

- To:
- Integrated care boards:
 - clinical leads
 - chief nurses
 - Trust and foundation trusts:
 - medical directors
 - executive directors of nursing
 - All general practitioners
 - All primary care nurses

NHS England
Wellington House
133-155 Waterloo Road
London
SE1 8UG

9 March 2023

- cc.
- Regional directors
 - Regional chief nurses
 - Regional medical directors

Dear Colleagues,

Do not attempt cardiopulmonary resuscitation (DNACPR) and people with a learning disability and or autism

We wrote to you at the start of the pandemic to remind you of the importance of the appropriate use of DNACPR decisions for people with a learning disability and autistic people.

The analysis by Kings College London¹ of the deaths of people with a learning disability in 2021 indicates that there were still a significant percentage of cases where good practice in DNACPR decision making was not demonstrated.

We are writing to you to remind you and your systems of the importance of implementing the [Universal principles for advanced care planning](#) and ensuring that DNACPR decisions for people with a learning disability and autistic people are appropriate, are made on an individual basis and that conversations are reasonably adjusted.

The NHS is clear that it is unacceptable that [people have a DNACPR decision on their record simply because they have a learning disability, autism or both](#).

[1] In the [2021 LeDeR \(Learning from lives and deaths – People with a learning disability and autistic people\) annual report](#) it was judged by LeDeR reviewers that DNACPR documentation and processes were only correctly followed for 60% of the deaths reviewed where a DNACPR was in place. For the remaining deaths, LeDeR reviewers either judged that procedures were incorrectly followed or had insufficient information to be able to form a judgment.

The terms 'learning disability' and 'Down's syndrome' should never be a reason for DNACPR decision making, nor used to describe the underlying, or only, cause of death. Learning disability itself is not a fatal condition: death may occur as a consequence of co-occurring physical disorders and serious health events.

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

A joint statement from NHS England and Baroness Campbell in May 2020 showed the importance of decisions around care and access to treatment being made on an individual basis, and reiterated that blanket decision making is never acceptable.

Discussions regarding cardiopulmonary resuscitation (CPR) preferences should take place as part of a wider conversation regarding a person's preferences, wishes and needs related to their future care.

It is very important that people are supported to talk about what they want and need if they become seriously ill and when they reach the end of their life. Some people will need [reasonable adjustments](#) to be able to have this conversation.

To support and encourage patients to discuss their individual wishes and concerns regarding their treatment preferences, NHS England published the [Universal principles of advanced care planning](#) in March 2022.

Advance care planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care.

Sometimes making an advance care plan includes thinking about and making a DNACPR decision.

We hope that this information is helpful in assisting your understanding in how to approach advance care planning for people with a learning disability and for autistic people.

High quality personalised decision making is key to eliminating poor and inappropriate practice when considering DNACPR.

Thank you for your continued hard work in caring for patients.

Yours sincerely,



Professor Sir Stephen Powis
National Medical Director



Dr Amanda Doyle
National Director for Primary Care and
Community Services



Professor Bee Wee
National Clinical Director for End of Life
Care



Tom Cahill
National Director for Learning Disability
and Autism



Dr Roger Banks
National Clinical Director for Learning
Disability and Autism



Dame Ruth May
Chief Nursing Officer for England