neurological admissions in England were an emergency⁹, many of which could have been avoided through appropriate specialist support at the right time. In parallel, huge strides have been made in our understanding of neurological conditions and how best to treat them. With exciting treatments so close, we must ensure that we have the right services and workforce in place to deliver them and change lives.

Neurological conditions, including neuromuscular and neurodevelopmental conditions, affect millions of people in the UK at a cost of billions of pounds. For too long, neurosciences have been at the back of the queue of Government priorities in health and social care. There is a clear alignment between neurological conditions and the stated aims of the proposed Major Conditions Strategy, offering a vital and long overdue opportunity to transform treatment, care and support for the one in six of us with a neurological condition.

We would welcome the opportunity to meet with you and your team to ensure the Major Conditions Strategy helps to meet this aim.

Yours faithfully,

Georgina Carr
Chief Executive
The Neurological Alliance (England)

Co-signed by members of the Alliance:

The Association of British Neurologists

Motor Neurone Disease Association

⁷ World Health Organization. Launch of first WHO position paper on optimizing brain health across life. [Online]. Available at: <https://www.who.int/news/item/09-08-2022-launch-of-first-who-position-paper-on-optimizing-brain-health-across-life> Last accessed: March 2023

⁸ Mathers C. D., Loncar D. (2006). Projections of global mortality and burden of disease from 2002 to 2030. PLoS Med. 3:e442. 10.1371/journal.pmed.0030442

⁹ The Neurological Alliance (2022) Neuro Numbers. To be published.

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Ataxia UK	MS National Therapy Centres
Brain Tumour Research	MS Society
British Paediatric Neurology Association	MS Trust
British Society of Physical Rehabilitation Medicine	MSA Trust
British Polio Fellowship	
Cavernoma Alliance UK	Nerve Tumours UK
CMT UK	Neurology Academy
CSF Leak Association	NeuroKey
Different Strokes	Overcoming MS
Dravet Syndrome UK	Parkinson's UK
Dystonia UK	Polio Survivors Network
Epilepsy Action	shift.ms
FND Hope UK	SUDEP Action
GAIN	Sue Ryder
Hampshire Neurological Alliance	The Brain and Spine Foundation
HBA Support	The Brain Charity
Hereditary Spastic Paraplegia Support Group	The Daisy Garland
Huntington's Disease Association	The Division of Neuropsychology, The British Psychological Society
The Independent Neurorehabilitation Providers Alliance	The Migraine Trust
Intractable Epilepsy	Tourette's Action
Matthew's Friends	UKABIF
	West Berkshire Neurological Alliance

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Open letter signatories: include neurological conditions in the proposed Major Conditions Strategy



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