



Health and Social Care Committee

House of Commons London SW1A 0AA

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From Rt Hon. Jeremy Hunt MP

22 October 2020

Rt Hon Matt Hancock
Secretary of State for Health and Social Care

Letter by Email

Dear Matt,

Re: treatment of people with learning disabilities for COVID-19

I am writing regarding alleged de-prioritisation of certain groups for COVID-19 treatment during coronavirus peaks.

During the first session of our joint *Coronavirus: lessons learnt* inquiry we heard from Helen Spalding, a woman who has had to care for her daughter Maja nearly around the clock since the withdrawal of most of her support at the beginning of the first wave of the pandemic.

One of the things Helen described that was particularly worrying for her as a mother was the information she was receiving that, as she described it, "if equipment became pushed, scarce and limited... if push came to shove, teams would have to make very difficult choices, and adults with learning disabilities were, sadly, on a list of people who would not be prioritised."

Charities have told us that this fear was also expressed by their supporters, while one member of the public contacted me directly following the hearing to describe how he was given the impression that his son, an adult with a learning disability, "would [not] receive the same medical care that someone not in the care system would expect."

Of course, thanks to the efforts of the NHS and this Government such prioritisation decisions did not have to be made during the first peak of the pandemic. However, I am concerned by the impression that has been given to people with learning disabilities. I would be grateful if you could tell me:

- Whether any official guidance exists to prioritise people for COVID-19 treatment on the basis of existing conditions, such as learning disabilities; and, if so, how this was communicated to patients;
- If not, how people with learning disabilities and their loved ones may have been given the impression that they would not be prioritised for COVID-19 treatment.

I hope you will be able to help me provide some reassurance in this matter.

Best wishes,

Rt Hon Jeremy Hunt MP
Chair, Health and Social Care Committee



Dear Jeremy

27 November 2020

Thank you for your letter about the important issue of the equitable treatment of people with learning disabilities during the Covid-19 pandemic.

We know that while the pandemic has caused hardships for many people, it has had a particularly severe impact on people with learning disabilities, and their loved ones.

Throughout this crisis, we have done our utmost to support disabled people. We have spoken many times with learning disability and autism stakeholders about their worries and the difficulties they – or those they represent – face. We have sought to address these worries by extending regular testing beyond care homes for over 65s to all care homes, rolling out regular testing in high risk supported living settings, working with the Social Care Institute of Excellence to develop tailored Covid-19 guidance for paid and unpaid carers of people with a learning disability and autistic people, providing £1.1m of additional funding for learning disability and autism charities to enable them to continue to support people with a learning disability through the pandemic, through for example moving services online. We continue to hear the concerns of stakeholders through fortnightly, ongoing, engagement and use that insight to inform reasonable adjustments to Covid-19 rules and restrictions wherever possible.

I watched Helen Spalding give evidence to the select committee and I was shocked and deeply concerned about what she described. I would like to assure you that there has never been any Government guidance to deprioritise the care of those with learning disabilities. Every person with learning disability should receive the same high-quality care that we would all expect, and that absolutely remains true during the pandemic.

I am sorry to say that Helen Spalding's account was not the first time I have heard that people felt they – or their family member with learning disabilities – had not been given parity of treatment.

There are two particular concerns which have been raised by stakeholders, both of which we have taken action to address.

Firstly, at the outset of the pandemic, the NICE COVID-19 rapid guideline on critical care was developed to support critical care teams in their management of patients during this very difficult period of intense pressure. The guideline originally stated that on admission to hospital, all adults should be assessed for frailty using the Clinical Frailty Scale (CFS), and that other comorbidities and underlying health conditions are also taken into account.

Families, carers and stakeholders were concerned that applying the CFS to people with learning disabilities, autistic people and people with other stable long-term disabilities could put them at a disadvantage when decisions were made about admission to critical care in this time of intense pressure.

In light of these concerns, the NHS Specialist Clinical Frailty Network rapidly updated their advice on using the CFS, stating that it should not be used in isolation to direct clinical decision making, and that clinicians should take any decisions about care in conjunction with patients and their carers where possible.

On 20th March, NICE updated the rapid COVID-19 critical care guideline to reflect this more clearly and to emphasise the need to consider additional patient factors when interpreting the CFS score. The guideline now states that clinicians working in critical care should be aware of the limitations of using the CFS tool as the sole assessment of frailty. It clarified that the CFS should not be used in younger people, people with stable long-term disabilities (for example, cerebral palsy), learning disabilities or autism. An individualised assessment is recommended in all cases where the CFS is not appropriate.

Secondly, there have also been concerns from stakeholders regarding the inappropriate use of Do Not Attempt Cardio-Pulmonary Resuscitation decisions (DNACPRs). We are crystal clear that it is unacceptable for DNACPRs to be applied in a blanket fashion to any group of people, which the Secretary of State emphasised during a daily press briefing earlier this year.

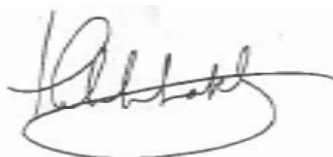
We have taken action across a number of fronts to ensure that this does not happen. Letters have been sent to adult social care providers, GP practices, NHS trusts, CCG Accountable Officers, and Acute and Community Trust CEOs clarifying best practice around use of DNACPRs and that blanket policies should never be applied to any patient group. NHS England and Improvement are also producing public-facing guidance which includes information on what a DNACPR is, how it should be applied, who should be involved and what to do if an individual or loved ones have concerns.

The Care Quality Commission will urgently raise cases of inappropriate use of DNACPR as it becomes aware with the relevant bodies, including the General Medical Council, and take action where registered providers are responsible.

Finally, we have commissioned CQC to undertake a review of how DNACPR decisions were applied during the pandemic. The scope and methodology of this work are being developed at pace but it is expected to look at people's experiences in care homes, primary care and hospitals.

I am absolutely clear that people with a learning disability must receive the same standard of care and treatment that we would all expect. I hope that this letter provides you with reassurance on this matter.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Helen Whately', written over a faint circular watermark or background.

HELEN WHATELY