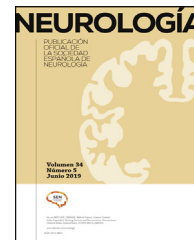




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CONSENSUS STATEMENT

Palliative care in stroke: Guidelines of the Spanish Society of Neurology's Stroke Study Group

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Abstract These guidelines address the relief of suffering and the optimal management of patients with stroke at the end of life. Their main purpose is to contribute to the development of skills in communication, setting treatment objectives, and decision-making. Furthermore, they focus on symptom management and specific care in patients with severe stroke. The recommendations are based on a systematic review of the literature and international guidelines

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PALABRAS CLAVE

Cuidados paliativos;
Ictus;
Cuidados al final de la vida;
Ictus hemorrágico

on the subject. The levels of evidence and grade of recommendation are based on those established in the 2016 classification of the American College of Cardiology and the American Heart Association Task Force.

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Guía de Cuidados Paliativos en el paciente con ictus: recomendaciones del Grupo de Estudio de Enfermedades Cerebrovasculares de la Sociedad Española de Neurología

Resumen La presente Guía aborda el alivio del sufrimiento y el manejo óptimo de los pacientes con ictus que se encuentran en el final de la vida. Su propósito principal es contribuir al desarrollo de habilidades en comunicación, definición de objetivos de tratamiento y toma de decisiones. Además, se enfoca en el manejo de los síntomas y los cuidados específicos de los pacientes con ictus grave. Para su elaboración, se llevó a cabo una revisión sistemática de la bibliografía y las Guías internacionales disponibles. Las recomendaciones se basan en niveles de evidencia y grados de recomendación establecidos por la clasificación de 2016 de la American College of Cardiology y la American Heart Association Task Force.

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Introduction

The relief of suffering and the optimal management of patients with stroke at the end of life was previously addressed in a manual developed by the Spanish Society of Neurology's Stroke Study Group.¹ That document constitutes the basis of the recommendations issued in these guidelines.

The primary purpose of these guidelines is to develop the necessary skills in communication, setting treatment objectives, clinical decision-making, symptom management, and the specific care of patients with severe stroke. They are based on a systematic review of the literature and of the available international guidelines, as well as the levels of evidence and grades of recommendation established in the 2016 classification of the American College of Cardiology and the American Heart Association Task Force.²

Palliative care (PC) is defined as person- and family-centred multidisciplinary care that seeks to anticipate, prevent, and relieve suffering at all stages of disease, including the end of life.^{3,4} Its application requires knowledge of the values of the patient and their family and their preferences regarding the quantity and quality of life that may be expected, analysing the impact of potential sequelae; and must address their physical, intellectual, emotional, social, and spiritual needs, with a view to facilitating patient independence, access to information, and the selection of the different treatment options available during the process.³⁻⁵

PC is a care need that is not sufficiently met at present, and is endorsed in the recommendations of numerous medical societies and recognised international guidelines.^{6,7} PC must be comprehensive and multidisciplinary, promoting communication and coordinated, patient-centred work.⁷ The acquisition of the skills needed for PC will equip physicians to manage difficult symptoms, define treatment

objectives, and make complex decisions for the patient and their family, including those related to ethical and legal issues.⁸ Multidisciplinary work is particularly useful in patients with stroke, in the light of the multiple variables at play and the difficulty of predicting prognosis, the specific considerations related to treatment options, and the need for immediate action during the acute phase, in which early aggressive treatment aiming to recover the patient is rapidly followed by the need for limitation of therapeutic effort and the onset of end-of-life care.^{9,10}

PC is particularly relevant in patients with severe stroke, who often have difficulty communicating or present other cognitive limitations that may diminish their ability to make decisions, which may require the participation of family members or representatives, who often experience considerable stress and struggle to assume the impact of a disease whose presentation is so sudden and so devastating.^{6,7} Acute stroke requires appropriate explanation of the different treatment options, such as arterial recanalisation (intravenous thrombolysis, mechanical thrombectomy) or decompressive craniectomy, and little time is available for decision-making.

In this context, physicians must incorporate working routines that promote a trusting, patient-centred relationship, emphasising transparency and understanding, and facilitating participation, respecting patients' dignity and capacity to choose in all matters, without exceptions.^{6,7} Physicians must develop skills for effectively estimating prognosis, establishing care outcomes, and evaluating and managing symptoms, and must be familiar with the limitation of therapeutic effort (Fig. 1). Informed selection of the available treatment options must be made jointly, after consideration of the potential risks and benefits,^{9,10} promoting the implementation of shared healthcare planning processes in health systems.¹¹

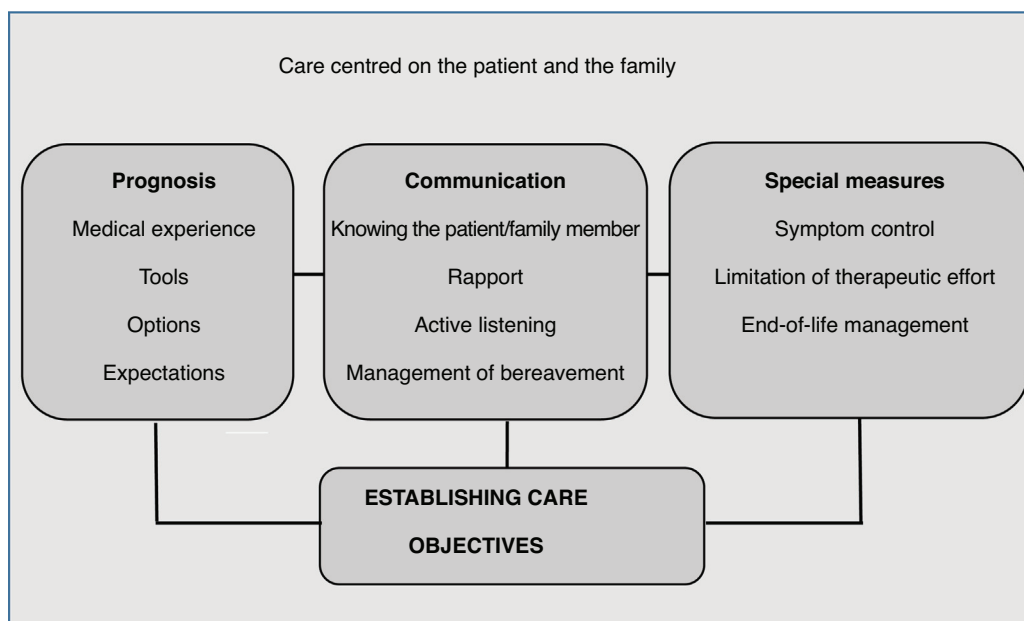


Figure 1 Basic principles and recommended practices in palliative care.

Estimation and communication of prognosis

Precise estimation of prognosis is a complex challenge in acute ischaemic stroke. Communication of prognosis to other healthcare professionals and to patients and their families is fundamental in guaranteeing quality decision-making to enable provision of the necessary PC.^{6,7}

This estimation may be based on clinical experience and predictive models. It is essential to consider a range of clinical variables as well as the individual characteristics of each case, as occurs in situations of malignant middle cerebral artery infarction or basilar artery infarction associated with coma, which are associated with poorer prognosis.^{9,10} Multimodal imaging studies may provide objective information about the established lesion, brain tissue at risk of damage, and the status of the collateral circulation, which are essential factors in evaluating prognosis.^{12,13} We may also use predictive models that account for all available information; an example in the case of ischaemic stroke is the iScore, which has been shown to be efficacious for estimating mortality risk.¹⁴

In haemorrhagic stroke, we may also use severity scales and predictive models that account for clinical variables and the location or volume of the haemorrhage; for instance, the ICH Score has been found to be useful for predicting mortality.^{15,16} Furthermore, head CT scans, with or without contrast, may reveal signs that are predictive of expansion of the haematoma (e.g., the spot sign), which are associated with poor prognosis.¹⁷ Finally, the following factors are predictive of poor prognosis in aneurysmal subarachnoid haemorrhage: initial clinical severity as established with such validated scales as the Hunt and Hess scale or the World Federation of Neurological Surgeons Scale, rebleeding of the aneurysm, advanced age, prior comorbidities, cerebral oedema, intraventricular or intracerebral

haemorrhage, symptomatic vasospasm, and delayed cerebral ischaemia, among others.¹⁸

Predictive models in stroke have benefits and limitations with which we must be familiar in order to avoid overtreatment or inappropriate limitation of therapeutic effort; this risk is particularly relevant in patients with haemorrhagic stroke, in which limitation of this effort is more frequent.¹⁹ In this regard, clinical experience is also useful in establishing prognosis; however, predictive capacity is limited, and it may be helpful to seek a second opinion from a more experienced physician with a view to minimising potential bias.²⁰

Prognosis should be communicated directly and empathetically, using accessible language, with a description of the best- and worst-case scenarios that may be expected, without ruling out hope; information should be paced, allowing for questions to be asked about the process and reiterating our commitment to the patient.²¹ When communicating prognosis, we must be alert to family members' emotional responses, attempting to anticipate and direct them and acknowledging their legitimacy; promoting this practice reduces anxiety and depression and increases perceived satisfaction.²²

Estimation and communication of prognosis. Recommendations

1. Estimation of prognosis should take place after comprehensive assessment of which aspects of recovery (e.g., ability to walk and communicate, tolerance of disability) are the most important to the patient and their family, and discussion of the prognosis should be guided in those terms (grade of recommendation 1; level of evidence C).

Table 1 Recommended strategies for communication and establishing care objectives.

- Selecting a quiet, private place
- Beginning with introductions and subjects for discussion
- Inviting the participation of other professionals involved
- Consulting the patient's previous preferences
- Establishing a hierarchy for decision-making, if needed
- Establishing what participants already know and have understood: "ask-tell-ask" technique
- Providing sufficient but not excessive information that is clear, realistic, and adapted to participants' level of understanding, disease stage, and emotional status
- Showing imaging findings may assist in the understanding of the process
- Proposing time-limited therapeutic trials in complex cases
- Avoiding cognitive biases
- Promoting active listening and empathy in conflict resolution

2. Physicians should be aware of the uncertainty, limitations, and potential biases inherent to prognosis estimation, whether this is based on experience or on predictive models (grade of recommendation 1; level of evidence C).
3. Prediction of survival and potential functional capacity after stroke should be based on the best available evidence in the literature, including relevant results based on predictive models, alongside the clinical impression based on personal experience (grade of recommendation 2a; level of evidence C).
4. Physicians should consider requesting a second opinion on prognosis from an experienced colleague in the event that uncertainty has an impact on therapeutic decision-making (grade of recommendation 3b; level of evidence C).
5. The knowledge and effective use of communication techniques is a decisive skill for improving quality of decision-making and the satisfaction of patients and their families (grade of recommendation 1; level of evidence B).

Care objectives

Care objectives should be established globally and consensually, incorporating a range of clinical and personal variables. These include age, prior functional status, comorbidities, and the risk/benefit balance of therapeutic interventions. Furthermore, it is essential to estimate prognosis in terms of death or disability, avoiding potential biases, and to assess the likely level of recovery and the time needed to achieve it.

We must also account for potential intercurrent complications and, crucially, the values and preferences of the patient and their family, including emotional and spiritual needs.^{23,24} The main strategies for communication and establishing care objectives are summarised in [Table 1](#).

The first conversation typically occurs after initial assessment of patients with acute stroke and, as this is one of the

moments of greatest uncertainty as regards progression, this conversation should be held in a quiet place. The first matter to be addressed is what the patient and their family know about the process, and how much they wish to know.²¹ The information shared should be sufficient but not excessive, and should be provided in clear language adapted to the level of education of the participants; it will depend on the stage of the disease, the stage of life of the patient, level of understanding, and emotional considerations.^{22,23} Further conversations should be held throughout the disease process, offering the different possible options at each stage of disease progression. In this regard, we may consider time-limited treatment trials to evaluate the response and whether or not to continue with treatments.²⁴ This time-limited resource offers some margin for reflection, facilitates adaptation to the process, opens the door to potential improvement, and promotes trust.

Care objectives in patients with stroke are numerous, and include seeking patient comfort and well-being, maintaining individual dignity, fostering communication, and sharing quality time with family members, decreasing the burden on them.²⁵

Setting care objectives: recommendations

1. The individuals responsible for the care process should integrate the best available scientific evidence and patient preferences and values when establishing care objectives (grade of recommendation 1; level of evidence C).
2. Objectives and treatment preferences should be reviewed periodically in the light of potential changes over time in the clinical situation and the preferences of the patient and their family (grade of recommendation 1; level of evidence B).
3. The professionals responsible for the care process may consider using time-limited treatment trials with defined objectives, in order to improve understanding of the prognosis or to allow more time to optimise other aspects of decision-making (grade of recommendation 2b; level of evidence C).

Complex decision-making

The aim of communication is to establish a relationship of trust and proper management of conflicts, taking into account the fact that emotional blocks may lead to errors in the interpretation of the expectations and values of the patient and their family.^{26,27} It is important to review whether advance directives have been established, obtain relevant information on the family and social dynamic, and enquire about any preferences regarding the sharing of medical information. If the patient is not legally competent, treatment decisions must take into account the expected prognosis, advance directives, and the opinion of the family member or legal representative responsible for the patient, within the applicable legislative framework (in Spain, Basic Law 41/2002, of 14 November, on the autonomy of the patient and the rights and obligations with regard to clinical information and documentation).²⁸

Table 2 Cognitive biases in decision-making.

- *Affective forecasting errors*: overestimating the emotional impact that a future health status might have on the individual.
- *Focusing illusion*: focusing excessively on one aspect of health (generally disability) without considering the remaining abilities.
- *Optimism*: optimism is omnipresent, to the point that it is probably beneficial to prognosis; it is often observed in healthcare professionals, patients, and family members.

We should also bear in mind various cognitive biases (Table 2) that may affect decision-making and prognosis, which we must recognise and avoid.^{19,20}

In severe stroke, decision-making may depend on a third party, who must bear a heavy emotional burden, which they must be able to share.²⁶ When family members are involved in the process, it is necessary to consensually establish a well-defined hierarchy with regard to who is the main actor in decision-making, respecting the preferences of those involved; in the event that conflicts arise, it may be useful to resort to specialists in PC or to the ethics committee, and to consult regional legislation.^{25–28}

Conflicts typically arise from differences in opinion and interpretation, which may be contrary to the objectives of the patient, and may also be related to emotions, such as the desire to do everything possible to prolong life and difficulties confronting death.²⁷ In these cases, active listening and following the above-mentioned recommendations about proper communication (Table 1) enable the implementation of strategies to assist family members in resolving these conflicts, with the focus always placed on the preferences of the patient.

Complex decision-making: recommendations

1. It may be helpful for the professionals responsible for the process to be aware, and to inform patients and their family members, of possible cognitive biases (affective forecasting errors, focusing illusion, and optimism bias) that arise when discussing treatment options and care objectives (grade of recommendation 2b; level of evidence C).
2. In the event of conflicts between the objectives of the patient and those of their representative in decision-making, the implementation of communication strategies (Table 1) should be considered to assist family members in resolving these differences (grade of recommendation 2b; level of evidence C).

Limitation of therapeutic effort

Limitation of therapeutic effort is defined as the adjustment of treatment measures to the situation of the patient in cases in which there is little hope of efficacy and prognosis is poor, and entails a change in treatment strategy, withdrawing or withholding some treatment; this is particularly relevant in the case of advanced life support

measures.²⁹ Some particularly significant situations share certain common characteristics: the lack of a simple, clear response, and a significant impact on quality of life and life expectancy.

Limitation of therapeutic effort may be influenced by cultural and religious differences. Certain cultures may see prolonging life at any cost as a moral or spiritual duty, whereas others prioritise quality of life and preventing suffering. These beliefs have an impact on such decisions as the suspension of life support measures or the onset of invasive treatments. Therefore, it is crucial for healthcare professionals to be familiar with the cultural characteristics of their patients and to maintain respectful communication based on their values.

- *Do-not-resuscitate (DNR) orders*: DNR orders establish the restriction of advanced life support measures, such as orotracheal intubation and mechanical ventilation. This limitation is considered in clinical circumstances in which there is little likelihood of satisfactory progression; in acute stroke, this question represents a considerable challenge due to the probable uncertainty about prognosis and the possible interference of cognitive biases (Table 2).^{30,31} The early use of DNR orders should be avoided, particularly in older patients in whom prognosis and care objectives are not well established, in order to minimise the so-called “self-fulfilling prophecy” effect, in which pessimism negatively affects patient management.^{30,31} This decision should be made within the shared healthcare planning process and in accordance with advance directives, if these exist, and should not involve limitations on other aspects of basic care.^{30,31}
- *Surgery or invasive treatments*: patients with stroke may be offered invasive treatment options that may improve prognosis and involve some risk. The potential indication of these interventions should be established in accordance with the objectives of the shared healthcare planning process, evaluating patient preferences, likelihood of survival, quality of life, and likely complications.^{6,7,32}
- *Artificial nutrition*: Dysphagia is frequent in acute stroke, affecting up to two-thirds of patients, and may contribute to the development of aspiration pneumonia, malnutrition, deficient rehabilitation, prolonged hospitalisation, and increased mortality.^{33,34} Early detection of dysphagia using screening tests, and appropriate selection of the feeding route and type of feeding, have been shown to reduce pneumonia rates.³⁵ Artificial nutrition is typically provided by nasogastric (NG) tube or percutaneous endoscopic gastrostomy (PEG). Given that half of patients recover within 2 weeks, nutrition is typically started with a time-limited trial of NG feeding, with an assessment of the possible recovery in the first weeks after stroke.^{34,35} If artificial nutrition is considered necessary in the long term, beyond 2–3 weeks, PEG has been shown to be more tolerable and to reduce the rate of complications.³⁶ This treatment may be started or suspended in accordance with clinical progression; it has a considerable emotional impact, and patients’ preferences must be taken into account.^{6,7} Patients and their families should be provided with adequate information on the benefits and risks of each treatment option.

Limitation of therapeutic effort: recommendations

1. The decision to receive such advanced life support measures as orotracheal intubation, mechanical ventilation, and other invasive procedures should be based on the care objectives established, with individual consideration of the benefits and risks of each treatment and the values and preferences of the patient (grade of recommendation 1; level of evidence B).
2. Patients with DNR orders in place should receive all other appropriate medical and surgical interventions, unless these are explicitly refused (grade of recommendation 1; level of evidence C).
3. In patients who are unable to ingest solid and liquid foods by mouth, a time-limited trial of NG feeding may be proposed to maintain hydration and nutrition while efforts are made to restore the ability to swallow (grade of recommendation 1; level of evidence B).
4. For long-term artificial nutrition (beyond 2–3 weeks after stroke onset), PEG is preferable to NG feeding (grade of recommendation 2a; level of evidence B).

Detection and management of disabling symptoms

Pain management

Nearly half of patients with stroke present pain, with central post-stroke pain (e.g., thalamic pain syndrome) being the most frequent.^{37,38} Antidepressants and antiseizure medications have been used to treat this pain, although only amitriptyline,³⁹ lamotrigine,⁴⁰ and duloxetine have shown benefits in small case series.^{41,42}

We must also be alert to the risk of painful hemiplegic shoulder, which is associated with stroke severity and local causes; treatment must therefore be considered on an individual basis.⁴³ The use of ice, heat, and soft tissue massage, as well as oral analgesics (non-steroidal anti-inflammatory drugs) may temporarily relieve pain.⁴⁴ If pain persists, injection with steroids or botulinum toxin A may be effective in selected patients.⁴⁵ Prognosis is generally good, with 80% of patients improving on standard treatment, including physiotherapy, simple analgesics, steroid injections, or amitriptyline.^{43,44}

Post-stroke spasticity is common, and is symptomatic in up to one-third of patients⁴⁶; oral antispastic medication and botulinum toxin may be useful.⁴⁷

Pain management: recommendations

1. Amitriptyline and lamotrigine are reasonable treatments for central post-stroke pain, although studies on these treatments are small (grade of recommendation 2a; level of evidence B).
2. Physiotherapy and non-steroidal anti-inflammatory drugs are recommended as the first-line treatment for painful hemiplegic shoulder, and intra-articular steroid injection may be reasonable in persistent cases (grade of recommendation 2b; level of evidence C).

Non-pain physical symptoms

- *Fatigability*: this frequent symptom is more common in thalamic and brainstem strokes and, in the absence of other disorders, has led to the concept of primary post-stroke fatigue.⁴⁸ Modafinil has shown benefits in small case series.⁴⁹ The evidence on amantadine and methylphenidate are limited.⁵⁰
- *Incontinence and sphincter disorders*: these disorders appear in 50% of patients in early stages, decreasing to 20% (urinary) or 10% (faecal) at 6 months.⁵¹ Preventive care includes early extraction of permanent catheters, bladder training programmes, and voiding programmes, although insufficient evidence is available on the benefit of these interventions. In patients with detrusor hyperreflexia, timed voiding, fluid restriction, and anticholinergics may be used, although no consensus has been established.⁵² Constipation is also common, and requires supervision of the frequency of bowel movements; stimulant laxatives (bisacodyl or sennosides) or osmotic agents (e.g., milk of magnesia, lactulose, or polyethylene glycol) may be used. Stool softeners, such as docusate, present limited efficacy.⁵³
- *Epilepsy*: onset of epileptic seizures is more frequent with cortical and more severe strokes, although anti-seizure medication is not recommended for primary prevention.^{54,55} Patients with late-onset seizures are at risk of developing epilepsy and may need these drugs. Drug selection depends on the type of seizure, comorbidities, and concomitant medications.^{54,55}
- *Sexual dysfunction*: sexual dysfunction may occur even in patients with mild or no deficits, and is associated with psychosocial factors, drug side effects, and comorbidities.⁵⁶ Phosphodiesterase inhibitors (e.g., sildenafil) are vasoactive and should be used with caution.⁵⁷
- *Respiratory sleep disorders*: these disorders are defined as the presence of 10 or more respiratory pauses (apnoeas) of >10 seconds' duration per hour (apnoea-hypopnoea index $\geq 10/h$), and occur in over half of stroke survivors.⁵⁸ The most common forms are obstructive sleep apnoea syndromes. A meta-analysis of patients with good adherence to the ventilatory support system observed a reduction in the risk of vascular events and benefits for functional status and cognition, which were reflected in greater patient quality of life.⁵⁹

Non-pain physical symptoms: recommendations

1. In patients with post-stroke fatigue, the utility of such pharmacological treatments as modafinil, amantadine, or methylphenidate is not well established (grade of recommendation 2b; level of evidence C).
2. Post-stroke sexual dysfunction should be consulted and evaluated, and the necessary resources for alleviating it should be provided (grade of recommendation 1; level of evidence C).
3. Patients with excessive daytime sleepiness after stroke should be evaluated at a specialist sleep disorders clinic (grade of recommendation 1; level of evidence B).

Cognitive, affective, and emotional symptoms:

- *Depression*: although at least one-third of patients present depression, it often goes undetected or untreated.⁶⁰ This issue may be addressed through informal questioning, evaluation of interference in everyday activities, or with structured questionnaires. It is recommended to educate patients and their families about how to treat chronic pain or other disabling symptoms, thus reducing their contribution to the development of depression.^{60,61} Trials with citalopram, fluoxetine, and sertraline, as well as psychosocial interventions, have shown benefits in depressive symptoms.^{62,63}
- *Anxiety*: anxiety is observed in up to 20% of stroke survivors, and negatively impacts their functional outcomes; assessment of anxiety is recommended. Up to two-thirds of these patients also present depression.⁶⁴ Antidepressants may be used in patients with associated depression, although short-term treatment with benzodiazepines may also be prescribed, particularly in patients receiving end-of-life care, or if symptoms are severe; however, insufficient evidence is available.^{65,66}
- *Delirium*: delirium is observed in 10%-48% of cases; secondary causes must be identified and excluded.⁶⁷ Preventive measures have been suggested, such as avoiding the use of sedatives, preventing dehydration, promoting regulation of the sleep cycle, maintaining a relaxing sensory environment, and facilitating orientation, stimulation, and mobilisation.⁶⁸ Antipsychotic drugs may be used, although there is a lack of specific studies in patients with stroke⁶⁹; furthermore, they are associated with increased risk of vascular events.⁷⁰ Benzodiazepines are not recommended, except in patients requiring sedation or presenting alcohol withdrawal syndrome.⁷¹ Dexmedetomidine may be beneficial, although no specific studies have been performed.⁷²
- *Emotional lability*: presence of pseudobulbar syndrome with exaggerated crying or laughing may be distressing, and has been described in up to one-fifth of stroke survivors. Antidepressants may reduce these symptoms, although it is difficult to recommend their use in patients without depression.⁷³ Open-label trials of dextromethorphan/quinidine have found benefits in patients with stroke.⁷⁴
- *Emotional suffering and burnout of the caregiver*: we must identify and manage emotional pain, addressing it empathetically, acknowledging the suffering both of the patient and of their caregivers, and providing the necessary resources to prevent burnout.^{75,76} In the event that the patient dies, proper communication with family members must be established, seeking to minimise suffering and helplessness, and helping to direct their grieving.⁷⁷
- *Burnout of healthcare professionals*: Professionals responsible for medical care must develop strategies to minimise emotional burnout, avoid potential emotion transfer, and remember the need for self-care.⁷⁵⁻⁷⁷

Cognitive, affective, and emotional symptoms: recommendations

1. The presence of depression should be evaluated in stroke survivors; if depression is observed, treatment should

be started, with selective serotonin reuptake inhibitors being particularly recommended (grade of recommendation 1; level of evidence B).

2. Antidepressants may be useful in patients with generalised anxiety (grade of recommendation 2a; level of evidence B). Benzodiazepines are recommended for the short-term treatment of patients receiving end-of-life care or those with severe symptoms (grade of recommendation 1; level of evidence C).
3. In patients with delirium, secondary causes must be identified and treated (grade of recommendation 1; level of evidence C). Antipsychotic drugs may be considered in the short term, after assessment of the associated risks (grade of recommendation 2b; level of evidence B).
4. Antidepressants may be considered in the event of emotional lability, particularly in patients with associated depression (grade of recommendation 2b; level of evidence B).
5. Caregiver education interventions are recommended to avoid burnout. Information should be provided about the nature of the process, including the potential outcomes, caregiver roles, and support resources (grade of recommendation 1; level of evidence C).
6. Healthcare professionals should develop self-care strategies to minimise potential emotion transfers (grade of recommendation 1; level of evidence C).

End-of-life care

Dying patients should receive structured care; to this end, we recommend the use of clinical pathways in which the whole care process is organised, and which are useful for implementing and monitoring best practices.⁷⁸

In the terminal phase, the majority of non-essential treatments may be withdrawn abruptly. However, such drugs as beta-blockers, clonidine, benzodiazepines, and antidepressants must be suspended gradually to avoid adverse effects. In the case of antianginal drugs, the decision must be made on an individual basis in accordance with the patient's needs.⁷⁹

Regarding the management of diabetes, it is important to adjust interventions according to the specific needs of the patient, avoiding unnecessary painful procedures, such as the use of needles for diagnostic or therapeutic procedures.⁸⁰

Antiseizure drugs may be maintained initially, and withdrawn if they were indicated for neuropathic pain, and an alternative administration route may be established to prevent seizures if the oral pathway is lost.⁷⁹

Counselling should be offered with regard to the early detection of such severe symptoms as pain, dyspnoea, or agitation, thus facilitating early management and discussion of the following scenarios⁸¹:

- *Decreased oral food intake and difficulty swallowing*: artificial feeding is not recommended in the terminal phase as it does not contribute to well-being or survival.^{82,83} Oral care is recommended and sips of water should be offered, as these may improve symptoms of thirst and mucosal irritation.^{82,83}

- *Dyspnoea*: supplementary oxygen therapy should be restricted to patients with hypoxaemia, although it may have a placebo effect and reduce suffering; in these cases, nasal goggles are preferable.⁸⁴ For patients with disabling dyspnoea, opiates are recommended, after assessing the risks.⁸⁵ Depending on clinical progression to terminal phases or palliative sedation, infusion systems may be used for continuous administration.⁸⁶
- *Accumulation of secretions in the respiratory tract*: accumulation of secretions may worsen dyspnoea, trigger coughing attacks, increase risk of infection, and cause distressing crackles and wheezing. Interruption of intravenous fluid administration or enteral feeding and positioning the patient on their side may be helpful, as well as aspiration of secretions.^{86,87} In Spain, hyoscine butylbromide is used; although insufficient evidence is available to recommend the drug, it is reasonable to consider a therapeutic trial with monitoring of the possible onset of secondary effects.⁸⁸
- *Infections and febrile processes*: prescription of antibiotics should be included in the care objectives established, and be aligned with advance directives, considering potential risks and benefits; however, high-quality results are not available.⁸⁹ Paracetamol and physical means may be useful for relieving fever and chills.
- *Withdrawal of advanced life support*: this decision must be reinforced by a commitment to the patient and their family that care provision will continue during the process. In palliative extubation, patients' families should be warned about the expected signs and symptoms (particularly the "death rattle"), advised about the treatments available, and prepared for the fact that death may or may not occur soon after extubation.¹⁰
- *Brain death and organ donation*: patients progressing to brain death after stroke are potential organ donors⁹⁰; therefore, it is necessary to optimise the identification of potential donors and to act in coordination with representatives of the Spanish National Transplant Organization.^{90,91}

End-of-life care: recommendations

1. In patients in the terminal phase after a severe brain lesion, withdrawal of life support treatments and onset of comfort care represents an appropriate treatment plan, which must be implemented in collaboration with the individuals responsible for decision-making identified in the shared care planning process (grade of recommendation 1; level of evidence C).
2. Patients undergoing palliative extubation should be closely monitored for signs of discomfort, such as dyspnoea, which must be appropriately treated with opioids or benzodiazepines (grade of recommendation 1; level of evidence C).
3. In the event of intractable physical symptoms (e.g., dyspnoea or pain) at the end of life, the minimum effective amount of sedation should be provided to relieve symptoms (grade of recommendation 1; level of evidence B).
4. Physicians must work in close collaboration with representatives of the Spanish National Transplant Organization to ensure that the option of organ donation is

presented to the families of all patients declared to have brain death (grade of recommendation 1; level of evidence C).

Euthanasia

Euthanasia is the act of deliberately ending a person's life through active, direct intervention, with a single, immediate relationship between cause and effect, according to that person's wishes, with the objective of preventing suffering. In Spain, a highly relevant legislative change took place with the entry into force on 5 June 2021 of Organic Law 3/2021, of 24 March, regulating euthanasia,⁹² which establishes the regulatory framework for respecting the autonomy and wish to die of a person in a situation of "serious, chronic and impossible suffering or serious and incurable disease, experiencing unbearable suffering that cannot be alleviated under conditions that he considers acceptable."

The procedure requires specific training, multidisciplinary collaboration, and scrupulous observance of legal obligations.^{1,92} In stroke care, it is very important to explain the differences between interventions in the acute stage, which may require limitation of therapeutic effort, and euthanasia, which is a response to a long-term situation of established sequelae.

Euthanasia: recommendations

1. Professionals must be aware of the legislation in force and the procedures for its implementation, resolve all related doubts, and avoid confusion with limitation of therapeutic effort during the acute stage of severe stroke (grade of recommendation 1; level of evidence C).

Training in palliative care

Training interventions for patients and their families are born out of recognition of their need for information; for professionals, they represent an opportunity to gain and improve their skills in communication, knowledge and management of symptoms, establishing functional and vital prognosis, and communicating and explaining the most appropriate tools for each situation.^{93,94} Healthcare professionals and patients' families should practise self-care techniques to relieve the emotional burden on all actors, and to help to accept bereavement.⁷⁵⁻⁷⁷

Training in palliative care: recommendations

1. Teaching about basic PC skills should be integrated into training programmes for all professionals, including interventions to prevent emotional burnout (grade of recommendation 1; level of evidence C).

Improving care quality and research

Patients receiving PC require safe, homogeneous treatment, regardless of where it takes place, in an efficiently organised setting that maximises care quality. At present, quality evaluation is limited due to the current lack of well-defined indicators and shortcomings in the planning of optimal PC.⁹⁵ Specific clinical pathways have shown benefits for PC quality, both at the end of life and for survivors.⁹⁶

New lines of research include communication techniques and assessment of the emotional status of patients and family members; predicting outcomes as accurately as possible; identifying medium- and long-term prognostic indicators to assess symptoms and likely outcomes; communicating prognosis; systems to assist in decision-making; establishing care objectives; optimal symptom management; stroke-specific quality indicators, and analysis of the role of time-limited therapeutic trials and suitability of care.^{95,96} Further research is needed to evaluate cognitive biases that may influence decision-making, particularly with reference to the so-called self-fulfilling prophecy and potential approaches to mitigate it. Furthermore, the role of social and cultural influences needs to be better understood.

Improving care quality and research: recommendations

1. Professionals involved in improving care quality must develop and implement active research into palliative care (grade of recommendation 1; level of evidence C).

Summary and conclusions

PC aims to prevent or alleviate all aspects of the suffering of patients with stroke and their families, with a patient-centred approach. Therefore, we must be prepared to provide the best possible care in each case, relieving symptoms and improving quality of life, both in the chronic stage and at the end of life.

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Conflicts of interest

The authors have no conflicts of interest to declare.

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