The Royal College of Pathologists
Pathology: the science behind the cure

# National Medical Examiner's Good Practice Series No. 3

## Learning disability and autism

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## Contents



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## About the National Medical Examiner's Good Practice Series

Medical examiners – senior doctors providing independent scrutiny of non-coronial deaths in England and Wales – are a relatively recent development.

While there is extensive guidance available on a wide range of topics for NHS and public sector staff, the National Medical Examiner's Good Practice Series highlights how medical examiners and medical examiner officers can better meet the needs of local communities and work more effectively with colleagues and partners.

The Good Practice Series is a topical collection of focused summary documents, designed to be easily read and digested by busy front-line staff, with links to further reading, guidance and support.

## Introduction

Medical examiners can play a unique role, enabling greater scrutiny and clarity of the reasons for a person's death, and acting as a contact point for the bereaved. They provide an opportunity for families and carers to raise any concerns, such as unsatisfactory interactions with health services. These sensitivities need to be understood by medical examiners and addressed with understanding and compassion following a death, and can be particularly important after the death of a person with a learning disability or an autistic person.

The LeDeR programme in England captures the largest body of evidence of the deaths of people with a learning disability at an individual level, anywhere in the world. Deaths of people with a learning disability are reported online. It is important that medical examiners engage with local LeDeR colleagues in England, providing information about the causes of death and quality of care provided. Wales are looking to formalise a system to support identifying and sharing lessons regarding care provision or delivery for patients with a learning disability across the NHS and other sectors. By working together, we can make progress to address the disproportionate number of avoidable deaths of people with a learning disability.

## Recommendations for medical examiners – learning disability and autism

Medical examiners should:

1. Note the sensitivity of dealing with the death of someone who had a learning disability or who was autistic, and pay particular attention to support for carers who may for many years have been 'the voice' and representative of the deceased.

2. Remain conscious that a patient with a learning disability or who was autistic may have found it difficult to communicate with staff in hospitals and other health and care staff, and this may have had an impact on the cause of death and/or the events leading to death. Health inequalities arising from a person having a learning disability or who was autistic may have contributed to the death.

3. If doctors completing Medical Certificates of Cause of Death (MCCDs) propose learning difficulty or learning disability as a standalone cause of death, remind them that all guidance (both the official ONS/Home Office guidance for doctors completing MCCDs, and the Cause of Death List) note this is not acceptable as a cause of death, and that 'if such a condition is considered to be relevant, the more immediate mechanism(s) or train of events leading to death must be made clear.'[1]

4. Where aspiration pneumonia is proposed as a cause of death, consider what caused the aspiration pneumonia and whether this may be an unnatural cause. For example, is there evidence of a recent aspiration event that led to the pneumonia?

5. Ensure processes are in place to record the number of medical examiner referrals for further review of deaths of people with a learning disability, and to include the number of such cases in routine reporting to the National Medical Examiner.

6. Be alert to cases where the death of a person with a learning disability or an autistic person may have been caused by neglect or self-neglect, or this may have been a contributory factor, and ensure all appropriate cases are notified to a coroner.

7. Ensure that it is clear who will make referrals to relevant agencies such as LeDeR in England, the review structure in Wales when established and other agencies where appropriate, such as the coroner.

[1] Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales, ONS and Passport Office, 4.6.

## Context and background

People with a learning disability experience significant inequalities in health and have higher rates of morbidity and mortality than the general population. The latest LeDeR annual report by the University of Bristol in England notes that only 38% of people with a learning disability live beyond the age of 65 (85% for the rest of the population) and 50% of people with a learning disability had a medical cause of death considered avoidable (52% in 2019 compared with 22% in the general population). The median age of death among people with a learning disability in 2020 was 61.[2] In 2019, the University of Bristol reported that men with a learning disability die on average 22 years younger and women with a learning disability die 27 years younger than the general population.[3] People with a learning disability are significantly more likely to die in hospital than the general population.

Respiratory and cardiovascular disease are the main certified causes, but congenital and chromosomal disorders are frequently listed. In 2020, the first most common certified cause of death was COVID-19 and the COVID-19 pandemic has raised concerns, and reported examples, about the inappropriate application of 'do not resuscitate' as blanket decisions for groups in care settings, or without adequate discussion with individuals and their family or carers.

NHS leaders and clinical guidance in relation to COVID-19 have emphasised that learning disability and autism are not health conditions, identifying 'diagnostic overshadowing', where symptoms of physical ill health are mistakenly either attributed to a mental health/behavioural problems, or considered inherent to the person's learning disability or autism diagnosis.

NHS England and NHS Improvement published a letter underlining that the NHS should deliver care and support in a way that achieves dignity and compassion for each and every person we serve. The letter noted the sensitivities regarding Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions in relation to people with a learning disability and autistic people. People with a learning disability and/or autism should not have a DNACPR on their record just because they have a learning disability, are autistic, or both.

The approach in Wales is set out in *Sharing and Involving, a clinical policy for DNACPR for adults in Wales*. The Chief Medical Officer and Chief Nursing Officer for Wales issued a joint letter to all health boards, to ensure there is clarity around ethical decision making for people with any protected characteristic under the Equality Act 2010. The letter made it clear that age, disability or long-term condition alone should never be a sole reason for issuing a DNACPR order against an individual's wishes. It emphasised that decisions should be made on an individual and consultative basis with patients. It is unacceptable for advance care plans, with or without DNACPR form completion, to be applied to groups of people of any description. NHS and third sector organisations in Wales should comply with the *Health and Care Standards for Wales for Communicating Effectively*.

The National Quality Board Learning from Deaths framework requires that deaths of those with a learning disability are subject to case record review. It notes this should be a LeDeR review if possible, and if not available, a Structured Judgement Review or another robust and evidence-based methodology should be used.[4]

[2] University of Bristol LeDeR annual report (2020).
[3] University of Bristol LeDeR report (2019).
[4] National Quality Board Learning from Deaths Framework, page 9.

Other useful resources include the third Action From Learning report, COVID-19 Action from Learning Report and Ask Listen Do, published by NHS England and NHS Improvement to support organisations to learn from and improve the experiences of people with a learning disability and autistic people. Learning from the LeDeR programme provides an important opportunity to improve the care and outcomes for people with a learning disability.

## Medical Certificates of Cause of Death

There has been concern about the causes of death recorded in some MCCDs for people with a learning disability and autistic people. The Royal College of Pathologists published the Cause of death list in June 2020. This is not intended to be an exhaustive list of all possible causes of death, but deals with conditions that have previously prompted discussion between certifying doctors, registrars and coroners. It includes clarification about common conditions. It also notes regarding 'learning disability/difficulties' that these terms are 'not acceptable as a standalone cause of death.'[5]

Doctors are required by law to certify the cause of death 'to the best of their knowledge and belief'. That means they use their medical expertise to decide the cause based on symptoms, physical examination, hospital records, laboratory tests and other information available to them. If death is certified by a coroner, the Coroner's Court follows legal rules of evidence when deciding the causes of death.

The Office for National Statistics (ONS) and Home Office (Passport Office/General Register Office) publish official guidance for doctors completing MCCDs, which notes that 'Long-term physical disabilities, mental health problems and learning difficulties (also known as learning disabilities or intellectual disabilities) are rarely sufficient medical explanation of the death in themselves. If such a condition is considered to be relevant, the more immediate mechanism(s) or train of events leading to death must be made clear…. A description such as 'learning difficulties' should not be the only cause of death.'[6] Doctors completing MCCDs are required to do so to the best of their knowledge and belief.

The guidance is important for ONS as accurate completion of MCCDs and Death Certificates facilitates research and understanding. In discussion with stakeholders, it was recognised that there are two opposite dangers. First, the unmerited inclusion of learning disabilities in MCCDs; and second, that in some cases doctors may fail to identify that a learning disability was a contributory cause of death.

It has been proposed that aspiration pneumonia is over-represented on MCCDs of people with a learning disability – 17% of adults and 3% of children reviewed through LeDeR died with aspiration pneumonia.[7] In discussion, stakeholders noted that aspiration pneumonia should not be used as a convenient label; that it may be a legitimate cause of death, but that it is important to consider what caused aspiration pneumonia.

[5] Cause of Death List, Royal College of Pathologists, page 17.
[6] Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales, ONS and Passport Office, 4.6.
[7] LeDeR 2019 Annual Report, page 10.

## Reporting medical examiner activity

Medical examiner offices provide periodic activity data to the National Medical Examiner, including the number of deaths that medical examiners have referred for further case record review. The subcategories are based on Learning from Deaths criteria, and include deaths of those with a learning disability and with severe mental illness. The reporting process is new and still being established. In quarters 3 and 4 of 2020/21, trusts that completed this section reported that 1,024 such cases had been referred for case record review. The Cause of Death list notes that aspiration pneumonia is not an acceptable cause of death without an underlying cause. Cases mentioning aspiration pneumonia without an acceptable cause of death should be notified to the coroner.

## Notification to coroners

The Ministry of Justice publishes guidance for medical practitioners that sets out clear criteria for notifying deaths to the coroner. Vigilance may be required to consider whether the death was due to neglect or self-neglect[8] as this is a notification requirement, but it is not appropriate to notify all deaths of people with a learning disability or autistic people automatically.

Doctors should be sensitive to whether the coroner notification criteria have been triggered by any of the circumstances of death, and whether the death therefore needs to be referred. Stakeholders noted Recommendation 2 of the LeDeR Report 2019, 'For the Department of Health and Social Care (DHSC) to work with the Chief Coroner to identify the proportion of deaths of people with learning disabilities (and possibly other protected characteristics) referred to a coroner in England and Wales.'

[8] 'Neglect applies if the deceased was in a dependent position (e.g. a minor, an elderly person, a person with a disability or serious illness) and it is reasonable to suspect that there was a failure to provide them with – or to procure for them – certain basic and obvious requirements.' Revised guidance for registered medical practitioners on the Notification of Deaths Regulations, Ministry of Justice, paragraph 14.

## Find out more

- LeDeR programme and LeDeR website
- Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021
- LeDeR 2020 annual report and other LeDeR annual reports
- Third Action from Learning report, NHS England and NHS Improvement
- Ask Listen Do, NHS England and NHS Improvement
- Cause of death list – Royal College of Pathologists
- Clinical guide for front line staff to support patients with a learning disability, autism or both during the coronavirus pandemic
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) and people, letter from NHS England and NHS Improvement, 4 March 2021
- Guidance for medical practitioners completing MCCDs, Office of National Statistics and Home Office (HM Passport Office)
- National Quality Board Learning from Deaths framework
- Notification of Deaths Regulations 2019 guidance, Ministry of Justice

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