Classification: Official

Publications approval reference: 001559

Learning Disability Mortality Review (LeDeR) programme

Action from learning: deaths of people with a learning disability from COVID-19

Introduction

On 12 November 2020 the University of Bristol published its report into the deaths of 206 people with a learning disability at the start of the COVID-19 pandemic. The report highlighted some good practice in the care of people with a learning disability, but it also highlighted concerns about the care that some people received.

The NHS is committed to working with partners and stakeholders to embed the learning from the report and implement the changes to services required. This short report is designed to outline the actions that we will be working with system partners to implement so that action is taken.

Issue 1: Identifying deterioration in health

Actions to improve the detection of deterioration in the health of people in community and home settings including people with a learning disability include:

- The primary care network (PCN) contract 2020 means that every care home in England will now have a lead GP with overall responsibility for delivering the 'Enhanced Health in Care Homes' service requirements. This framework published in March 2020[1] provides guidance for primary care and community health services to ensure that people living in care homes receive the same level of access to healthcare and support as they were when living in their own home; and moves towards proactive care that is centred on the needs of individual residents, their families and care home staff.

- CCGs are being asked to roll out COVID-19 virtual wards to monitor patients at risk of deteriorating with COVID-19 at home. This includes in care homes for people with a learning disability. Staff, supported by a primary care clinician, monitor the health of a patient to help them identify when someone's health is deteriorating. Carers record symptoms and observations such as oxygen saturation in a patient diary to monitor trends. Carers have clear instructions on what to do if a patient is deteriorating. As part of this programme, pulse oximeters are currently being provided to help monitor deterioration where they are needed.

[1] https://www.england.nhs.uk/wp-content/uploads/2020/03/the-framework-for-enhanced-health-in-care-homes-v2-0.pdf

- We are rapidly progressing work to train at least 5,000 paid and unpaid carers of people with a learning disability in the use of RESTORE2™ mini. This tool is a condensed version of the full RESTORE2™ tool and uses 'soft signs' to help carers identify deterioration in the health of people they care for. This piece of work is particularly important in giving family carers the confidence to report deterioration in health of the people who they care for.

- Our (NHS England and NHS Improvement) Learning Disability Mortality Review (LeDeR) programme is working with the Royal College of Physicians to produce a toolkit on the management of deterioration in the health of people with a learning disability in acute hospital settings. It aims to support clinical teams on the frontline in understanding the different needs of people with a learning disability and to consider that, when their condition deteriorates, this may present differently to the general population.

These large-scale national projects are supported by several on a regional level such as:

- A project being undertaken by the NHS South West regional team, which will roll out the use of pulse oximetry and RESTORE2™ across community settings in the region in early 2021. It will start in 100 care settings in Devon in the initial phase and then build up rapidly to benefit a larger number of people as the project progresses.

- A similar piece of work in North East and Yorkshire overseen by the regional team aims to roll out sleep activity monitoring and RESTORE2™ training to 1260 care workers who support 3,062 individuals. It will provide pulse oximeters to staff working in 180 care settings across Sheffield, Doncaster and Rotherham including some smaller care homes and supported living units.

Issue 2: Do not attempt cardiopulmonary resuscitation (DNACPR) and learning disability as a cause of death

Actions we have taken:

- Throughout the pandemic, there has been clear guidance to ensure that clinicians are using DNACPR recommendations appropriately. The table below shows the timeline of these interventions:

20 May 2019	Professor Stephen Powis, National Medical Director for NHS England and NHS Improvement, wrote to clinicians reminding staff that learning disabilities should never be used as a cause of death or rationale for a DNACPR recommendation.
1 April 2020	Joint statement on advance care planning published by the BMA, Care Provider Alliance (CPA), CQC, RCGP
3 April 2020	Senior leaders from NHS England and NHS Improvement, Dr Roger Banks, National Clinical Director for Learning Disability and Autism, Claire Murdoch, National Mental Health Director, and Dr Nikita Kanani MBE, Medical Director for Primary Care, sent a joint letter to the system to provide clarity on the use of DNACPR where people have a learning disability or are autistic.
7 April 2020	Joint 'maintaining standard and quality of care under pressurised circumstances' letter to Chief Execs of NHS Trusts and Foundation Trusts, CCG Accountable Officers, GP practices and Primary Care Networks and Providers of Community Health Services from Professor Stephen Powis and Ruth May, NHS England and NHS Improvement's Chief Nursing Officer stating that: '.....each person is an individual whose needs and preferences must be taken account of individually. By contrast blanket policies are inappropriate whether due to medical condition, disability, or age. This is particularly important in regard to 'do not attempt cardiopulmonary resuscitation' (DNACPR) orders, which should only ever be made on an individual basis and in consultation with the individual or their family.'
15 April 2020	Statement on advance care planning during the COVID-19 pandemic, including DNACPR from Chief Executives and Registrars of the Nursing and Midwifery Council and the GMC.

20 May 2020	Joint statement on personalised approaches to care and treatment – From Baroness Campbell of Surbiton, DBE (Disability Rights UK) and James Sanderson
October 2020	Publication of document on 'Cardiopulmonary Resuscitation (CPR) and Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)' on NHS England and NHS Improvement's website by the Palliative and End of Life Care Team providing information on CPR and DNACPR whilst under the care of healthcare professionals and what to do if the individual or those important to them have concerns.

- GP practices have been asked via the Quality and Outcomes Framework to review all DNACPRs for people with a learning disability registered with their practice and confirm that they were determined appropriately and continue to be clinically appropriate. This is included in the primary care/ GP contract for 2020-21.

- The Oliver McGowan training coordinated by Health Education England and Skills for Care will ensure staff working in health and social care receive learning disability and autism training at the right level for their role. This means that staff will have a better understanding of people's needs, resulting in better services and improved health and wellbeing outcomes.

- In May 2020 Learning Disability England and Turning Point developed joint advice and support for people affected by DNACPR. Their information pack and DNACPR checklist, helps families and carers understand the issues and jargon involved in DNACPR decisions and enable them to raise questions and concerns appropriately.

- The NHS has previously stated and made clear that Down's syndrome should never be included in part 1A of a medical certificate of cause of death (MCCD).

- The learning disability and autism programme is working closely with the National Medical Examiner to inform the work of medical examiners in relation to the deaths of people with a learning disability. Medical examiners will, where necessary, support bereaved families and will work with all doctors who write death certificates to use the correct terminology in all parts of the MCCD.

- The Department of Health and Social Care has asked the Care Quality Commission to review how DNACPR decisions were used during the COVID-19 pandemic, building on concerns that CQC reported earlier in the year. This will report back in Spring 2021.

Issue 3: Diagnostic overshadowing

This occurs when the symptoms of physical ill health are incorrectly either attributed to a mental health/behavioural problem or considered inherent to the person's learning disability or autism diagnosis.

Action we have taken:

- Specialty guidance was produced for all clinicians providing care for people with a learning disability (including an easy read version).
- We also co-produced a Grab and Go hospital passport. It gives the information that front line clinical staff will need if a person with a learning disability goes in to hospital because of COVID-19.
- In July 2020 a letter was sent to NHS system leaders setting out actions to tackle inequalities, including the prioritisation of annual health checks and vaccinations for people with a learning disability in the coming months.
- The learning disability and autism programme is working with the national NHS 111 team.
- GP practices across England have been asked to use their clinical judgement to determine who, on their GP register, should be considered at a higher risk of serious illness from COVID-19 and to take appropriate action to advise those individuals and their carers (as appropriate) of the need to take additional precautions.
- In addition GPs will be reminded about the risks of diagnostic overshadowing in people with a learning disability and that the presentation of people with a learning disability with COVID-19, or another condition which causes health to rapidly deteriorate, may be different to the general population so that people with a learning disability are not overlooked in terms of access to appropriate and timely health care.

Issue 4: Reasonable adjustments

Under the requirements of the Equality Act 2010, organisations have a duty to make reasonable adjustments if someone is at a disadvantage due to their disability. This means by law healthcare providers must make reasonable adjustments to ensure that people with a learning disability have equal access to health services.

Actions we have taken:

- In 2019 NHS Improvement produced guidance for all NHS hospital trusts about meeting the needs of people who have a learning disability. The Learning Disability Improvement Standards for NHS Trusts help NHS trusts measure the quality of care they provide to people who are autistic and people with a learning disability. These standards are benchmarked each year to measure providers' compliance with the standards and collect the views of staff, people who use NHS services and their families/carers.

- A key project already underway within NHS England and NHS Improvement and NHS Digital before the pandemic is the Reasonable Adjustments Flag. The flag has been built into the NHS Spine to enable health and care professionals to record, share and view details of reasonable adjustments across the NHS, wherever the person is treated. Having been successfully piloted, the flag will be available for wider use from the end of 2020.

- During the pandemic, a significant amount of guidance has been published both for the health and social care system and for people with a learning disability. Many of these pieces of guidance highlighted the importance of making reasonable adjustments. Key pieces of guidance included:

  – Grab and Go Guide (March 2020): This guide was coproduced with people with a learning disability, families and clinical staff. It gives the information that frontline staff will need if a person with a learning disability goes into hospital because of COVID-19.

  – Demand and Capacity guidance (March 2020): This document provides information and guidance for providers and their clinical and non-clinical teams who are planning for how best to manage their capacity across

inpatient and community services, and should support contingency planning, already underway, for a range of resource constrained scenarios.

  - Visitor letter sent to all specialist inpatient providers to emphasise the importance of reasonable adjustments in relation to family visiting.

  - Annual health checks and flu vaccinations campaign including easy read resources to encourage the uptake by people with a learning disability

- We will remind system leaders of relevant clinical organisations of the need to continue to make reasonable adjustments including highlighting the role of staff with particular experience and expertise in the field of learning disability and health liaison, eg learning disability nurses, in ensuring that reasonable adjustment needs are understood by front line clinicians and are implemented.

NHS England and NHS Improvement
Skipton House
80 London Road
London
SE1 6LH

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Publication approval reference: 001559