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

National Medical Examiner's Good Practice Series No. 14

Palliative and end-of-life care

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About the National Medical Examiner's Good Practice Series

Medical examiners are senior doctors providing 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.

Introduction

Palliative care

Palliative care is a broad term describing the process to reduce or alleviate symptoms for any condition at any stage; however, it is particularly associated with symptom control and holistic care for patients with severe or terminal illness. Palliative care in general should not be confused with specialist palliative care, which must meet formally commissioned standards.

Specialist palliative care

Trained specialists in palliative care, associated professionals and volunteers within the NHS and hospice systems provide specialist support to people with terminal conditions. Services are provided in many settings, frequently in independent hospices, and through specialist home care. The focus is particularly on patients with complex symptoms, or where a patient has psycho-social needs not met within general palliative care.

End-of-life care

This term is sometimes used interchangeably with palliative care but is not identical. National standards deem patients to be in receipt of end-of-life care in their last year of life. Many patients may have longer term, progressive or life-limiting conditions that require palliative care prior to their last year of life. Medical examiners should speak to a specialist palliative medicine consultant if they are uncertain about the care pathway at the end of life to better understand whether it was appropriate.

Recommendations for medical examiners

Medical examiners should:

- provide the same independent scrutiny of deaths after palliative or end-of-life care as they would for all other deaths, and ensure that concerns or deficiencies are detected and referred or reported appropriately
- note that opioids should only be used with the intention of ensuring the patient is comfortable, taking into consideration the findings of the Review of Deaths of Patients at Gosport War Memorial Hospital[1]
- consider whether appropriate guidance was followed, such as:
  - Ambitions for Palliative and End-of-Life Care[2]
  - nutrition and hydration (including Clinically Assisted Nutrition and Hydration (CANH)[3]
  - palliative care of children and young adults[4]
  - palliative care of people with protected characteristics such as disabled people or those with learning difficulties[5]
- pay particular attention to care before death in relation to:
  - the Mental Capacity Act
  - capacity and consent
  - the involvement of family and carers

[1] *A Review of Deaths of Patients at Gosport War Memorial Hospital*. Published October 2003. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/226263/review_gosport_war_memorial_hospital.pdf
[2] National Palliative and End of Life Care Partnership. *Ambitions for Palliative and End of Life Care: A national framework for local action 2021–2026*. Published May 2021. Available at: www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf
[3] General Medical Council. *Clinically assisted nutrition and hydration*. Available at: www.gmc-uk.org/professional-standards/professional-standards-for-doctors/treatment-and-care-towards-the-end-of-life/clinically-assisted-nutrition-and-hydration
[4] Royal College of Pathologists. *National Medical Examiner's Good Practice Series No. 6 Medical examiners and child deaths*. Published March 2022. Available at: www.rcpath.org/static/7fa7a9d6-ada5-4597-b16f4602c93d3e91/Good-Practice-Series-Child-Deaths.pdf
[5] Royal College of Pathologists. *National Medical Examiner's Good Practice Series No. 3 Learning disability and autism*. Published June 2021. Available at: www.rcpath.org/static/daf86eaa-d591-40d5-99d54118d10444d2/Good-Practice-Series-Learning-disability-and-autism-For-Publication.pdf

  - best interest plans for patients who lack capacity for decisions, for example life-sustaining treatment or its withdrawal
  - advance decisions to refuse treatment (including life-sustaining treatment)
- consider features of good end-of-life care when scrutinising relevant deaths, bearing in mind different arrangements in hospitals and community settings
- consider whether cultural or faith characteristics and preferences were taken into account.

Context and background

This guidance paper focuses on the role of medical examiners in relation to deaths after palliative and end-of-life care. Several independent reports have highlighted shortcomings of service delivery in end-of-life care that have caused or contributed to death. The Leadership Alliance for the Care of Dying People published One chance to get it right[6] (2014) following a review of the Liverpool end-of-life care pathway. Ambitions for Palliative and End-of-life Care[2] was first published on behalf of the National Palliative and End-of-life Care Partnership in 2015 and updated for 2021–2026. This framework sets out 7 ambitions and a vision to improve end-of-life care through partnership and collaborative action between organisations throughout England.

As these documents note, end-of-life care is relevant to everyone. There are many complex and sensitive areas including culture, religion, spirituality, emotional intelligence, community belonging and legal requirements. While it is not feasible to explore these in depth in this good practice paper, links to further information are included.

Medical examiners can clearly play a key role in identifying positive examples of good end-of-life care and providing feedback, and detecting when care could have been better, so that healthcare providers can prevent recurrence for future patients. While most such deaths will be of adults, a small minority will be of children. The National Medical Examiner

[6] Leadership Alliance for the Care of Dying People. *One chance to get it right*. Published June 2014. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

has provided guidance about the relationship between medical examiner scrutiny and statutory child death review processes.[4]

Most deaths in the UK are expected (i.e. attributable to a known problem or problems). However, some deaths are not expected and may require more understanding of circumstances and care towards the end of life. End-of-life and palliative care should maintain dignity and comfort as far as possible. Good practice in end-of-life care is for health professionals to have identified that the patient may be in the last year of life and to plan accordingly, including advance care planning discussions, and putting in place care, support and anticipatory medications. It is important that concerns detected in deaths after palliative and end-of-life care are reported and referred appropriately, in the same way as they would be for other deaths. This supports learning and improvement, and aligns with the principles of transparency and accountability set out in the National Quality Board's Learning from Deaths policy.[7]

Bereaved people are often very positive about the quality of care of the deceased and the support the family received, and there are many examples of excellent care that can be fed back to treating teams. However, as with all specialties, there can be problem areas in a minority of deaths.

The sections below set out some specific areas to consider, but are not exhaustive. It should also be recognised that there are important differences between expected deaths in hospitals and in the community. In hospital, delays to seeing a consultant may be associated with worse outcomes. In community settings, professionals from many backgrounds may be in contact with the patient.

Principles set out in the Ambitions for Palliative and End-of-life Care have been incorporated into individualised care plans (ICP) for people in their last days or weeks of life in England. Medical examiners should consider if the person was appropriately *Recognised as Dying*; that they or those close to them were involved in their care, there was good communication, that support was offered and provided where appropriate, and, lastly, the tasks required to deliver the ICP were planned and done in a timely manner.

[7] National Quality Board. *National Guidance on Learning from Deaths*. Published March 2017. Available at: www.england.nhs.uk/wp-content/uploads/2017/03/nqb-national-guidance-learning-from-deaths.pdf

Advance care plans, treatment escalation plans and DNACPR orders

Patients can voluntarily plan for a time in the future when they may lose mental capacity. This can include preferences for treatment and care, a record of advance decisions to refuse treatment and, as part of the Mental Capacity Act, the appointment and registration of Lasting Powers of Attorney. Electronic patient records systems often have templates and icons to identify advance care plan and treatment decisions.

Do Not Attempt Cardio-Pulmonary Resuscitation (or 'Do Not Resuscitate' or 'DNACPR') orders are recommendations made by a senior responsible clinician in anticipation the patient might arrest and die (from a presumed natural death). Statutory law and case precedents are in place for the process, and include communication to people close to the patient. The Tracey ruling at the Court of Appeal in 2014[8] made clear that NHS trusts have a legal duty to tell a patient with mental capacity if a DNACPR order is placed on their medical records, unless such a disclosure would cause psychological harm.

DNACPR orders can be a source of contention and great distress to bereaved people if not implemented appropriately. The recommended summary plan for emergency care and treatment[9] provides a framework in agreeing clinical care in emergency situations where the patient would not be able to make decisions or express their wishes. DNACPR orders should be part of advance care plans or treatment escalation plans.

There are specific legal requirements under the Mental Capacity Act to ensure the issues around capacity to consent or refuse treatment and care, lasting power of attorney and best interest assessments are properly considered and acted on. There are additional standards set out for patients living with mental health conditions relevant to the Mental Health Act.

In some circumstances, doctors have to make difficult decisions around stopping routine tests and treatments, observations or refusal of treatment. Consideration as to whether the patient had capacity and whether relevant circumstances were documented properly will be important considerations. In some cases, refusal of treatment could constitute self-

[8] Tracey v Cambridge Uni Hospital NHS Foundation Trust & Others, 2014. Available at: www.judiciary.uk/wp-content/uploads/2014/06/tracey-approved.pdf
[9] Resuscitation Council UK. *ReSPECT for patients and care*. Available at: www.resus.org.uk/respect/respect-patients-and-carers#:~:text=What%20is%20ReSPECT%3F,decisions%20or%20express%20your%20wishes

neglect and require coroner notification. However, refusal of treatment at end of life should not automatically be considered a matter for coroner notification, if the decision was clearly made with capacity.

Anticipatory medication

These medications help control core symptoms of breathlessness, pain, agitation, nausea and secretions. They are prescribed before the potential onset of these symptoms to prevent delays in prescribing and administration. Their use should be proportionate. Good palliative or end-of-life care is when the patient dies comfortably with their final wishes taken into consideration.

Communication

Medical examiners and officers should consider whether there were appropriate levels of communication with the patient, their representative, and their family or carers. The patient or those close to the patient may wish to be involved in the delivery of care or decisions supporting the delivery of care. An ICP, if in place, should indicate if this has been considered and achieved where possible.

Medication and nutrition management

Medication reviews are an essential process for any patient, especially where there are significant changes to treatment and care. Critical medicines (such as insulin for patients with diabetes mellitus) may need to be continued where others can be stopped (e.g. for hypertension).

Patients have the basic human right to be offered food and drink by mouth. Adjustments in the type, texture and normal assistance might need to be made to maximise this opportunity. For other methods of assisted nutrition and hydration, the General Medical Council (GMC) notes the guidance from the Royal College of Physicians and British Medical Association to support clinically assisted nutrition and hydration.[10]

[10] General Medical Council. *Clinically assisted nutrition and hydration for doctors and healthcare colleagues including senior hospital management*. Available at: www.gmc-uk.org/professional-standards/learning-materials/canh-for-doctors-and-healthcare-colleagues-including-senior-hospital-management

Religious and spiritual needs

Many religions require specific ceremonies or tasks before and/or after death. Providers of palliative and end-of-life care should take all reasonable steps to accommodate these requirements. The National Medical Examiner's good practice paper on urgent release of bodies provides guidance that can help in meeting the needs of faiths which may require burial within a limited period.[11]

Second opinions and safeguards

It is important that safeguards are in place to protect the patient from harm. There are several processes in law to achieve this. The principles of best interest decision-making and the wider safeguards that are set out in the Code of Practice (MCA 2007) of the Mental Capacity Act 2005 (MCA 2005) must be followed. Further national and local guidance helps to ensure the safeguards are effective. Where there is an element of doubt it may be appropriate to involve the Court of Protection.

There is an existing provision of requesting a second opinion in the medical profession, which can be requested by the patient or family. These requests usually relate to significant diagnoses or proposed treatments. The senior clinician can also request a second opinion. In September 2023, the Secretary of State announced that the government will introduce 'Martha's Rule'[12] as soon as possible. This will be a 3-step process to allow patients or their families to request a clinical review of their case from a doctor or nurse if the patient's condition is deteriorating or not improving as expected.

GMC guidance in Good Medical Practice[13] already states that doctors must respect the patient's right to seek a second opinion. All reasonable steps should be taken to get a second clinical opinion where it is proposed to stop, or not to start a treatment.

The second-opinion clinician should:

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[11] Royal College of Pathologists. *National Medical Examiner's Good Practice Series No. 2 How medical examiners can facilitate urgent release of a body.* Published April 2021. Available at: www.rcpath.org/static/3590bf7f-a43e-4248-980640c5c12354c4/Good-Practice-Series-Urgent-release-of-a-bodyFor-Publication.pdf

[12] UK government. Oral statement to Parliament Lucy Letby statutory inquiry: Secretary of State statement. Published 4 September 2023. Available at: www.gov.uk/government/speeches/secretary-of-state-oral-statement-on-lucy-letby-statutory-inquiry

[13] General Medical Council. Good medical practice. Available at: www.gmc-uk.org/professional-standards/professional-standards-for-doctors/good-medical-practice

- have relevant clinical knowledge and experience
- have experience of best interests' decision-making
- not be part of the current treating team
- be able to act independently.

Second-opinion clinicians should examine the patient, consider and evaluate the medical records, and review information about the patient's best interests. They should write a report summarising the review they have undertaken and outlining their own judgement as to the decision to withdraw support.

There are explicit requirements for second opinions set out in the national guidance for clinically assisted nutrition and hydration. Experts have identified 3 groups of patients with persistent disorders of consciousness that should be subject to second opinions:[14]

- patients with neurodegenerative conditions
- patients with multiple comorbidities or frailty, which is likely to shorten life expectancy, who have suffered a brain injury
- previously healthy patients in vegetative state or minimally conscious state following sudden-onset brain injury.

Different care settings

Palliative and end-of-life care may be provided in a wide range of settings. While it is not possible to cover all scenarios, some are worth noting.

Care homes can have different degrees of support for the dying. There are often specific arrangements with local services such as GPs, community nurses and other professionals to support the dying resident in the care home (which might be their preferred place of care and death).

[14] The British Medical Association. *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent: Guidance for decision-making in England and Wales*. 2:2 *A proportionate approach to decision-making (page 21).* Available at: www.rcplondon.ac.uk/news/bma-and-rcp-publish-guidance-clinically-assisted-nutrition-and-hydration

Patients experiencing serious **mental health conditions** may be detained under 'Sections' of the Mental Health Act. It is always important to confirm whether these were still active at the time of death as any person under state detention requires notification to the coroner. The Sections may be rescinded if the patient does not pose a threat to themselves or others in the last days of life. Medical examiners should also consider the National Medical Examiner's guidance regarding mental health and eating disorders.[15]

Intensive care unit (ICU) patients tend to have more complex needs. As a result of sedation, ventilation and other interventions, decisions and care process must be explicitly considered and recorded before decisions are made to withdraw life-sustaining treatment. Specialist nurse and multidisciplinary team processes support this transition to end-of-life care and care after death. Many ICUs also have bereavement support services that can provide an opportunity for relatives to raise questions or concerns.

[15] Royal College of Pathologists. *National Medical Examiner's Good Practice Series No. 7 Mental health and eating disorders*. Published June 2022. Available at: www.rcpath.org/static/48cf2e7b-3bbe-4a56-ace6ea20a48850ed/Good-Practice-Series-Mental-health-and-eating-disordersFor-Publication.pdf

Find out more

- Care Quality Commission (CQC): A different ending: Addressing inequalities in end-of-life care
- GMC: Treatment and care towards the end of life
- Gosport Memorial Hospital: Review of deaths of patients
- National audit of care at end of life: https://www.nacel.nhs.uk/
- NHS England:
  - Palliative and End-of-life Care: Statutory Guidance for Integrated Care Boards (ICBs)
  - Universal Principles for Advance Care Planning
  - National Quality Board's Learning from Deaths Policy
- National Medical Examiner's good practice papers regarding deaths of children; learning disabilities and autism; and mental health and eating disorders.
- National Institute for Health and Care Excellence:
  - service delivery for end-of-life care for adults: https://www.nice.org.uk/guidance/ng142
  - quality standards for end-of-life care for infants, children and young people: https://www.nice.org.uk/guidance/qs160
  - quality standards for end-of-life care for adults: https://www.nice.org.uk/guidance/qs13
- Royal College of Physicians and British Medical Association: National guidance for Clinically Assisted Nutrition and Hydration

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