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<https://www.dailymail.co.uk/news/article-10811807/Hope-250-000-patients-Sajid-Javid-promises-radical-new-approach-tackling-condition.html>

Hope for 250,000 ME patients as Sajid Javid promises radical new approach to tackling the 'incredibly disabling condition'

* He said he was committed to better care and support for people living with ME

* Condition affects up to 250,000 people in the UK and 17 million around the world

* Javid is the first senior government minister to speak about the condition

Sajid Javid has promised a radical new approach to tackling the 'incredibly disabling condition' of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Speaking to parliament on World ME Day yesterday, the health and social care secretary claimed he was 'committed to better care and support for people living with ME and their families'.

The condition affects up to 250,000 people in the UK and 17million around the world.

Javid, who is the first senior government minister to speak about the condition, will lead a plan for new research and better patient care. He will work with his department's chief scientific adviser, Professor Lucy Chappell, and is already liaising with the Scottish government, according to The Times.

<https://www.thetimes.co.uk/article/sajid-javid-promises-radical-action-for-patients-debilitated-by-me-9bkq6qf5g>

He said: 'At the heart of the delivery plan will be two core principles; firstly, that we do not know enough about ME/CFS, which must change if we are to improve experiences and outcomes. Secondly, we must trust and listen to those with lived experience of ME/CFS.'

ME is a long-term and poorly understood condition that causes a range of symptoms. Its main symptom is extreme tiredness and feeling generally unwell. There is no diagnostic test for ME, so doctors decide whether a patient has the condition based on their symptoms and ruling out other conditions. As it stands, the treatments offered to patients for ME are cognitive behavioural therapy (CBT), a talking therapy used for anxiety

and depression, and a structured exercise programme called graded exercise therapy (GET).

Javid continued: 'ME/CFS affects the lives of children and adults across the country. It can be an incredibly disabling condition with fluctuating symptoms making it difficult to take part in everyday activities, enjoy a family or social life, access services and engage in work or education - especially for the estimated 25 per cent of people who have severe or very severe symptoms. 'The government recognised that ME is an under-researched area and pledges to support research funders and the academic community to respond to this independent report. It is so important that the voice of those with lived experience of ME and those that represent them is at the heart of all future work to improve the lives of people living with this debilitating illness.'

Last year, the NHS postponed indefinitely long-awaited NHS guidelines on how to treat chronic fatigue syndrome. Health watchdogs halted the publication of advice because of disagreements about treatment recommendations they were planning to make. The National Institute for Health and Care Excellence said it was unable to produce guidelines on ME/CFS which were 'supported by all'.

It is understood the final advice would have urged doctors to stop offering patients graded exercise therapy (GET). The controversial therapy - which charities say suggest it's psychological - involves doing increasingly more exercise to build-up a tolerance for carrying out physical activity. Health chiefs were also set to advise against the routine use of cognitive behavioural therapy (CBT) - commonly used to treat anxiety and depression.

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