End of life care in adults - assessment and care planning

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Information resources for patients and carers

Updates to this pathway

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End of life care in adults - assessment and care planning

1 Background information

Quick info:

Scope:
- identification of people approaching the end of life and initiating discussions about preferences for the end of life care
- care planning:
  - assessing the needs and preferences
  - agreeing a care plan for both patient and carer
  - reviewing these regularly
- coordination and rapid access to care delivery of high quality services in all settings
- management of the last days of life
- care after death
- support, care, and information for carers and families
- spiritual care for patients and families

Out of scope:
- children

Definition and principles:

- end of life care:
  - helps all those with advanced, progressive, incurable illness to live as well as possible until they die
  - enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement
  - includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support

- the definition of the beginning of end of life care varies according to the individual and professional perspectives:
  - in all cases, with the consent of the patient, the beginning is marked by a comprehensive assessment of supportive and palliative care needs

- end of life care aims to ensure that:
  - all people are treated with respect and dignity at the end of their lives
  - pain and suffering amongst people approaching the end of life are kept to an absolute minimum with access to skilful symptom management for optimum quality of life
  - all those approaching the end of life have access to physical, psychological, social, and spiritual care
  - people’s individual needs, priorities, and preferences for end of life care are identified, documented, reviewed, respected, and acted upon wherever possible
  - the many services people need are well coordinated, so that patients receive seamless care
  - high quality care is provided in the last days of life and after death in all care settings
  - carers are appropriately supported both during a patient’s life and into bereavement
  - cost-effective services are provided
  - the family, including children, close friends, and informal carers of people approaching the end of life, have a vital role in the provision of care – they need to be closely involved in decision making, with the recognition that they also have their own needs

- palliative care:
  - is the active holistic care of patients with advanced, progressive illness
  - includes management of pain and other symptoms and provision of psychological, social and spiritual support
  - aims to achieve the best quality of life for patients and their families
  - many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments

- palliative care is based on a number of principles, and aims to:
  - provide relief from pain and other distressing symptoms
  - integrate the psychological and spiritual aspects of patient care
  - offer a support system to help patients to live as actively as possible until death
  - help the family to cope during the patient’s illness and in their own bereavement
  - be applied early in the course of illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy), including investigations to better understand and manage distressing clinical complications

This information was drawn from the following references:


2 Information resources for patients and carers

Quick info:
Patients and carers in England and Wales can access this pathway through NHS Choices at http://healthguides.mapofmedicine.com/choices/map/palliative_and_end_of_life_care1.html

The following resources have been produced by organisations certified by The Information Standard:

- ‘Managing symptoms in the last few weeks of life’ (URL) from Cancer Help UK at http://www.cancerhelp.org.uk
- ‘Carers’ resource’ (URL) from Carers resource at http://www.carersresource.org/
- ‘Palliative Care’ (URL) from Datapharm at http://www.medguides.medicines.org.uk
- "What is the difference between supportive care, palliative care and terminal care, or are they the same thing?" (URL) from Macmillan Cancer Support at http://www.macmillan.org.uk
- "Supportive and palliative care" (PDF) from National Institute for Health and Clinical Excellence (NICE) at http://www.nice.org.uk
- "Benefits for the Terminally Ill" (PDF) from Patient UK at http://www.patient.co.uk
- “Palliative care” (URL) from Sue Ryder Care at http://www.suerydercare.org
- "Planning For Your Future Care" (URL) http://www.endoflifecareforadults.nhs.uk

Information for carers and people with disabilities is available at:
- ‘Caring for someone’ (URL) from Directgov at http://www.direct.gov.uk
- "Disabled people" (URL) from Directgov at http://www.direct.gov.uk

Patient stories describing their care journeys are available at ‘Healthtalkonline’ (URL) from DIPEX at http://www.healthtalkonline.org

Explanations of clinical laboratory tests used in diagnosis and treatment are available at ‘Understanding Your Tests’ (URL) from Lab Tests Online-UK at http://www.labtestsonline.org.uk

The Map of Medicine is committed to providing high quality health and social care information for patients and carers. For details on how these resources are identified, please see Map of Medicine Patient and Carer Information.

NB: This information appears on each page of this pathway.

3 Updates to this pathway

Quick info:
Date of publication: 29-Oct-2010

Three floating nodes now appear at the top of each pathway page. These provide:
- easy access to scope and background information on each page of the pathway whilst reducing repetition between nodes
- easy access to patient resources/leaflets
- information on pathway updates

This pathway was updated in line with the following guidelines: [1-2,4-6,8-22,24-27].

Further information was provided by the following references: [3,7,23].

For further information, please see the pathway’s Provenance.

Practice-based knowledge has been contributed to this pathway by:
- Bee Wee: Consultant in Palliative Medicine, Sir Michael Sobell House, Oxford, UK (clinical facilitator)
- Robin Carr: GP, Oxford Radcliffe Hospital (ORH) Trust, Oxford, UK
- Penelope Curtis-Smith: Occupational Therapist, ORH, Oxford, UK
- Maxine Hardinge: COPD lead, ORH and South Central SHA, Oxford, UK
- Claire Henry: National Programme Director, National End of Life Care Programme, Oxford, UK
- Richard Lehman: Health Experiences Research, Oxford University, Oxford, UK
- Rachael Marsden: MND Specialist Nurse and Care Co-ordinator, ORH Trust, Oxford, UK
- Jo Noble: Heart Failure Nurse and Clinical lead, ORH Trust, Oxford, UK
- Jo Riley: Lead Respiratory Nurse (CHO), ORH Trust, Oxford, UK
- Wendy Robinson: Practice Development Facilitator for End of Life Care, ORH Trust, Oxford, UK
- Amelia Sayce: Hospital Palliative Care CNS, ORH Trust, Oxford, UK
- Bridget Taylor: Nurse Educator, Sir Michael Sobell House, Oxford, UK
- Selected members of Map of Medicine (MoM) Clinical Editorial team and Fellows board

The pathway has been completely restructured and redrafted in line with the Map of Medicine editorial methodology and to bring it in line with current clinical practice.

NB: This information appears on each page of this pathway.

4 Identify people approaching end of life
End of life care in adults - assessment and care planning

Quick info:
The Prognostic Indicator Guidance [5]:
- is an assessment tool used to estimate prognosis
- is part of the Gold Standards Framework, which aims to optimise the care of people nearing the end of life who are looked after by primary care teams in the community
- includes the ‘surprise question’ to try to identify people approaching the end of life, however this should only be used as a guide and some experts in the field question the positive predictive value of this question [7]

Identify factors that should trigger discussions about the end of life [1, 5]:
- ‘surprise question’:
  - would you be surprised if this patient were to die in the next 6-12 months?
  - the surprise question can be applied to years, months, weeks, or days, and trigger the appropriate actions enabling the right thing to happen at the right time
- clinical indicators for each of the three main end of life patient groups; cancer, organ failure (mostly heart and lung failure), and elderly (frail or dementia), suggest which adult patients predicted to be in the final 6-12 months of life might be in need of supportive or palliative care
- patients with advanced disease may choose comfort care only, and not curative treatment eg refusing renal transplant, or is in special need of supportive or palliative care
- at the time of diagnosis of a condition which usually carries a poor prognosis, eg motor neurone disease (MND), advanced liver disease
- at a point when there is a deterioration in a chronic illness and the likely diagnosis is measured in months or possibly a year or two, eg an acute episode on the background of longstanding COPD
- changes in social circumstances, such as a move from independent living to sheltered or extra care accommodation, or into a care home

There are three main trajectories of decline at the end of life [1, 5]:
- people with long-term conditions remain in reasonably good health until shortly before their death, with a steep decline in the last few weeks or months of life (typical of cancer)
- people will experience a more gradual decline, interspersed with episodes of acute ill health from which they may, or may not, recover (typical for people with organ failure)
- people are very frail for months or years before death, with a steady progressive decline (typical of physical and cognitive frailty)

References:

5 Cancer

Quick info:
Depending on what treatment they are receiving, patients may remain in reasonably good health until shortly before their death, with a steep decline in the last few weeks or months of life (typical of cancer) [1, 7].

Clinical indicators [5]:
- any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis, eg lung cancer
- a useful predictive factor in cancer is performance status and functional ability, eg Eastern Cooperative Oncology Group (ECOG) Performance Status or Karnofsky Performance Status Score – if patients are spending more than 50% of their time in bed or lying down, prognosis is estimated to be about 3 months or less [7]

Reference:

6 Organ failure

Quick info:

Clinical indicators [5]:

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- chronic heart failure (CHF) – at least two of the following:
  - CHF New York Heart Association (NYHA) stage III or IV – shortness of breath at rest or minimal exertion
  - patient thought to be in the last year of life by the care team – the ‘surprise’ question
  - repeated hospital admissions with symptoms of heart failure
  - difficult physical or psychological symptoms despite optimal tolerated therapy
- chronic obstructive pulmonary disease (COPD) [5]:
  - disease assessed to be severe, eg forced expiratory volume (FEV1) less than 30% predicted – with caveats about quality of testing
  - recurrent hospital admission (more than 3 admissions in 12 months for COPD exacerbations)
  - fulfils long term oxygen therapy criteria
- Medical Research Council (MRC) dyspnoea scale grade 4/5:
  - shortness of breath after 100 meters on the level; or
  - confined to house through breathlessness
- signs and symptoms of right heart failure
- combination of other factors, eg:
  - anorexia
  - previous admissions to ITU
  - history of non-invasive ventilation (NIV)
  - infection with resistant organisms
  - depression
  - greater than 6 weeks of systemic steroids for COPD in the preceding 12 months
  - some experts in the field suggest that hypercapnic respiratory failure is a helpful prognostic indicator, however it may not be suitable for younger patients with obstructive sleep apnoea
- renal disease [5]:
  - patients with stage 5 chronic kidney disease (CKD) – ie estimated glomerular filtration rate (eGFR) less than 15mL per minute – whose condition is deteriorating and who are not seeking or are discontinuing renal replacement therapy – this may be:
    - from choice
    - because they are too frail
    - because they have too many co-morbid conditions
  - patients with stage 5 CKD for whom the one year ‘surprise question’ is applicable, ie overall you would not be surprised if they were to die in the next year?
  - symptomatic renal failure – nausea and vomiting, anorexia, pruritus, reduced functional status, intractable fluid overload
  - increasingly severe symptoms from co-morbid conditions requiring more complex management or which are difficult to treat
- motor neurone disease (MND) [5]:
  - evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
  - barely intelligible speech
  - difficulty swallowing
  - poor nutritional status
  - needing assistance with activities of daily living
  - medical complications, eg pneumonia, sepsis
  - a short interval between onset of symptoms and diagnosis
  - a low vital capacity (below 70% of predicted using standard spirometry)
- Parkinson’s disease – at least two of the following [5]:
  - drug treatment is no longer as effective or an increasingly complex regime of drug treatments is necessary
  - reduced independence, need for help with daily living
  - recognition that the condition has become less controlled and less predictable with “off” periods
  - dyskinesia, mobility problems, and falls
  - swallowing problems
  - psychiatric signs, eg depression, anxiety, hallucinations, psychosis
- multiple sclerosis (MS) [5]:
  - significant complex symptoms and medical complications
  - dysphagia (swallowing difficulties) is a key symptom, leading to recurrent aspiration pneumonia and recurrent admissions with sepsis and poor nutritional status
  - communication difficulties (eg dysarthria) with or without fatigue
  - cognitive impairment, notably the onset of dementia
  - breathlessness may be in the terminal phase

This information was drawn from the following references:
End of life care in adults - assessment and care planning


7 Elderly

Quick info:
Clinical indicators [5]:
• frailty, characterized by:
  • multiple co-morbidity
  • poor mobility [7]
  • weight loss
  • functional decline [7]
• multiple co-morbidities with signs of impairments in day to day functioning
• dementia, characterized by:
  • inability to walk without assistance; and
  • urinary and faecal incontinence; and
  • poor oral intake
  • frequent intercurrent illness eg. aspiration pneumonia
• stroke:
  • persistent vegetative or minimal conscious state / dense paralysis / incontinence
  • medical complications
  • lack of improvement within 3 months of onset
  • cognitive impairment or post-stroke dementia

This information was drawn from the following references:

8 Assessment and care planning

Quick info:
Perform a holistic assessment of needs in the following domains [1,8-9]:
• physical (symptoms, effects on daily living) – common symptoms include:
  • pain
  • dry mouth
  • nausea and vomiting
  • constipation
  • bowel obstruction
  • lack of appetite and poor nutrition
  • shortness of breath
  • cough
  • respiratory secretions
  • fatigue
  • cognitive impairment
  • confusion and agitation
  • lymphoedema
  • stiffness
  • insomnia
• psychological:
  • effects on mood
  • anxiety
  • relationships
  • spiritual needs
• social:
  • effects on family
  • carers
  • employment
  • social interactions
  • financial status
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• effects on sexuality [7]
• spiritual:
  • religious attitudes towards disease, suffering, dying, and death
  • meaning and purpose of illness and death
  • patient's need for dignity
  • need for hope
  • patient's feelings of self-worth and identity
• cultural – cultural attitudes towards disease, suffering, dying, and death
• environmental needs, where appropriate:
  • quality of the environment of different settings, including hospitals and care homes – this has a direct impact on the experience of care of people at the end of life
• nutrition and hydration needs:
  • benefits, burdens, and risks of providing clinically assisted nutrition and hydration
  • cultural and religious views
  • document the needs and preferences of those approaching the end of life [1]
  • identify, assess, and document the needs and preferences of carers of those approaching the end of life [1]
• a care plan should be agreed and there should be regular reviews of needs and preferences as the condition changes [1]
• care plans, including the person’s preferences, wishes and views on resuscitation, should be available to all who have a legitimate reason to access them, including out of hours and emergency or urgent care services [1]

References:


9 Coordination of care

Quick info:
Each person approaching the end of life should receive coordinated care in accordance with their care plan, across sectors, and at all times of day and night [1]:
• consider coordination of the care needs of individuals at the end of life and their carers' needs at several levels:
  • within an individual team
  • between teams working within a single institution
  • across organisational boundaries
• the Gold Standard Framework (GSF) provides an approach to coordinate care within an individual team or location, eg primary care and GP practice registers of people approaching the end of life ensure that care given by the multidisciplinary primary care team is well coordinated
• coordination between teams can be achieved by members of one team attending meetings of another team, eg cancer team and a specialist palliative care team
• coordination across organisational boundaries can be achieved by adopting a whole system approach and introducing interventions which impact on the whole patient pathway, eg providing a single port of call for booking home care for patients across the full range of service providers
• rapid response services which enable patients to access out of hours services in their own homes [7]
• locality-wide registers for people approaching the end of life provide the following advantages:
  • access to a 24-hour telephone helpline for the person and their carer
  • access to rapid response services in the community
  • a person's wishes regarding advanced decisions and expressed preferences about where they would prefer to die are known to all relevant services

References:


10 Prognosis less than 1 year
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Quick info:
Prognosis estimated at less than 1 year [5,10]:
- initiate end of life care management, eg Gold Standards Framework (GSF), Keep Improving The Experience (KITE) standards, or equivalent
- enter patient onto practice-based end of life care register
- nominate a key worker
- record the patient’s wishes and preferences about their future treatment and care, with permission of the patient, in an advance care plan (ACP), eg the Preferred Priorities for Care (PPC)
- the patient may appoint a person to make treatment decisions on their behalf by authorising the person to do so under a Lasting Power of Attorney (for welfare) – any decision taken by the appointed person must be made in the individual’s best interest
- the patient may wish to make an advance decision to refuse treatment (ADRT) – the decision must relate to refusal of a specific medical treatment and must be both valid and applicable

References:

11 Prognosis less than 6 months

Quick info:
Prognosis estimated at 6 months [5,11]:
- complete a DS1500 form:
  - designed to speed up the payment of financial benefits
- can be issued when a patient is considered to be approaching the terminal stage of their illness – a patient is considered as terminally ill if:
  - they are suffering from a progressive disease; and
  - they are not expected to live longer than six months
- communicate and explain “Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)” decisions where appropriate with the patient
- communicate and explain DNACPR decisions where appropriate and with due respect for confidentiality with the patient’s family, friends, other carers, or other representatives
- record DNACPR decisions in a form that is recognised by all those involved in the care of the patient
- communicate DNACPR decisions between all healthcare workers and organisations involved with the patient in a timely fashion
- with the patient's permission, inform out of hours (OOH) services of the patient’s advance care plan

References:

12 Prognosis of weeks

Quick info:
Prognosis estimated to be within weeks [1,5]:
- review patient’s advance care plan (ACP) or advance decision to refuse treatment (ADRT)
- review the needs of the carer
- supply anticipatory medication
- consider ‘fast track’ assessments for continuing healthcare funding (eg NHS Continuing Healthcare) if a patient has a rapidly deteriorating condition to enable their needs to be met urgently
- arrange for provision of palliative care in the patient’s preferred place of care, where possible [7]

References:
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13 Prognosis of days

Quick info:
Prognosis estimated to be within days [1,5]:
• initiate care pathway management for people in the dying phase, eg Liverpool Care Pathway for the Dying Patient
• consider rapid discharge in line with the patient’s preferred place of care
• update out of hours (OOH) providers on the patient’s deteriorating condition

References:

15 Advance care plan

Quick info:
Advance care planning should take place in the context of an anticipated deterioration in a patient’s condition with the attendant loss of capacity to make decisions and/or communicate wishes to others [10]:
• initiate advance care plan (ACP) discussion following careful consideration:
  • ACP is voluntary and should not be initiated simply as part of routine care or record keeping
  • there may be cues which indicate a desire to make specific wishes known
  • ACP should not be initiated as a result of outside pressure
  • the outcome of ACP discussion may be the completion of a statement of wishes and preferences
• consider patient’s statement of wishes, preferences, beliefs, and values:
  • patient may wish to write down or tell others their wishes and preferences for future treatment and care, or explain their feelings and values that govern how they make decisions
  • a statement of wishes and preferences is not legally binding but it does have legal standing and must be taken into account when making a judgement in a person’s best interest
  • act in the patient’s best interests if the patient has been assessed as lacking capacity to make decisions about their care and treatment:
    • make reasonable efforts to find out what a person’s wishes, preferences, values, and beliefs might be

Reference:

16 Advance decision to refuse treatment

Quick info:
The outcome of advance care planning discussions may be the patient’s wish to make an advance decision to refuse treatment (ADRT) [10]:
• an ADRT can be made by someone over the age of 18 who has mental capacity
• the individual should be guided by a professional with the appropriate knowledge and the decision should be documented according to the requirements of the Mental Capacity Act (MCA) 2005
• the decision must relate to a refusal of specific medical treatment and may be in specific circumstances
• an ADRT is a legally binding document if the advance decision can be shown to be valid and applicable to the current circumstances
• if an ADRT relates to life-sustaining treatment, it must be a written document which is signed and witnessed and include the statement ‘even if life is at risk’
• an ADRT only comes into effect if the individual loses capacity

Reference:
End of life care in adults - assessment and care planning

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Evidence summary for End of life care in adults - assessment and care planning

This pathway has been developed according to the Map of Medicine editorial methodology (http://mapofmedicine.com/whatisthemap/editorialmethodology). The content of this pathway is based on high-quality guidelines [1-6,8-23,25-28], and critically appraised meta-analyses and systematic reviews [24]. Practice-based knowledge has been added by contributors with front-line clinical experience [7].

Search date: Apr-2010

References

This is a list of all the references that have passed critical appraisal for use in the pathway End of life care in adults

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