

**FAO:**

- CCG Clinical leads
- CCG Chief nursing officers
- Trust and foundation trust medical directors
- Trust and foundation trust chief nursing officers
- All General Practitioners
- All primary care nurses

**CC:**

- Regional directors
- Regional chief nursing officers
- Regional medical directors

Thursday 4<sup>th</sup> March 2021

Dear colleague,

**Re: Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and people with a learning disability and or autism**

The NHS Constitution is clear that we should deliver care and support in a way that achieves dignity and compassion for each and every person we serve. We should be cognisant of the principle of equity of access for those who could benefit from treatment escalation, the principle of autonomy and a presumption of involving patients in decision making.

Even under pressure we will deliver personalised care and high standards of patient experience. For patients who might benefit from an advance care plan, we should encourage and support them to discuss their individual wishes and concerns regarding their treatment preferences should they develop COVID-19 symptoms and record those preferences in the advance care plan.

It very important that people are supported to talk about what they want and need if they become seriously ill and if they reach the end of their life. Some people will need reasonable adjustments to be able to do this.

Sometimes making an advance care plan includes thinking about and making a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision.

The British Medical Association, Care Provider Alliance, Care Quality Commission and the Royal College of General Practitioners [issued a statement](#) on the role of general practitioners in this regard which provides an excellent basis for the approach required, not just in general practice but throughout the health and care system.

The key principle is that each person is an individual whose needs and preferences must be taken account of individually.

Blanket policies are inappropriate whether due to medical condition, disability, or age. This is particularly important in regard to DNACPR orders, which should only ever be made on an individual basis and in consultation with the individual or their family.

**The NHS is clear that [people should not have a DNACPR on their record just because they have a learning disability, autism or both](#). This is unacceptable. The terms “learning disability” and “Down’s syndrome” should never be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death. Learning disabilities are not fatal conditions.**

Every person has individual needs and preferences which must be taken account of and they should always get good standards and quality of care.

Additionally, the [joint statement](#) from NHS England and NHS Improvement and Baroness Campbell in May 2020 showed the importance of decisions around care and access to treatment, being made on an individual basis and that blanket decision making is **never acceptable**.

The NHS has published [specialty guides on NICE’s website](#) for the active management of patients with suspected and confirmed COVID-19 which include specific guidance on the management of people with a learning disability and autistic people to which clinicians are strongly recommended to refer. The health of some people who have a learning disability and / or a diagnosis of autism may be at risk from the presence of co-existing physical conditions. Access to and delivery of appropriate and timely assessment and treatment for physical health conditions is vital.

The 2020/21 [General Medical Services \(GMS\) contract Quality and Outcomes Framework \(QOF\)](#) states that all DNACPR decisions for people with learning disabilities are to be reviewed to ensure they were appropriately determined and continue to be clinically indicated.

We know that the overwhelming majority of clinicians are helping patients make these important decisions in the right way and we understand that these conversations are never easy.

But we hope that this information is helpful to assist your understanding in how to approach advance care planning for people with a learning disability and the importance of ensuring there is no inappropriate notice applied.

Thank you for your continued hard work in these difficult times.

Yours faithfully,



Professor Stephen Powis

National Medical Director



Ruth May

Chief Nursing Officer for  
England



Dr. Nikki Kanani

Medical Director for  
Primary Care



Professor Bee Wee

National Clinical Director  
for End of Life Care



Claire Murdoch

National Director for  
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Dr. Roger Banks

National Clinical Director  
for Learning Disabilities  
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