

North East and Cumbria Learning Disability Network
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Email: england.learningdisabilitynetwork@nhs.net

Date: 18th June 2020

RE: DNACPR – People with Learning Disability

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

Prof Stephen Powis, National Medical Director, NHS England & NHS Improvement in May last year sent [this](#) letter reminding 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. During the COVID19 crisis a further letter was issued [here](#).

The North East & North Cumbria Learning Disability Mortality (LeDeR) Steering Group Aware (responsible for co-ordinating the LeDeR programme, interpreting & analysing data and information from reviews and identifying & leading service improvement initiatives into action) is aware this issue is still very high on the agenda.

Work within the Critical Care Cell for COVID-19 response in Northern and Yorkshire has focussed on the ethical basis for decision-making for escalation of care. The recommendations of the national Intensive Care Society were endorsed. Central to that guidance is the requirement that difficult decisions must be made on an individual patient basis, balancing the risks and benefits of any complex treatment proposed. While this is, and has always been, a medical decision, the law requires that an appropriate discussion is held with the patient and/or carers. Blanket exclusion of any patient group is not appropriate. We're sure you agree that 'Learning Disability' can never be used as a reason for issuing a DNACPR.

We hope it might also be helpful to provide you will some tools and resources that could be usefully shared with colleagues within your NHS Trusts and CCG organisations.

- Guidance on Mental Capacity Act and Best Interest Decision making can be found here:



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APPENDIX 2

- Learning Disability Liaison nurses – acute and primary care. In each NHS Trust and CCG locality there are Learning Disability Liaison nurses who can provide advice, support and guidance both in an acute hospital and primary care setting in relation to DNACPR if needed. There are also CCG Learning Disability Clinical Leads in each CCG organisation who can provide support. Contact information can be found here:



NHS contact
details.docx

The NCNE LeDeR Steering Group is underpinned by principles that ensure people with learning disability are afforded the same respect, value, access to treatment and rights as the rest of the population. Can we rely on you to make sure your organisation is also underpinned by these same principles?

Please do not hesitate to contact us if you have any questions regarding this letter.

Yours faithfully

Gill Findley

Chair, NENC LeDeR Steering Group

Judith Thompson

NENC Learning Disability Network
Manager