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Dear NHS Trust Medical Directors, Chief Nurses, CCG Chief Medical Officers / Medical Directors, Chief Nurses.

Learning disability, death certification and DNACPR orders

The third annual Learning Disability mortality review (LeDeR) report is due to be published on the 21st May and will include analysis from over 1000 deaths. It has found that the rationale for a number of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) were cases documented as “learning disability” and “Down Syndrome”.

I am writing to remind you and your staff of the guidance on the use of DNACPR and Medical Certificate Cause of Death (MCCD) for people with a learning disability or down syndrome. The guidance on these issues is detailed in the appendix.

The terms “learning disability” and “down syndrome” should never be a reason for issuing a DNACPR order or be used to describe the underlying, or only, cause of death on part I of the MCCD.

Learning disabilities are not fatal conditions and should never be used as a cause of death. The need for accurate recording of causes of death as part of the process of learning, is one of the ways to reduce premature mortality for people with a learning disability. Please disseminate this message to your staff to ensure the recording of death and DNACPR reflects the appropriate guidance.

Yours sincerely,



Professor Stephen Powis
National Medical Director
NHS England and NHS Improvement

Copied: Prof. Carrie McEwan, Chair of the Academy of Medical Royal Colleges;
Charlie Massey, Chief Executive, General Medical Council;
Andrea Sutcliffe, Chief Executive, Nursing and Midwifery Council
Dame Donna Kinnair, Chief Executive, Royal Colleges of Nurses
Chaand Nagpaul, Chair of Counsel, British Medical Association

Annex

DNACPR

Guidance on decisions relating to cardiopulmonary resuscitation from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing is quite clear in relation to the considerations for a DNACPR order regarding a person with a disability:

“Decisions about CPR must be free from any discrimination, for example in respect of a disability. A best-interests decision about CPR is unique to each person and is to be guided by the quality of future life that the person themselves would regard as acceptable or, in the case of children taken into account the views of the child and parents”.

Source: Decisions relating to Cardiopulmonary Resuscitation (3rd edition - 1st revision); June 2017; Resuscitation Council;

<https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/>

Completing Medical Certifications of Cause of Death in England and Wales

Having a learning disability is not a discrete condition fatal in and of itself.

Impairment of intellect (learning disability / learning difficulty) may result from a wide range of aetiological factors, often unknown, but can be associated with congenital and acquired physical conditions that may be direct or contributory causes of death. If a condition is considered to be relevant it should be recorded on part two. The two parts of the MCCD are designed to capture the direct cause of death (part 1) with the facility to describe the sequence of events of conditions that led to death.

Any other conditions which may include conditions causing a learning disability which are not part of the sequence of events or conditions leading to death should be recorded in part two of the MCCD.

Source: Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales; September 2018; HM Passport;

<https://www.gov.uk/government/publications/guidance-notes-for-completing-a-medical-certificate-of-cause-of-death>