

Rt Hon Matt Hancock MP
Secretary of State
Department for Health and Social Care
39 Victoria Street
London
SW1H 0EU

21st April 2020

Dear Secretary of State,

I write during one of the worst health crises the world has ever seen. The deaths of so many of our fellow citizens is truly heartbreaking, and the efforts and selfless dedication of our health and care workforce humbling. On behalf of the team at the Lewy Body Society, I would like to pay tribute to everyone working tirelessly as part of that health and care system in hospitals, care homes and community settings across the country.

I write to raise several issues specifically relating to the impact of COVID-19 on people living with Lewy body dementia. It is a particularly anxious time for them, and their families and carers. Along with Newcastle University, we have produced an advice sheet to support them, which is available from our website. We will also publish this letter there.

As you may be aware, Lewy body dementia is the second most frequent cause of age-related neurodegenerative dementia. Around 10-15 per cent of people with dementia have Lewy body dementia, although the official rate of diagnosis is significantly lower at around 6 per cent. It is particularly difficult to manage as people with Lewy body dementia can have movement problems similar to those with Parkinson's disease, distressing symptoms such as hallucinations and sleep disturbance, as well as the the progressive decline found in other forms of dementia. It is thought that around 130,000 people in the UK may be living with this common, but little known, disease.

Firstly, we are concerned that during the COVID-19 crisis, the pressure on health professionals and systems may lead to a greater use of anti-psychotic drugs, rather than the non-pharmacological approaches usually recommended for treatment of Lewy body dementia.

Reports from the Admiral Nurse Dementia Helpline support this concern, and it has heard cases of GPs prescribing anti-psychotic drugs without assessing for underlying causes including possible Lewy body dementia. **These drugs can have serious, even fatal, consequences for people with Lewy body dementia.**

The British Geriatric Society, in its guidance on '*Coronavirus: Managing delirium in confirmed and suspected cases*', urges caution with the use of such medication in older people, and especially certain medications in people with Parkinson's disease or dementia with Lewy bodies.

We ask that you do anything you can to emphasise the importance of holistic treatment decisions and the use of this guidance, and that health and care services put safeguards in place to prevent suboptimal medication decisions, especially with staff changes and professionals working in services outside of their usual specialisms.

Secondly, we are concerned that the Clinical Frailty Score (CFS), used to make judgements about access to critical care, may put patients with Lewy body dementia at a significant disadvantage.

Assessment and completion of CFS is likely to be carried out by clinicians working under intense pressure, who may have little experience of Lewy body dementia. This may lead to unduly high results, as mild symptoms of dementia would increase the score to above the cut off where referral for critical care is recommended.

We believe that people with Lewy body dementia are at a further disadvantage than other types of dementia as they often present with atypical dementia symptoms such as hallucinations, sleep disturbances and fluctuations in thinking abilities and alertness. These are all common with Lewy body dementia and would not necessarily increase their level of frailty.

Furthermore, we believe that access to critical care must not be determined by the presence of a diagnosis alone. Dementia is a complex syndrome in which each person is affected differently according to specific diagnosis and individual factors. Lewy body dementia differs significantly from other types of dementia and a global application of a score which uses the term 'dementia' alone is likely to lead to inaccurate assessments.

Whilst the guidance recommends the use of the CFS as part of a holistic assessment, the ability to carry out detailed assessments is likely to be challenging in urgent situations. This increases the likelihood of use of the CFS alone. We would also welcome reassurance that living in a care home does not place an individual at further disadvantage in access to critical care treatment, since many people with Lewy body dementia are resident in care homes.

We fully understand the huge pressure that NHS staff are under, and that decisions need to be taken extremely quickly in order to save lives. We believe in these circumstances it is even more important that difficult decisions are made in a fair, ethical and equitable way. We would welcome your support in raising and tackling these issues through the health and care system.

Once the current crisis has passed, we would very much welcome the opportunity to meet with you or fellow Ministers to discuss our work. The Lewy Body Society was founded in 2006 and our main priorities are to fund research into Lewy body dementia and to raise awareness of the disease. We have funded research to the tune of £1.4m, provide information materials for patients and carers through our website, and recently appointed the first ever Consultant Admiral Nurse for Lewy body dementia to support clinical practice across health and care.

Finally, we would like to thank you for your personal commitment to our NHS and we are glad that you have fully recovered from your own illness a couple of weeks ago.

Yours sincerely,



Ms Jacqueline Cannon FRSA, Chief Executive

cc

Helen Whately MP, Minister of State (Minister for Care)

Sir Simon Stevens, Chief Executive Officer, NHS England

Dr Alistair Burns, National Clinical Director for Dementia, NHS England

Professor Gillian Leng CBE, Chief Executive, National Institute for Health and Care Excellence