

No QIPP indicators were found during the review of this topic.

NICE quality standards

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NICE have defined Quality Standards relevant to end of life care for adults [NICE, 2013 ([/palliative-care-general-issues#!references](#))]. See [h](#) ([http:// https://www.nice.org.uk/guidance/QS13](http://https://www.nice.org.uk/guidance/QS13).)<https://www.nice.org.uk/guidance/QS13> (<https://www.nice.org.uk/guidance/QS13>).

What is palliative care?

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- The World Health Organization (WHO) defines palliative care as follows [WHO, 2002 ([/palliative-care-general-issues#!references](#))]:
 - 'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual'.
 - 'Palliative care:
 - Provides relief from pain and other distressing symptoms.
 - Affirms life and regards dying as a normal process.
 - Intends neither to hasten nor postpone death.
 - Integrates the psychological and spiritual aspects of patient care.
 - Offers a support system to help patients live as actively as possible until death.
 - Offers a support system to help the family cope during the patient's illness and in their own bereavement.
 - Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
 - Will enhance quality of life, and may also positively influence the course of illness.
 - Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.'
- The National Institute for Health and Care Excellence defines palliative care as [NICE, 2004 ([/palliative-care-general-issues#!references](#))]:
 - 'The active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of 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'.

General palliative care

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- Much of the support given to people is from professionals who are not specialists in palliative care.
- Professionals providing general palliative care services (for example members of primary care teams) should aim to meet the needs of a person and their family within the limits of their knowledge and

competence. Specialist advice should be sought or the person referred to specialist services when necessary.

- The aim of general palliative care is to provide:
 - Information for the person and their carers, with 'signposting' to relevant services.
 - Accurate and holistic assessment of a person's needs.
 - Co-ordination of care teams in and out of hours and across boundaries of care.
 - Basic levels of symptom control.
 - Psychological, social, spiritual, and practical support.
 - Open and sensitive communication with the person, their carers, and professional staff.

[NICE, 2004 ([/palliative-care-general-issues#!references](#))]

Specialist palliative care

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- Specialist palliative care services manage complex palliative care problems that cannot be dealt with by generalist services.
- Ideally, professionals who are not specialists in palliative care, who care for people with advanced cancer, should have access to specialist advice at all times.
- Specialist palliative care services are likely to include:
 - Multidisciplinary specialist palliative care teams to provide assessment, advice, and care for people with advanced cancer in all locations.
 - Specialist in-patient facilities (for example hospice beds) for people with complex problems that cannot be managed adequately in other settings.
 - Bereavement support services.
- Specialist palliative care services may be provided by statutory and voluntary organizations. Care may be provided in community, hospice, and hospital settings.

[NICE, 2004 ([/palliative-care-general-issues#!references](#))]

Scenario: Management approach

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From age 16 years onwards.

How should I assess and manage the person's physical symptoms?

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- Assess the person's physical needs at key points during the course of the illness (for example at the time of diagnosis, around treatment episodes, as treatments end, at the time of a relapse, and when death is approaching).
- Assess and manage the person systematically (for example assess symptoms, set treatment goals, review regularly, and refer if necessary).
- Enquire about symptoms, rather than waiting for the person to report them.
 - Determine the impact of each symptom on the person's life by enquiring about time of onset, exacerbating factors, and effects on everyday life (such as sleep disturbance).

- Even if cancer is the underlying cause, different mechanisms may be responsible for the symptom (for example vomiting due to hypercalcaemia or gastric outflow obstruction).
- Bear in mind that all symptoms may be made worse by insomnia, exhaustion, anxiety, and depression.
- Ensure that any prescribed drug treatment is as pragmatic and straightforward as possible, avoiding medication which is no longer required, for example statins.
 - Do not delay starting treatment as symptoms become more difficult to manage the longer they are left untreated.
 - If a symptom is persistent, prescribe regular prophylactic treatment as opposed to treatment on an 'as required' basis.
 - Discuss and agree on achievable goals with the person.
- Refer to a specialist if a problem occurs which is outside the expertise of the primary care team.

Basis for recommendation

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These recommendations are based on guidance from the National Institute for Health and Care Excellence [NICE, 2004 ([/palliative-care-general-issues#!references](#)); NICE, 2015 ([/palliative-care-general-issues#!references](#))], expert opinion from the literature based on clinical experience [Regnard, 2010 ([/palliative-care-general-issues#!references](#)); Twycross, 2014 ([/palliative-care-general-issues#!references](#))], and the General Medical Council guidance for doctors, *Treatment and care towards the end of life: good practice in decision making* [GMC, 2010 ([/palliative-care-general-issues#!references](#))].

- A qualitative study found that doctors tend to underestimate the severity of symptoms (for example dyspnoea) and this is associated with under-treatment of those symptoms [Roberts et al, 1993 ([/palliative-care-general-issues#!references](#))].
- Expert opinion in a review article on palliative cancer care is that symptom management to optimize quality of life is the foundation of cancer care, irrespective of the stage of the disease or the person's chemotherapy regimen [Reville et al, 2009 ([/palliative-care-general-issues#!references](#))].

How should I assess and manage the person's psychological needs?

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- Assess the person's psychological state at key points during the course of the illness (for example at the time of diagnosis, around treatment episodes, as treatments end, at the time of a relapse, and when death is approaching).
- If the person or their carers have significant levels of psychological distress, offer prompt referral to specialist psychological care services.
- The appropriate psychological intervention will depend on the person's current and previous psychological problems, the level of support available, and their prognosis.
 - Psychological assessments and interventions should be undertaken somewhere that is quiet, comfortable, and private.
 - Staff providing psychological care should be adequately trained and supervised, and mechanisms to ensure support for staff should be available.
 - Emergency psychiatric interventions should be sought for people with severe mental health problems.

Basis for recommendation

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These recommendations are based on guidance from the National Institute for Health and Care Excellence on improving supportive and palliative care for adults with cancer [[NICE, 2004 \(/palliative-care-general-issues#!references\)](#)].

- Around 50% of people with cancer experience anxiety and depression around the time of diagnosis which is significant enough to adversely affect their quality of life.
- In the year after diagnosis, 10% of people have symptoms that require specialist intervention by psychiatric or psychology services.
- Around half of people with advanced disease experience anxiety and depression.
- Professional psychological support is likely to benefit people with cancer and their carers, whatever the severity of their psychological distress.
- Psychological symptoms are often not recognized, so services may not be offered.
- Health and social care professionals often lack appropriate assessment skills and may underestimate the benefits of psychological support.

How should I assess the person's social needs?

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- Assess the person's social needs at key points during the course of the illness (for example at the time of diagnosis, around treatment episodes, as treatments end, at the time of a relapse, and when death is approaching).
 - Be aware that assessment of need can be difficult because some people and their carers may be reluctant to ask for help.
 - Social care and support needs include: emotional support, help with personal care (such as bathing and dressing), housework and shopping, practical aids (for example wheelchairs), caring for dependents (such as children or elderly relatives), and advice on work and employment issues.
- Offer the person and their carers informed professional assistance to obtain benefits for which they are eligible.
- Local authorities, NHS, or voluntary organizations may provide respite or day care, support groups, volunteer visitors, assisted transport, and bereavement care.

Basis for recommendation

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These recommendations are based on guidance from the National Institute for Health and Care Excellence on improving supportive and palliative care for adults with cancer [[NICE, 2004 \(/palliative-care-general-issues#!references\)](#)].

How should I assess the person's religious or spiritual needs?

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- Assess the person's spiritual needs at key points during the course of the illness (for example at the time of diagnosis, around treatment episodes, as treatments end, at the time of a relapse, and when death is approaching).
 - Spiritual need relates to a person's search for meaning within his or her life. Religion is a means of expressing underlying spirituality, but spiritual belief may not always be expressed in a religious way.
- Ensure that the person and their carers have access to staff who are sensitive to their spiritual needs.

- The level of support people need may range from an informal sharing of ideas about life, death, and the ultimate purpose of our existence, to the provision of formalized religious ritual.
 - Key issues in delivering effective spiritual support to people who are receiving treatment or at the end of life include:
 - Listening to the person's experience and discussing their questions.
 - Affirming the person's humanity.
 - Protecting the person's self-worth, dignity, and identity.
 - Ensuring that spiritual care is offered as part of a holistic approach to health that also includes psychological, social, and emotional care.
 - Multidisciplinary teams should have access to suitably qualified, authorized, and appointed spiritual caregivers and should also be aware of local community resources for spiritual care.
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Basis for recommendation

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These recommendations are based on guidance from the National Institute for Health and Care Excellence on improving supportive and palliative care for adults with cancer [[NICE, 2004](#) ([/palliative-care-general-issues#!references](#))].

How should I address the needs of the family and carers?

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- Offer family members and carers the opportunity for their needs (for example for support and information) to be assessed separately from those of the person receiving palliative care. They may have specific concerns such as:
 - Fear of the person dying.
 - Anxiety about an emergency occurring (for example what constitutes an emergency and how to deal with it).
 - Feelings of inadequacy with regard to caring for the person at home (for example lack of knowledge about how to make the person comfortable or appropriate lifting techniques).
 - Suppression of their true emotions in order to protect the person they are caring for.
 - Financial worries.
 - Altered role and lifestyle.
- Whenever possible and appropriate, invite family members and carers to be involved during clinical encounters and decisions about treatment and care (if this reflects the wishes of the person receiving palliative care).
- Ensure that family members and carers are made aware of local sources of information, advice, and support, to address their own needs.
- Particularly address the needs of the family and/or carers at demanding times in the person's illness, and when extra help may be needed.
- Consider that people of different ethnic backgrounds or cultures may have specific preferences regarding family involvement.
- Be aware that the demands of being a carer can sometimes present as physical symptoms (for example fatigue or weight loss).
- The family can be helped by:
 - Facilitating communication between the person and their family and health care professionals.
 - Recognizing areas of stress in other areas (for example work or coping with children).

- Education to provide the skills and knowledge to provide the necessary aspects of care to enhance the person's comfort.
- Discussion of pain management to reduce anxiety regarding potential addiction or tolerance.
- Encouraging expression of fears, concerns, uncertainty, and emotional strain.
- Providing information regarding the person's death and what to expect.

Basis for recommendation

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These recommendations are based on guidance from the National Institute for Health and Care Excellence [NICE, 2004 ([/palliative-care-general-issues#!references](#))], the General Medical Council's guidance for doctors *Treatment and care towards the end of life: good practice in decision-making* [GMC, 2010 ([/palliative-care-general-issues#!references](#))], and expert opinion in the Oxford textbook of palliative medicine [Hardy, 2015 ([/palliative-care-general-issues#!references](#))].

- Cancer can affect the whole family, who often provide vital support for the person who is receiving palliative care [NICE, 2004 ([/palliative-care-general-issues#!references](#))].
- Carers can feel helpless and frustrated when they are unable to provide comfort to their relative, but often do not express their own needs [NICE, 2004 ([/palliative-care-general-issues#!references](#)); Hardy, 2015 ([/palliative-care-general-issues#!references](#))].
- Healthcare providers may not always teach specific care-giving skills, which would be valuable to families [Hardy, 2015 ([/palliative-care-general-issues#!references](#))].

Scenario: Terminal phase

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From age 16 years onwards.

How should I assess prognosis?

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- Attempt to estimate the person's prognosis and discuss this with them, if appropriate.
 - Estimating the prognosis helps in the planning of appropriate treatment and care — if prognosis is not discussed, or predictions are inaccurate, people may make inappropriate treatment decisions, or inadequately prepare for death.
 - The [Prognostic Indicator Guidelines \(pdf\)](http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf) (<http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>) can be used to estimate prognosis.
 - It is part of the Gold Standards Framework, which aims to optimize the care of people nearing the end of life who are looked after by primary care teams in the community. It includes the question 'Would you be surprised if this patient were to die in the next 6 to 12 months?' to try to identify people nearing the end of their lives.
 - Some people may request not to know their prognosis. This should be respected and they should be given the opportunity to discuss it again at a later date.
- A discussion of prognosis should involve:
 - Identifying the person's own thoughts regarding their prognosis.
 - Explaining the difficulty of providing an accurate prognosis.
 - Providing a rough estimate only (for example days, weeks, months, or years).
- Risks associated with assessing the prognosis include:
 - Overestimating the length of survival — families may feel 'robbed' of time with their relative.

- Underestimating the length of survival — the person and their family may question the credibility of the source of information.
- It is therefore important to emphasize that an estimate of the person's prognosis is not a guarantee of what will happen.

Basis for recommendation

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This recommendation is based on the Prognostic Indicator Guidance from the Gold Standards Framework, the development of which involved collaboration with the Royal College of Physicians, the Royal College of General Practitioners, GPs with a special interest in palliative care, and national disease associations [[Gold Standards Framework, 2005a \(/palliative-care-general-issues#!references\)](#); [Gold Standards Framework, 2005b \(/palliative-care-general-issues#!references\)](#); [Gold Standards Framework, 2011 \(/palliative-care-general-issues#!references\)](#)]. Expert opinion from published literature was also considered [[Ngo-Metzger et al, 2008 \(/palliative-care-general-issues#!references\)](#); [Hardy, 2015 \(/palliative-care-general-issues#!references\)](#)].

- Estimating the prognosis helps in the planning of appropriate treatment and care [[Gold Standards Framework, 2011 \(/palliative-care-general-issues#!references\)](#)].
- If prognosis is not discussed, or predictions are inaccurate, people may make inappropriate treatment decisions, or inadequately prepare for death [[Hardy, 2015 \(/palliative-care-general-issues#!references\)](#)].
- Doctors may lack confidence when predicting how long someone might live, but if the discussion is avoided, people may be less likely to discuss their own fears and worries, resulting in increased anxiety [[Hardy, 2015 \(/palliative-care-general-issues#!references\)](#)].
- The challenge for doctors is to communicate prognosis accurately without giving false hope or mixed messages [[Ngo-Metzger et al, 2008 \(/palliative-care-general-issues#!references\)](#)].

How should I recognize the terminal phase?

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- It can often be difficult to be certain that a person is dying, but it is essential to recognize the signs of dying in order to appropriately care for people at the end of life.
- The terminal phase may last hours to several days.
- People are likely to be in the terminal phase of their illness when they:
 - Deteriorate day by day or more rapidly.
 - Have a reduced mobility and become progressively weak and fatigued without an apparent cause (for example hypercalcaemia).
 - Express a realization that they are dying.
 - Have reduced cognition, ability to communicate and social withdrawal.
 - Have a deterioration in level of consciousness.
 - Are delirious, characterized by increased restlessness, confusion, and agitation.
 - Are bed-bound.
 - Take little food or fluid, and have difficulty taking oral medication.
 - Are peripherally cyanosed, have mottled skin and are cold to the touch.
 - Have apnoea (whether awake or asleep) or an altered breathing pattern, such as Cheyne-Stokes breathing.

Basis for recommendation

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- The definition of the terminal phase in terms of timescale is based on a prospective study of 100 terminally ill cancer patients [Morita et al, 1998 ([/palliative-care-general-issues#!references](#))].
 - These recommendations are largely based on the National Institute for Health and Care Excellence (NICE) guideline *Care of dying adults in the last days of life* [NICE, 2015 ([/palliative-care-general-issues#!references](#))]. The basis for the NICE recommendations has been briefly summarized in this section. For detailed information on the evidence NICE used to make these recommendations, see the full [NICE guideline](https://www.nice.org.uk/guidance/ng31/chapter/Recommendations). (<https://www.nice.org.uk/guidance/ng31/chapter/Recommendations>)
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What adjustments should be made to care in the terminal phase?

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- The terminal phase requires a careful discussion with the person and their family and/or carers. It is important that healthcare professionals caring for adults at the end of life take into consideration the person's current mental capacity to communicate and actively participate in their end of life care.
- Healthcare professionals need to establish the communication needs and expectations of people who may be entering their last days of life, these include;
 - A consideration of whether the person would like someone important to them to be present when making decisions about their care.
 - The person's current level of understanding that they may be nearing death.
 - The person's cognitive status and if they have any specific speech, language or other communication needs.
 - How much information the person would like to have about their prognosis.
 - A sensitivity to the dying person's cultural, religious, social or spiritual needs or preferences.
- When it is clear a person has entered the terminal phase of their illness healthcare professionals should provide the dying person, and those important to them, with;
 - Accurate information about their prognosis (unless they do not wish to be informed), explaining any uncertainty and how this will be managed, but avoiding false optimism.
 - An opportunity to talk about any fears and anxieties, and to ask questions about their care in the last days of life.
 - Information about how to contact members of their care team.
 - Opportunities for further discussion with a member of their care team.
 - An individualised care plan.
- Discuss whether the dying person has an advance statement or has stated preferences about their care in the last days of life (including any anticipatory prescribing decisions, or an advance decision to refuse treatment, or details of any legal lasting power of attorney for health and welfare).
- Determine whether the dying person has understood and can retain the information given about their prognosis.
- Communicate the dying person's prognosis with other members of the multi-professional care team (including out of hours, on-call services), and ensure that this is documented in the dying person's care plan.

Individualised Care Plan

- An individualised care plan should include the dying person's:
 - Realistic personal goals (including treatment and resuscitation) and wishes.
 - Current and anticipated care needs including preferences for symptom management, any identified needs for care after death, and any identified resource needs.
 - Preferred care setting.

- Continue to explore the understanding and wishes of the dying person and those important to them, and update the care plan as needed. Recognise that the dying person's ability and desire to be involved in making decisions about their care may change as their condition deteriorates or as they accept their prognosis.
- While it is normally possible and desirable to meet the wishes of a dying person, when this is not possible explain the reason why to the dying person and those important to them.
- Ensure that shared decision-making can be supported by experienced staff. Seek further specialist advice if additional support is needed.

Management of end of life and symptom control

- The overriding principle of end of life care is to manage commonly experienced symptoms to maintain the person's comfort and dignity without causing unacceptable side effects.
- This approach includes:
 - Maintaining hydration.
 - Appropriate pharmacological interventions including stopping any unnecessary drug treatments and continuing other drug treatments by an appropriate route.
 - Anticipatory prescribing, for example the use of medications including cyclizine, diamorphine, hyoscine hydrobromide, and midazolam, so that new or developing symptoms can be treated without delay.
 - Managing specific common symptoms in end of life care, including oral symptoms, breathlessness, pain, nausea and vomiting, anxiety, agitation and delirium, and noisy respiratory secretions. For more information see CKS topics on [Palliative care - constipation \(/palliative-care-constipation\)](#), [Palliative care - cough \(/palliative-care-cough\)](#), [Palliative care - dyspnoea \(/palliative-care-dyspnoea\)](#), [Palliative care - malignant skin ulcer \(/palliative-care-malignant-skin-ulcer\)](#), [Palliative care - nausea and vomiting \(/palliative-care-nausea-and-vomiting\)](#), [Palliative care - oral \(/palliative-care-oral\)](#), [Palliative cancer care - pain \(/palliative-cancer-care-pain\)](#), [Palliative care - secretions \(/palliative-care-secretions\)](#).

Managing hydration

- Support the dying person to drink if they wish to and are able to.
 - Check for any difficulties, such as swallowing problems or risk of aspiration.
 - Discuss the risks and benefits of continuing to drink, with the dying person, and those involved in the dying person's care.
- Ensure that healthcare professionals and carers involved in end of life care offer frequent care of the mouth and lips to the dying person including:
 - Frequent sips of fluid.
 - Providing any necessary drinking aids.
 - Help with cleaning their teeth or dentures.
- Assess, preferably daily, the dying person's hydration status, and review the possible need for starting clinically assisted hydration, respecting the person's wishes and preferences. Clinically assisted hydration is provided by intravenous or subcutaneous infusion of fluids. Providing this hydration by drip infusion may provide symptom relief, or prolong or improve the quality of the patient's life, but may present additional problems.
- For someone who is in the last days of life, advise the person and carer that:
 - Clinically assisted hydration may relieve distressing symptoms or signs related to dehydration but may cause other problems such as fluid overload.
 - It is uncertain if giving clinically assisted hydration will prolong life or extend the dying process.
 - It is uncertain that if clinically assisted hydration is not given, death will hasten.
- Ensure that any concerns raised by the dying person or those important to them are addressed before starting clinically assisted hydration.

- When considering clinically assisted hydration for a dying person, use an individualised approach and take into account:
 - Whether they have expressed a preference for or against clinically assisted hydration, or have any cultural, spiritual or religious beliefs that might affect this documented in an advance statement or an advance decision to refuse treatment.
 - Their level of consciousness.
 - Any swallowing difficulties.
 - Their level of thirst.
 - The risk of pulmonary oedema or other complications of fluid overload.
 - Whether even temporary recovery is possible.
- Consider a therapeutic trial of clinically assisted hydration if the person has distressing symptoms or signs that could be associated with dehydration, such as thirst or delirium, and oral hydration is inadequate.
- For people being started on clinically assisted hydration:
 - Monitor at least every 12 hours for changes in the symptoms or signs of dehydration, and for any evidence of benefit or harm.
 - Continue with clinically assisted hydration, if there are signs of clinical benefit.
 - Reduce or stop clinically assisted hydration, if there are signs of possible harm to the dying person; such as fluid overload, or if they no longer want it.
- For people already dependent on clinically assisted hydration before the last days of life:
 - Review the risks and benefits of continuing clinically assisted hydration with the person and those important to them.
 - Consider whether to continue, reduce or stop clinically assisted hydration as the person nears death.

Pharmacological interventions

- When it is recognised that a person may be entering the last days of life, review their current medicines. After discussion and agreement with the dying person and those important to them (as appropriate), stop any previously prescribed medicines that are not providing symptomatic benefit or that may cause harm.
- When considering prescribing for symptom control, health professional should take into account:
 - Place of care and the time it would take to obtain medicines.
 - The likely cause(s) of any symptoms.
 - The dying person's individual preferences.
 - The benefits and harms of prescribed medicine.
 - Any risks of the medicine that could affect prescribing decisions including drug interactions and relevant past medical history.
 - The most effective route for administering medicines tailored to the dying person's condition, including their ability to swallow safely and personal preferences.
- Consider the subcutaneous route for administering medicine if the dying person is unable to take or tolerate oral medicines.
- Consider using a syringe driver to administer subcutaneous delivery of medicines for continuous symptom control. Particularly if more than 2 or 3 doses of any 'as required' medicines have been given within 24 hours.
- For people starting treatment who have not previously been given medicines for symptom management, start with the lowest effective dose and titrate as clinically indicated.
- Regularly reassess, at least daily, the dying person's symptoms during treatment to inform appropriate titration of medicine.
- Seek specialist palliative care advice if the dying person's symptoms do not improve promptly with treatment or if there are undesirable side effects, such as unwanted sedation.

Anticipatory prescribing

- Use an individualised approach to prescribing anticipatory medicines for people who are likely to need symptom control in the last days of life. Indications for use and the dosage of any medicines prescribed should be clearly documented in the individualised care plan.
- Assess what medicines the person might need to manage symptoms likely to occur during their last days of life (such as agitation, anxiety, breathlessness, nausea and vomiting, noisy respiratory secretions and pain).
- Discuss any prescribing needs with the dying person, those important to them and the multi-professional team.
- Ensure that suitable anticipatory medicines and routes are prescribed as early as possible. Review these medicines as the dying person's needs change.
- Health professionals should consider;
 - The likelihood of specific symptoms occurring.
 - The benefits and harms of prescribing or administering medicines.
 - The benefits and harms of not prescribing or administering medicines.
 - The possible risk of the person suddenly deteriorating (for example, catastrophic haemorrhage or seizures) for which urgent symptom control may be needed.
- If anticipatory medicines are administered:
 - Monitor for benefits and any side effects at least daily, and give feedback to the lead healthcare professional.
 - Adjust the individualised care plan and prescription as necessary

Basis for recommendation

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These recommendations are largely based on the National Institute for Health and Care Excellence (NICE) guideline *Care of dying adults in the last days of life* [NICE, 2015 ([/palliative-care-general-issues#!references](#))]. The basis for the NICE recommendations has been briefly summarized in this section. For detailed information on the evidence NICE used to make these recommendations, see the full [NICE guideline](#) (<https://www.nice.org.uk/guidance/ng31/chapter/Recommendations>).

Recommendations on clinical assisted hydration are based on General Medical Council guidance for doctors, *Treatment and care towards the end of life: good practice in decision making* [GMC, 2010 ([/palliative-care-general-issues#!references](#))]. The GMC advise that 'The current evidence about the benefits, burdens and risks of these techniques as patients approach the end of life is not clear-cut. This can lead to concerns that patients who are unconscious or semi-conscious may be experiencing distressing symptoms and complications, or otherwise be suffering either because their needs for nutrition or hydration are not being met or because attempts to meet their perceived needs for nutrition or hydration may be causing them avoidable suffering. Nutrition and hydration provided by tube or drip are regarded in law as medical treatment, and should be treated in the same way as other medical interventions. Nonetheless, some people see nutrition and hydration, whether taken orally or by tube or drip, as part of basic nurture for the patient that should almost always be provided. For this reason it is especially important that you listen to and consider the views of the patient and of those close to them (including their cultural and religious views) and explain the issues to be considered, including the benefits, burdens and risks of providing clinically assisted nutrition and hydration. You should make sure that patients, those close to them and the healthcare team understand that, when clinically assisted nutrition or hydration would be of overall benefit, it will always be offered; and that if a decision is taken not to provide clinically assisted nutrition or hydration, the patient will continue to receive high-quality care, with any symptoms addressed.'

Scenario: Communication

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What communication issues are important?

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- Communicate effectively with the person and their family or carers. Those who need to communicate particularly complex or distressing information should have enhanced skills or be supported by someone who has those skills.
- Communicate with professionals within [multidisciplinary teams](#) ([/palliative-care-general-issues#!scenarioClarification](#)), and other service providers caring for the person. Aim to achieve continuity of care (for example nominate a 'key-worker' for individual people).
 - Effective communication enables professionals to exchange information, plan interventions, and share responsibility for the person's care.
 - Documentation, especially using multidisciplinary records and clinic letters, facilitates communication between professionals.
- Assess, on an ongoing basis, how the person wishes to be involved in making decisions about their own care, and what information they and their family/carer need.
- Arrange appropriately trained interpreters for people who may otherwise find it difficult to communicate in their preferred language.
- Offer the person the opportunity to discuss topics which are important to them at that time, for example:
 - Treatment options and preferences.
 - Disease status, progression, and estimated prognosis.
 - Social implications (for example work and income).
 - Issues relating to those important to them (for example their partner and children).
 - Spiritual and religious issues.
 - Advance care planning issues, including preferences, hopes, and wishes (such as preferred place of care and issues around dying, including cardiopulmonary resuscitation, and whether they have any expressed views about organ or tissue donation).
 - If advance care plans are made, they need to be reviewed and updated as the person's situation or views change.
 - The Gold Standards Framework also includes advance care planning and has developed an advance statement of wishes template to support discussion and recording of a person's preference for place of care. For more information, see www.goldstandardsframework.nhs.uk (<http://www.goldstandardsframework.org.uk/advance-care-planning>).
- Give information verbally to the person and their family, although written materials may be useful for some.
 - It is not recommended that children be asked to interpret for parents or other family members.
 - A clinician may wish to offer the person a written record of consultations they have had with them.
- The Gold Standards Framework in the community supports good communication and coordination of care, with a practice Supportive Care Register. For more information, see www.goldstandardsframework.nhs.uk (<http://www.goldstandardsframework.org.uk/advance-care-planning>).

Basis for recommendation

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This recommendation is based on guidance from the National Institute for Health and Care Excellence on improving supportive and palliative care for adults with cancer [[NICE, 2004](#) ([/palliative-care-general-issues#!references](#))], expert opinion from palliative care literature in a textbook [[Hardy, 2015](#) ([/palliative-care-general-issues#!references](#))], and General Medical Council guidance for doctors, *Treatment and care towards the end of life: good practice in decision making* [[GMC, 2010](#) ([/palliative-care-general-issues#!references](#))].

- Most people wish to know their diagnosis and what is happening with their treatment and disease [Faulkner, 1998 ([/palliative-care-general-issues#!references](#))].
- Realistic hopes and aspirations can only be achieved by honest discussions [Hardy, 2015 ([/palliative-care-general-issues#!references](#))].
- Attempts to protect people from the reality of what is happening to them can lead to inconsistent messages being given by different members of the healthcare team [Hardy, 2015 ([/palliative-care-general-issues#!references](#))].
- Establishing and documenting a management plan in advance can help to ensure that a person's wishes and preferences about treatment can be taken into account, including a Do Not Attempt CPR (DNACPR) decision, if appropriate [GMC, 2010 ([/palliative-care-general-issues#!references](#))].

What sources of help and advice are available in primary care?

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- Care of people with advanced cancer, by health and social care professionals, should be based on locally agreed protocols and guidelines, delivered within the context of a managed system or pathway.
- Both the GP and district nurse should be involved as early as possible after diagnosis and can contact their local specialist palliative care team for support or advice. The multidimensional nature of problems in palliative care requires a [multidisciplinary team](#) ([/palliative-care-general-issues#!scenarioClarification](#)) approach.
 - Discuss with the local specialist palliative care service (community, hospice, or hospital-based, as appropriate) to decide whether further involvement by the specialist team is required.
- Available resources for healthcare professionals caring for people receiving palliative care include:
 - **The Gold Standards Framework** — also includes advance care planning and has developed an advance statement of wishes template to support discussion and recording of a person's preference for place of care. It also supports good communication and coordination of care, with a practice Supportive Care Register. For more information, see www.goldstandardsframework.nhs.uk (<http://www.goldstandardsframework.org.uk/advance-care-planning>).
 - **The Leadership Alliance for the Care of Dying People** has published new standards of care that dying people and their families should expect to receive. This takes the form of five new Priorities for Care and replaces the Liverpool Care Pathway. For more information, see www.nhs.uk ([pdf](http://www.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff_-_with_prompts_for_practice.pdf)) (http://www.nhs.uk/media/2485900/duties_and_responsibilities_of_health_and_care_staff_-_with_prompts_for_practice.pdf).
 - **The End of Life Care Patient Charter** developed by the Royal College of General Practitioners (RCGP) and the Royal College of Nursing — implements the key recommendations of the RCGP's End of Life Care Strategy. It provides an example of best practice that people receiving palliative care should be able to expect from their primary healthcare team. For more information, see [EOLC Patient Charter](#) ([pdf](http://www.rcgp.org.uk/~media/Files/CIRC/CIRC_EOLCPatientCharter.ashx)) (http://www.rcgp.org.uk/~media/Files/CIRC/CIRC_EOLCPatientCharter.ashx).
 - **The Prognostic Indicator Guidelines** ([pdf](#)) (<http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf>) — can be used to estimate prognosis. It is part of the Gold Standards Framework, which aims to optimize the care of people nearing the end of life who are looked after by primary care teams in the community. It includes the question 'Would you be surprised if this patient were to die in the next 6 to 12 months?' to try to identify people nearing the end of their lives.
 - **The General Medical Council's guidance for doctors, *Treatment and care towards the end of life: good practice in decision making*** — has detailed information regarding issues of advance care planning, advance requests and refusals for treatment, recording and communicating decisions, and discussions about whether to attempt cardiopulmonary resuscitation.

- The palliative care team may include any or all of the following specialities:
 - Palliative medicine consultants and doctors.
 - General practitioner.
 - Palliative care nurses, including:
 - Palliative care nurse specialist/Macmillan nurse.
 - Marie Curie nurse.
 - Palliative care pharmacist.
 - Physiotherapist.
 - Occupational therapist.
 - Counsellor (particularly bereavement counsellors) or psychologist.
 - Dietitian.
 - Social worker.
 - Spiritual adviser.
 - Benefits adviser.
 - Complementary therapists.
- Macmillan nurses provide support and information to people with cancer and their families [[Macmillan Cancer Relief, 2004 \(/palliative-care-general-issues#!references\)](#)].
 - They do not usually provide 'hands-on' care, but give advice to the primary care team, including advice regarding medication for symptoms (for example pain, nausea, vomiting).
 - The person and their family can self-refer to the Macmillan nursing team.
- Marie Curie Cancer Care provides nurses who care for terminally ill people and give them the choice of dying at home supported by their families [[Marie Curie Cancer Care, 2007 \(/palliative-care-general-issues#!references\)](#)].
 - Marie Curie nurses can provide hands-on care at home through the day or night.
- Marie Curie and Macmillan nursing services are free of charge to the person and their family and their services can be accessed via the person's GP or district nurse.

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Search strategy

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Scope of search

A literature search was conducted for guidelines, systematic reviews and randomized controlled trials on primary care management of palliative care - general issues.

Search dates