Clinical practice guideline on palliative care for adults in the last days of life

Short version

Clinical Practice Guidelines in the Spanish NHS

Ministry of Health

MINISTERIO DE SANIDAD
RED ESPAÑOLA DE AGENCIAS DE EVALUACIÓN DE TECNOLOGÍAS Y PRESTACIONES DEL SISTEMA NACIONAL DE SALUD
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AXENCIA GALEGA DE COÑECEMENTO EN SAÚDE

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Introduction.

The main aim of the Clinical Practice Guideline on palliative care for adults in the last days of life is to serve as a tool for improving the healthcare provided to people in the last days of their life and their families, across the various levels of care and settings where they are seen (hospital, primary and home care, emergency services, and health and social care centres).

The target population of this CPG is adult patients (over 18 years of age) at the end-of-life stage when death occurs gradually and when -during this stage- there is severe physical deterioration, extreme weakness, a high rate of cognitive impairment and/or disorders of consciousness, relational and eating/drinking difficulties, and a life expectancy of days or hours, regardless of whether patients are on a palliative care pathway.

This version in English contains the following types of information:

- **Clinical questions**
- **Recommendations**
- **Rationale**
- **Complete clinical question** (link to the version in Spanish)
- **References.**

To access the full version of the CPG (as a multilayer presentation or PDF), the methods employed, materials for patients, families and other caregivers, and other information in Spanish, please click on the following link:

https://portal.guiasalud.es/gpc/atencion-paliativa-ultimos-dias/

1. Recognising the last days of life

Question:

What signs and symptoms should be evaluated when it is suspected that an adult patient with an advanced chronic condition may be in the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. When caring for people with progressive disease, at a very advanced stage, always establish their prognosis and identify whether they are in the last days of life (clinical status assessment) and record this in their medical record.

2. Support clinical judgement (the cornerstone for identifying the last days of life) by the following:
    - Assessment of possible reversible causes of deterioration, especially when symptoms that appear are not consistent with the expected clinical trajectory
    - Monitoring of changes in patients' physical, psychosocial and spiritual needs
    - Assessment of functional status and speed of decline. If considering the use of instruments for supporting this assessment, we suggest the Palliative Performance Scale (PPS) or the Eastern Cooperative Oncology Group (ECOG) Performance Status.
    - Consideration of the opinions of other members of the multidisciplinary team, and if in doubt, consultation with experts.

WEAK RECOMMENDATION IN FAVOR

3. Look for the following:
    - Cardiovascular changes:
        - Reduction in blood pressure
        - Oliguria
        - Mottling of the skin
    - Respiratory changes:
        - Noisy breathing (rattling)
        - Changes in breathing pattern: Cheyne-Stokes breathing, apnoea
        - Dyspnoea
        - Mandibular breathing
    - Changes in physical condition:
        - Severe and progressive weakness
        - Loss of ability to close eyes
        - Loss of interest in eating and drinking
        - Swallowing difficulties
        - Urinary incontinence or retention
    - Cognitive and neurological changes:
        - Reduced level of consciousness (from somnolence to coma)
        - Hypoactive delirium or hyperactive delirium (characterised by agitation)
    - Psychosocial and emotional changes:
        - Isolation
        - Changes in mood
    - Changes in spiritual experience.

GOOD CLINICAL PRACTICE

4. Thoroughly investigate, in a proportionate manner and considering patients' and relatives' values and preferences, possible reversible causes of deterioration, such as dehydration, infection, opioid toxicity, steroid withdrawal, acute renal failure, and metabolic disturbances, to rule them out or initiate appropriate treatment, if applicable.

Rationale

We have made a weak recommendation in favour of assessing various signs and symptoms in patients with advanced progressive conditions, and a series of good clinical practice recommendations which aim to promote systematised assessment and the recording of the needs and preferences of patients and their relatives. The guideline development group (GDG) has taken into account the good benefit-risk balance, the importance for patients, and that such assessment might not imply significantly higher costs than usual clinical practice.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-1

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2. Communication and information

Question:

What factors are associated with good communication between the patient, their family and close friends, and the attending clinicians in the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. Foster an appropriate climate based on warmth, empathy, assertiveness, and active listening, paying special attention to non-verbal communication. As and when possible, find a physical space to safeguard privacy, and dedicate sufficient time, allowing questions to be asked and doubts resolved, and also time for reflection.
2. Identify the communication needs and expectations of people at the end of life taking into account:
    - Whether they do or do not want someone in particular to be present when decisions are made
    - Their current awareness of and knowledge about the end-of-life situation.
    - How much information they want regarding the process they are going through
    - Their social, cultural, religious and spiritual preferences and needs
    - Their fears and concerns.

Rationale

These recommendations aim to promote effective communication in the last days of life that would improve the drafting of the care plan and the quality of care provided. The recommendations, although they concern good clinical practice, are based on qualitative studies on the factors that influence good end-of-life communication.

Complete clinical question

For full information on this question (available in Spanish), see:
http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-2

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3. Shared decision-making and development of a care plan

Question:

What factors help foster shared decision-making on a personalised care plan for the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. Despite the prognostic uncertainty in many cases, start a shared decision-making process as soon as possible during the course of the disease, or at the beginning of the clinical relationship if this has not been done previously by other clinicians.
2. At the start of the shared decision-making process, explore the level of involvement the patient wants or can have, and be honest and transparent in discussions on the development and implementation of a care plan.
3. During the decision-making process, explore patients' expectations, wishes, and preferences regarding the care they would like to receive, in line with their values. In cases in which patients cannot make decisions, review:
    - Whether there is a living will or other type of advance directive document
    - Any notes in the clinical history regarding shared advanced care planning
    - Any preferences expressed to their families and close friends concerning the care they would like to receive
    - Whether the patient has a designated representative. If there is no representative or family and/or close friends, the healthcare team takes decisions, seeking the greatest possible level of consensus and always working to provide the greatest benefit for and in the best interest of the patient.
4. Record the topics addressed and the care plan developed in a suitable place in the medical record, accessible to all the clinicians involved in the patient's care, and share this information not only with the rest of the care team but also with the family and close friends involved in caring for and/or accompanying the patient.

Rationale

The GDG has issued a series of recommendations to promote appropriate shared decision-making and development of a care plan. The recommendations are based on qualitative evidence on barriers and facilitators, and the experience of the group. The GDG considers that it is important to promote shared decision-making and an ongoing process of planning throughout the entire course of the disease, as it is common that patients in their last days lose the ability to make their own decisions or are not willing to do so. In any case, the approach of clinicians should be to promote patient involvement as far as possible until death.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-3

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4. Hydration

Question:

Is artificial hydration effective in improving the symptoms and general comfort of patients in the last days of life?

Recommendations:

WEAK RECOMMENDATION AGAINST

1. In general, do not provide artificial hydration in patients in the last days of life. Exceptionally, consider it if:

- There is poor control of symptoms that could be related to dehydration (for example, delirium) and other control measures have failed
- The reduction in oral intake causes unrest or emotional concern in the patient and their relatives despite appropriate communication with the care team.

GOOD CLINICAL PRACTICE

2. Review medical records to check whether the patient has previously expressed preferences regarding artificial hydration in an advance directive when considering artificial hydration in the last days of life and the patient is unable to decide.
3. If artificial hydration is indicated:
    - Address the concerns of the patient and their family and inform them about the evidence of the benefits and risks of artificial hydration in the last days of life
    - Consider it a measure to be taken for a limited time (previously agreed with the patient/relatives)
    - Do not use a daily volume of more than 1 l
    - Do not use the enteral route of administration; rather, subcutaneous administration is the route of choice in home care patients or when an IV line is not already in place.
4. Once artificial hydration has been set up
    - Monitor changes in signs or symptoms of dehydration and any evidence of benefit or harm approximately every 24 h
    - Continue hydration if there are benefits perceived by the patient and/or family
    - Reduce or stop hydration if there are signs of potential harm such as fluid overload or increased respiratory secretions, or if the patient or their family or close friends request its withdrawal.
5. In cases in which artificial hydration (via the enteral or parenteral route) is already in place before the last days of life:
    - Review the risks and benefits of continuing this type of hydration in the last days of life with the patient and family/close friends
    - Consider whether to continue, reduce or stop artificial hydration as the patient approaches death.

Rationale

These recommendations have been formulated seeking to promote appropriate clinical management of hydration in the last days of life, based on the evidence of the risks and benefits and taking into account the values and preferences of patients and their families.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-4

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5. Management of symptoms

General considerations

Recommendations:

GOOD CLINICAL PRACTICE

1. To guide decisions on symptom management, assess the main symptoms systematically, to reduce the risk of any being underestimated, and quantify their severity using scales that enable us to assess the results of any measures taken.
2. Thoroughly review treatment given in the last stage of a patient´s life and adapt it to therapeutic objectives focused on well-being and symptom control.
3. Stop all treatments that are futile, that is, that do not provide any benefit in the patient´s current condition, discuss the risks and benefits of any medication proposed, and explain that the withdrawal of a medication is due its futility given the patient's current condition.
4. Leave clear instructions regarding the treatment in writing, indicating the baseline dosages and alternatives for use at times of crisis.

Rationale

The GDG has issued recommendations on good clinical practice focused on the general principles of prescribing in palliative care. Further, a list of key clinical considerations has been drawn up, related to the implementation of the recommendations.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-5

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Question:

Which medications are most effective for alleviating pain in the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. Within an overall palliative care approach, encourage appropriate assessment and management of pain in order that patients reach the last days of life with their pain under control, with medication continued and adjusted appropriately. Anticipate patients' potential needs for analgesia and prescribe medication to provide appropriate pain control in advance, enabling families/close friends and/or the healthcare team to manage the situation as and when necessary.

2. Do not routinely prescribe analgesic drugs because, though pain is a very common symptom, it is not experienced by everyone in the last days of life.

3. Consider non-pharmacological ways of managing pain in the last days of life together with pharmacological treatments.

4. Once reversible causes have been ruled out, the pharmacological treatment of choice for moderate-to-severe pain is opioids. If patients experience mild pain, use "first step" drugs, except when a poor response is expected or there are problems with the route of administration, in which case, consider low-dose opioids.

5. If opioids are given, fast-acting morphine (oral or parenteral) is the medication of choice in the last days of life.

6. Do not reduce or stop opioids abruptly, as both such a reduction or withdrawal and poorly controlled pain are known risk factors for disorientation and delirium in patients with advanced chronic conditions.

7. In patients with neuropathic pain, maintain baseline medication as far as possible, although some may need to be discontinued since the oral route is often not an option in the last days of life, and therefore, take this into account in opioid dosing.

Rationale

Given the paucity of scientific evidence on the effectiveness of various drugs for managing pain in patients in the last days of life, the GDG has made recommendations based on the general principles of pain control and management in stages before palliative care and its members' clinical experience. These recommendations seek to encourage appropriate assessment and control of pain in the last days of life, bearing in mind the major impact of pain.

Complete clinical question

For full information on this question (available in Spanish), see:
http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-5

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Question:

Which medications are most effective for alleviating dyspnoea in the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. Maintain or start specific treatment if the problem that causes dyspnoea (for example, pulmonary oedema, or pleural effusion) is known and the risk-benefit balance is positive.
2. Use non-pharmacological strategies first, adding pharmacological treatment as and when necessary, to manage dyspnoea in the last days of life.
3. In the event that the non-pharmacological measures do not alleviate dyspnoea, offer a trial of oxygen therapy regardless of the hypoxemia severity and maintain the therapy if the patient/family perceives a benefit.

WEAK RECOMMENDATION IN FAVOR

4. If dyspnoea is poorly controlled with the aforementioned measures, add symptomatic treatment with morphine, midazolam, or a combination thereof.

Rationale

Three good clinical practice recommendations have been made regarding the indications for pharmacological treatment and starting of non-pharmacological measures. Taking into account the quality of the evidence and the risk-benefit balance, we make a weak recommendation in favour of the use of drugs (opioids, benzodiazepines, or a combination of thereof).

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-5

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Question:

Which drugs are most effective for alleviating nausea and vomiting in the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. In patients in the last days of life, perform a proportionate assessment of potential causes of nausea and vomiting, which could include:
    - Certain drugs
    - Chemotherapy and/or radiotherapy
    - Psychological factors
    - Biochemical factors, for example, hypercalcemia
    - High intracranial pressure
    - Poor gastrointestinal motility
    - Bowel obstruction.
2. Consider non-pharmacological measures to treat nausea and vomiting in the last days of life.

WEAK RECOMMENDATION IN FAVOUR

3. For the treatment of nausea and vomiting in people with bowel obstruction, as well as other pharmacological and non-pharmacological measures, use the following treatments:
    - Hyoscine butylbromide, also known as scopolamine butylbromide, as first-line antisecretory treatment
    - Octreotide if symptoms do not improve within 24 hours after starting treatment with hyoscine butylbromide.

GOOD CLINICAL PRACTICE

4. In other clinical scenarios, use standard antiemetic medication for palliative care: neuroleptics, antihistamines, prokinetic agents, 5-HT3 receptor antagonists, corticosteroids and benzodiazepines.

Rationale

Two good clinical practice recommendations have been made focusing on assessing the causes of nausea and vomiting and starting of non-pharmacological measures. In the event of bowel obstruction, a weak recommendation has been made in favour of the use of certain medications, taking into account the quality of the evidence; for other clinical scenarios, one good clinical practice recommendation has been made, due to the scarcity of end-of-life research addressing this question.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-5

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Question:

Which drugs are most effective for alleviating anxiety, delirium and agitation in the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. Assess all patients in the last days of life for anxiety and delirium (with or without agitation).

2. Explore and manage potential causes of anxiety and delirium, for example, pain, urinary retention and faecal impaction, in a proportionate manner, in the context of the last days of life and considering the preferences of patients and their families and close friends.

3. Use non-pharmacological measures for the prevention and management of anxiety and delirium. Give support and training to the family.

4. Consider using benzodiazepines for managing anxiety.

5. Consider using traditional antipsychotic medication, and if there is a poor response, its combination with benzodiazepines, for managing delirium.

Rationale

Five good clinical practice recommendations have been made focused on improving assessment and the use of non-pharmacological measures. Given that no studies were found assessing the effectiveness and safety of medications for the treatment of anxiety or delirium in the last days of life, the GDG recommend using the medications most widely employed in clinical practice and for which there is considerable experience of their use at this stage.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-5

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Question:

Which drugs are most effective for alleviating noisy breathing in the last days of life?

Recommendations:

GOOD CLINICAL PRACTICE

1. As a person enters the last days of life, be alert to the onset of noisy breathing to consider early initiation of treatment.
2. Provide information about the causes of noisy breathing and address any concerns, underlining that, although the noise can be distressing, it is unlikely to cause discomfort to the patient due to the low level of consciousness.
3. Take non-pharmacological measures to alleviate noisy breathing to reduce any potential discomfort in people in the last days of life and their family and friends.
4. Consider pharmacological treatment of noisy breathing when non-pharmacological measures and communication with the patient and their family prove to be insufficient.

WEAK RECOMMENDATION IN FAVOUR

5. Use scopolamine (hyoscine) butylbromide as the first-line treatment, although atropine or scopolamine hydrobromide can be used as alternatives.

Rationale

One weak recommendation has been made in favour of the use of drugs for noisy breathing in the last days of life, taking into account the quality of the evidence, which is very low according to the GRADE system, and the risk-benefit balance of the treatments. This recommendation is accompanied by a series of clinical practice recommendations focused on the identification and early management of noisy breathing, improvement of the communication process, and use of non-pharmacological measures.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-5

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6. Palliative sedation

Question:

Is palliative sedation beneficial for alleviating suffering caused by refractory symptoms in the last days of life?

Recommendations:

WEAK RECOMMENDATION IN FAVOUR

1. Use palliative sedation in patients in the last days of life who are suffering due to one or more refractory symptoms.

Rationale

GDG has made a weak recommendation in favour of using palliative sedation in such patients (patients in the last days of life who are suffering due to one or more refractory symptoms), given that the quality of the evidence on the effects is overall very low and there is substantial uncertainty about and variability in how patients and their families value the outcomes.

Additionally, a list of key clinical considerations has been drawn up regarding the implementation of the recommendation made. These focus on improving the process of palliative sedation, including the need to reach a consensus among the multidisciplinary team on the indication of sedation, the obtaining of informed consent, types of sedation, monitoring, measures to tailor therapy and achieve a reasonable level of comfort, and the approach of health professionals, as well as the documentation of the process in the medical record.

Complete clinical question

For full information on this question (available in Spanish), see:

http://portal.guiasalud.es/guia-en-capas/gpc_612__atencion_paliativa_sud-2/#question-6

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