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

# National Medical Examiner's Good Practice Series No. 11

## Medical examiners and dementia

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# About the National Medical Examiner's Good Practice Series

Medical examiners are senior doctors who provide independent scrutiny of non-coronial deaths in England and Wales – 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.

# Recommendations for medical examiners – dementia

- Medical examiners should ensure that dementia is recorded accurately on the Medical Certificate of Cause of Death (MCCD), where this is an appropriate clinical judgment. If the type of dementia is known, this should be recorded fully.
- Medical examiners should scrutinise all relevant medical records required for proportionate scrutiny, including patient records from mental healthcare providers, where relevant.
- It is important to distinguish on the MCCD between dementia that has a direct causal relationship to terminal events and dementia that has a contributory effect. In general, dementia should only appear in 1(a) in the absence of more specific pathology or causality.
- If there was not a formal diagnosis of dementia before death, but the doctor completing the MCCD and the medical examiner agree that dementia is indicated by the clinical path and it contributed to or caused death, dementia should be recorded on the MCCD.
- Consider whether treatment has been appropriate. Issues raised by relatives may include concerns about care being inappropriately withheld owing to a dementia diagnosis and unjustified, avoidable interventions during final illness, such as invasive investigation and treatment. Feedback to mental health and hospital teams regarding deceased patients with dementia will help improve care for future patients.
- Similarly, medical examiners should consider whether end of life planning has been appropriate and inform providers of any concerns expressed by the bereaved family.
- Be alert for circumstances and decisions that may have a bearing on whether the coroner should be notified, for example patients detained under the Mental Health Act 1983.

# Dementia and diagnosis

Dementia is one of the most common underlying causes of death in England and Wales recorded by the Office for National Statistics. In 2021, as in 2020, the leading cause of death in England and Wales was the coronavirus (COVID-19), with 67,350 deaths (11.5% of all deaths); dementia was the second most common cause of death (along with Alzheimer's disease, accounting for 10.4% of all deaths registered in 2021 [61,250 deaths]).

Dementia is an umbrella term and there are many underlying pathological diagnoses. There are reportedly more than 200 subtypes of dementia. The diagnosis of dementia is usually formalised by a consultant psychiatrist in older persons' mental health, although many geriatricians and GPs are also confident and able to diagnose the more common subtypes in older patients who present typically. The rate of diagnosis among those with suspected symptoms is currently about 62.2%, so there will be a number of people awaiting diagnoses or who have not presented to services as yet. Young onset dementia patients may have been seen by adult mental health professionals or a neurologist with a special interest in dementia. Rarer presentations of dementia that are more prevalent in younger patients can present extra challenges for diagnosis.

Alzheimer's dementia (or dementia in Alzheimer's disease) and vascular dementia are the most common subtypes. Mixed dementia is frequently documented in medical notes and usually refers to a mixed Alzheimer's dementia/vascular dementia diagnosis, although it can also be applied to a mix of any 2 or more subtypes. Other less common subtypes include Parkinson's disease dementia, dementia with Lewy bodies, frontotemporal dementia, alcohol-related dementia and primary progressive aphasia. This list is not exhaustive.

Dementia can be a distressing condition for patients, their families and carers. Bereaved people may feel patients with dementia suffered discrimination or perceive a lack of transparency in deciding which treatments are appropriate and which are withheld.

# Bereaved people and diagnoses of dementia

Dementia is often misunderstood and therefore recording dementia on the MCCD can be emotive for bereaved people. Some families may find use of the word upsetting or even shocking in the period after a bereavement. Navigating these concerns and questions bereaved people may ask can be difficult; medical examiners should work closely with the treating doctor to gain proper understanding of the patient's medical and care history.

Bereaved people and some clinical professionals may not fully appreciate the natural progression of a dementia illness and that it is possible for a person to die of dementia without another acute event causing death.

It can be difficult to distinguish between delirium and dementia. Many older people have evidence of degeneration within the brain on imaging, but do not have a clinical syndrome of cognitive impairment or dementia. Difficulties are more likely to arise when there has not been a formal diagnosis of dementia, but the clinical path indicates this is likely. If dementia is to be recorded on the MCCD (see next section), communication to the bereaved family will need to be handled with sensitivity, particularly if the possibility of the deceased patient having had dementia has not been mentioned previously to the next of kin or relatives.

It should also be recognised that, when recording dementia on the MCCD without formal prior diagnosis, families are more likely to question whether diagnosis and care prior to death were accurate and appropriate. However, in some cases families and carers may have suspected the deceased had a dementia illness, even when this has not been formally diagnosed and recorded.

# Medical examiner scrutiny and the Medical Certificate of Cause of Death

Patients with dementia may otherwise be physically fit and well with minor cognitive and functional impairment. However, those in the more advanced stages can become frail, with a high risk of dying particularly during acute admissions. In advanced stages, it may be more appropriate not to admit such patients to hospital; palliative care, rather than active investigation and treatment of other conditions, may be more appropriate. Most people with dementia die in care homes, with those dying in hospitals the next largest group and a relatively low percentage dying in their own homes. Referrals to palliative care services may happen at a late stage because it was not recognised that people with dementia were nearing death. Teams caring for such patients may also be conscious that people with dementia are entitled to all appropriate treatment and do not wish to be seen to request palliative care before it is necessary.

Poor communication with bereaved people and families/carers of patients with dementia is a concern frequently highlighted to medical examiner offices. In circumstances where a patient lacks capacity, the quality of engagement and communication by medical professionals with the family and carers while the patient is living will significantly influence whether bereaved people raise concerns. Providing feedback to treating teams where communication was lacking can help improve care for future patients. In the same way, positive feedback of examples of good care should be provided to front line staff, as this can often go unrecognised.

Patients are unlikely to die while under the care of an older peoples' mental health consultant psychiatrist in a mental health hospital. Consequently, it will often be a hospital junior doctor or a GP writing the MCCD. Medical examiners may need to seek further information from the doctor when responding to questions from bereaved people regarding care and the causes of death. Information from carers and the psychiatrist's patient record provide other means of understanding the patient's needs and care prior to death. The original dementia diagnosis may be held within mental health patient records or the GP patient record.

Causes of death for patients with dementia should be articulated as carefully as for all other patients. However, unlike other medical conditions where the cause of death is

usually clear, deaths of patients with dementia present a range of causality. Patients may die of dementia or with dementia.

It is important to distinguish on the MCCD between dementia that has a direct causal relationship to terminal events and dementia that has a contributory effect. Generally, dementia should only appear in 1(a) in the absence of more specific pathology or causality. This is more likely to occur in non-acute settings. Where the death is caused by dementia, it is good practice to record the specific dementia type code, if this is known, or, if it is not known, to record ‘dementia of unknown aetiology’. If the patient has been in an acute hospital near the time of their death, there are usually diagnostic tests available to inform construction of causes of death. Examples are set out in the appendix.

Both the bereaved and some clinical professionals may not fully appreciate the natural progression of a dementia illness or that it is possible for a person to die of dementia without another acute event causing death. In cases where this occurs, it may be helpful to explain the disease progression on the MCCD through the duration of illness, for example writing ‘frailty syndrome’ in 1a, before ‘dementia’ in 1b.

If both the doctor completing the MCCD and the medical examiner agree that dementia is indicated by the clinical path and has contributed to or caused death, but there was not a formal diagnosis of dementia before death, recording dementia on the MCCD is appropriate. Dementia should not be used as a convenient label – there will need to be a clear reason for including it on the MCCD. Many reversible factors can cause or contribute to acute confusion (i.e. delirium) in patients. If delirium was present, then medical examiners should confirm there are grounds to include dementia on the MCCD before doing so, for example a dementia diagnosis or, as set out in the previous section, agreement that the clinical path indicates this was likely.

# Notification to coroners

The *Notification of Deaths Regulations 2019* apply to people who die with dementia in the same way as they do for all other people. There are particular criteria for notification in the regulations that will apply in some cases where people die with dementia.

Details related to the deceased's dementia should never be omitted as a means of avoiding notification to the coroner. Dementia is a life-limiting condition and there are many potential complications. It also can limit the patient's ability to recover after setbacks, but poor care may also contribute in some cases and it is important to recognise this where applicable.

Many older patients with dementia become both cognitively and physically frail as a result of the condition; this can lead to falls. Such patients may have other comorbidities and a significant number of these patients may be admitted for orthopaedic, surgical, general internal medicine or geriatric care. Fractures, significant head injuries and other organ trauma are common. Where there has been a fall with a traumatic injury that caused or contributed to the death, this would require notification to the coroner.

When a patient with dementia has become cognitively impaired, making their own decisions and physically looking after themselves may become more difficult. The poor physical condition of a patient may raise questions about potential neglect and self-neglect. Where there is reason to suspect neglect, it is a requirement for deaths caused by neglect to be notified to the coroner. However paragraph 19 of the *Notification of Deaths Regulations* states 'there may be cases where people fail to take adequate nourishment or proper personal care owing to the natural progression of an underlying illness, such as dementia. Although this may hasten their death, this death should not be notified to the coroner unless there was neglect by others'. Medical examiner scrutiny can help attending doctors to make appropriate decisions about notification to coroners and resulting information can help the coroner to make appropriate investigation decisions.

In some cases, a person with dementia may be detained under the Mental Health Act 1983 (MHA 1983); if they die while being detained, the coroner must be notified. This may include instances when the deceased is on a period of formal leave. Medical examiners should pay close attention to any patient who was detained under the Mental Health Act 1983 but discharged from it shortly before death and consider whether coroner notification

is required and whether appropriate decisions and treatments were implemented. A coroner notification is not required if the deceased was subject to a Deprivation of Liberty Order, as long as there is no other reason to refer.

# Find out more


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# Appendix – Examples of how an MCCD might be constructed

If the patient has been in an acute hospital, there are usually diagnostic tests available that help to inform what has led to their death. An example might be:

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| 1a Aspiration pneumonia<br>1b Dysphagia<br>1c Alzheimer's dementia |

or

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| 1a Pneumonia<br>1b Alzheimer's dementia |

In other cases, there may be a separate but related cause of death and it may become appropriate to document the dementia process at 2 (if it has contributed to death):

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| 1a Acute myocardial infarction<br>1b Coronary artery atheroma<br>2 Vascular dementia |

In some patients who are living with a dementia diagnosis, especially those who are still relatively independent physically and cognitively, the dementia diagnosis may be considered not to have contributed to the death and should not be included on the MCCD:

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| 1a Pancreatitis<br>1b Gallstones |

If a patient with dementia dies in a residential or nursing home or community setting after a prolonged period of general decline, with weight loss, reduced oral intake and reduced physical and cognitive function, it may be appropriate to simply record the dementia diagnosis at 1a, or to add Frailty syndrome at 1a then record the dementia diagnosis as 1b to better articulate the clinical course.

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| 1a Frailty syndrome<br>1b Alzheimer's dementia |