

AHA/ASA Scientific Statement Palliative and End-of-Life Care in Stroke

**A Statement for Healthcare Professionals from the American
Heart Association/American Stroke Association**



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On behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology

Stroke Council Professional Education Committee

This slide presentation was developed by a member of the Stroke Council Professional Education Committee.

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2010 Statistics

- 130,000 stroke-related deaths contributing to over 5% of all deaths in the US
 - 73% are due to ischemic stroke
 - 16% are due to intracerebral hemorrhage (ICH)
 - 13% are due to sequelae of stroke
 - 4% are due to subarachnoid hemorrhage (SAH)
- 50% of deaths occur in hospitals (including EDs and acute rehab facilities)
- 35% occur in nursing homes
- 15% occur in the home or other places

Palliative Care Definition

According to the National Consensus Project for Quality Palliative Care

- Palliative care means patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering.
- Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.
- The majority of palliative care provided to patients and families is not delivered by palliative care specialists but should be the responsibility of the stroke team.

Palliative Care Definition

According to the National Consensus Project for Quality Palliative Care

- Care is provided and services are coordinated by an interdisciplinary team;
- Patients, families, and palliative and non-palliative healthcare providers collaborate and communicate about care needs;
- Services are available concurrently with, or independent of, curative or life-prolonging care;
- Patient and family hopes for peace and dignity are supported through the course of illness, during the dying process, and until death.

Stroke System of Care Needs

- Palliative care is provided and services are coordinated by an interdisciplinary team.
- Patients, families, and palliative and non-palliative health care providers collaborate and communicate about care needs.
- Services are available concurrently with, or independent of, curative or life-prolonging care.
- Patient and family hopes for peace and dignity are supported throughout the course of illness, during the dying process, and until death.

Primary versus Specialty Palliative Care

- All stroke patients should have access to primary palliative care.
 - Primary palliative care should be provided by the primary stroke team members.
 - The Specialty palliative care should be consulted by the primary team for the complex care issues.

Primary Palliative Care

- Primary palliative care should begin at the diagnosis of an acute, serious, and life-threatening stroke.
- Palliative care needs of patient and family should be
 - Individualized during each phase of illness and
 - Determined by patients life stage and values, benefits and treatment burden, comorbidities, and cultural attitudes.

Successful Integration Recommendations

- Promote and practice patient- and family-centered care.
- Effectively estimate prognosis
- Develop appropriate goals of care.
- Be familiar with the evidence for common stroke decisions with end-of-life implications.
- Assess and effectively manage emerging stroke symptoms.
- Possess experience with care at the end of life.
- Assist with care coordination, including referral to a palliative care specialist or hospice if necessary.
- Provide the patient and family the opportunity for personal growth and make bereavement resources available if death is anticipated.
- Actively participate in continuous quality improvement and research.

Level of Evidence Treatment Recommendations:

Stroke Team (Primary Palliative) Care Decisions

Primary Palliative Care

1. All patients and families with a stroke that adversely affects daily functioning or will predictably reduce life expectancy or quality of life should have access to and be provided with primary palliative care services appropriate to their needs. **(Class I, Level of Evidence B)**
2. Stroke systems of care should support a well-coordinated and integrated health care environment that enables an informed and involved patient and family and is receptive and responsive to health professionals who can focus on both the disease process and getting to know the patient and family in making decisions that are in-line with their preferences. **(Class I, Level of Evidence C)**

Patient- and Family-Centered Care

1. The stroke community of providers, researchers, educators, payers, and policymakers should promote patient- and family-centered care as its own quality dimension requiring measurement and improvement. **(Class I, Level of Evidence C)**
2. It is reasonable that the stroke community support interventions, evaluation methods, and resources to encourage providers to focus on improving and refining patient-centered communication skills throughout their careers. **(Class IIa, Level of Evidence C)**

Estimating Prognosis of Stroke Patient

1. Before making a prognostic statement, to the extent possible, clinicians should obtain a thorough understanding of what aspects of recovery (e.g. ability to walk, communicate, tolerance for disability, are most important to the individual patient and family and then frame the subsequent discussion of prognosis in these terms. **(Class I, Level of Evidence C)**
2. Clinicians should be aware of the inherent uncertainty, limitations, and potential for bias surrounding prognostic estimates based on either clinician experience or a prognostic model (risk score). **(Class I, Level of Evidence C)**
3. In formulating a stroke prediction of survival and the spectrum of possible outcomes, it can be useful for clinicians to use the best available evidence from the literature, including relevant model-based outcome prediction, in conjunction with their clinical impression based on personal experience. **(Class IIa, Level of Evidence C)**

Estimating Prognosis of Stroke Patient

4. Rigorously developed and externally validated prognostic models may be useful to inform an estimate of outcome after stroke. Caution is advised because the value of model-based estimates has not been established for end-of-life treatment decisions after stroke. **(Class IIb, Level of Evidence B)**
5. Providers might consider asking for a second opinion about prognosis from an experienced colleague when the range of prognostic uncertainty will impact important treatment decisions. **(Class IIb, Level of Evidence B)**
6. Explicit disclosure of prognostic uncertainty to patients and family members may be reasonable. **(Class IIb, Level of Evidence C)**

Goal Setting Process

1. Knowledge and use of effective communication techniques is a critical to improve the quality of stroke decision-making, as well as patient/family satisfaction and outcomes. **(Class I, Level of Evidence B)**
2. Knowledge, skills, and competency in running an effective patient/family meeting are important in management of patients and families with stroke. **(Class I, Level of Evidence B)**
3. Providers should integrate the best available scientific evidence as well as patient values and preference when making a recommendation about continued care. **(Class I, Level of Evidence B)**
4. Because patient preferences change over time, it is important to periodically revisit discussions to re-affirm or revise goals and treatment preferences as needed. **(Class I, Level of Evidence B)**
5. A structured approach to setting patient goals in patients with stroke care may be reasonable to improve the quality of healthcare. **(Class IIb, Level of Evidence C)**

Approaches to Overcome Challenges with Decision-Making

1. Providers should recognize that surrogate decision-makers use many other sources of information in addition to the doctor's expertise in understanding their loved one's prognosis. **(Class I, Level of Evidence B)**
2. Providers should recognize that making surrogate decisions has a lasting negative emotional impact on a sizeable minority of surrogates who should be provided access to bereavement services. **(Class I, Level of Evidence B)**
3. Providers should be knowledgeable and respectful of diverse cultural and religious preferences when establishing goals of care and refer to social workers and chaplains when appropriate. **(Class I, Level of Evidence B)**
4. It might be useful for providers to practice self-awareness strategies (prognostic time out, self-reflection) of one's own biases and emotional state to minimize errors in prognostic estimates and goal setting recommendations. **(Class IIb, Level of Evidence B)**

Approaches to Overcome Challenges with Decision-Making

5. It might be reasonable for providers to recognize the existence of a possible self-fulfilling prophecy (ie, a prediction that might directly or indirectly cause itself to become true) when prognosticating and making end-of-life decisions in patients with stroke. **(Class IIb, Level of Evidence B)**
6. It might be reasonable for providers to be mindful of and to educate patients and surrogate decision-makers about possible cognitive biases (affective forecasting errors, focusing effects, and optimism bias) that might exist when discussing treatment options and establishing goals of care. **(Class IIb, Level of Evidence C)**
7. Providers might consider the use of time-limited treatment trials with a well-defined outcome to better understand the prognosis or to allow additional time to optimize additional aspects of decision-making. **(Class IIb, Level of Evidence C)**
8. If there are conflicts between the patient's goals and those of the family surrogate, providers may consider implementing strategies to help family members reconcile these differences. **(Class IIb, Level of Evidence C)**

Common Preference-Sensitive Decisions

1. The decision to pursue life-sustaining therapies or procedures, including CPR, intubation and mechanical ventilation, artificial nutrition, or other invasive procedures, should be based on the overall goals of care taking into account an individualized estimate of the overall benefit and risk of each treatment and the preferences and values of the patient. (**Class I, Level of Evidence B**)
2. DNR orders should be based on patient's pre-stroke quality of life and/or his/her view of the risks and benefits of CPR in hospitalized patients. In patients with acute ischemic stroke, ICH, or SAH (with no preexisting DNR orders), providers, patients, and families should be cautioned about making early DNR decisions or other limitations in treatment before fully understanding the prognosis, including the potential for recovery. (**Class I, Level of Evidence B**)
3. Patients with a DNR order in place should receive all other appropriate medical and surgical interventions unless otherwise explicitly indicated. (**Class I, Level of Evidence C**)

Common Preference-Sensitive Decisions

4. Patients with a Do Not Intubate (DNI) order in place should receive all other appropriate medical and surgical interventions unless a Do No Resuscitation is ordered. This should be explained to the patient or surrogate. **(Class IIa, Level of Evidence C)**
5. Patients who cannot take solid food and liquids orally should receive NG, nasoduodenal, or PEG tube feedings to maintain hydration and nutrition while undergoing efforts to restore swallowing. **(Class I, Level of Evidence B)**
6. In selecting between NG and PEG tube routes of feeding it is reasonable to prefer NG tube feeding until 2 to 3 weeks after stroke onset. **(Class IIa, Level of Evidence B)**
7. To maintain nutrition over the longer-term, PEG tube routes of feeding are probably recommended over NG routes of feeding. **(Class IIa, Level of Evidence B)**

Common Preference-Sensitive Decisions

8. Patients who elect not to have artificial nutrition and hydration should be provided with safest method of natural nutrition and educated about the potential risks and benefits of this approach. **(Class I, Level of Evidence B)**
9. Decompressive craniectomy for hemispheric infarctions with malignant edema can be effective by reducing mortality and increasing the chances of survival with moderate disability. **(Class IIa, Level of Evidence B)**
10. Patients with large cerebellar hematomas or massive cerebellar infarctions who develop neurological deterioration, brainstem compression, or obstructive hydrocephalus should undergo emergent decompressive surgery. **(Class I, Level of Evidence B)**
11. Initial aggressive treatment is recommended for most patients with poor grade aneurysmal SAH, including ventilatory assistance, vasopressors, ventriculostomy if hydrocephalus is present, and early occlusion of the aneurysm if the patient can be stabilized. **(Class I, Level of Evidence B)**

Symptom Detection and Management

1. For the treatment of central post-stroke pain, pharmacological treatment with amitriptyline or lamotrigine is reasonable although studies are few. In older adults, given the side effects associated with amitriptyline, nortriptyline may be a reasonable substitute. **(Class IIa, Level of Evidence B)** Venlafaxine and gabapentin may be considered based on their efficacy in other neuropathic pain syndromes. **(Class IIb, Level of Evidence C)** Treatment with pregabalin, carbamazepine, levetiracetam, or opioids is not effective. **(Class III, Level of Evidence B)**
2. For patients with post-stroke hemiplegic shoulder pain (HSP), ice, heat, soft tissue massage, and NSAIDs before or after exercise are reasonable for temporizing pain relief. **(Class IIa, Level of Evidence C)** For patients with persistent HSP, interventions that may be reasonable to perform include intraarticular steroid injections **(Class IIb, Level of Evidence C)**, intramuscular Botox injections in the case of local spasticity **(Class IIb, Level of Evidence A)**, intramuscular electric stimulation **(Class IIb, Level of Evidence B)**, aromatherapy and slow-stroke back massage. **(Class IIb, Level of Evidence B)**

Non-Pain Physical Symptom

1. In patients with primary post-stroke fatigue, the usefulness of pharmacological treatment such as modafinil, amantadine, or methylphenidate is not well established. **(Class IIb, Level of Evidence C)**
2. Post-stroke epilepsy should be treated similarly to epilepsy from any other etiologies. **(Class I, Level of Evidence B)** Prophylactic administration of anticonvulsants to patients with stroke but who have not had seizures is not recommended. **(Class III, Level of Evidence C)**
3. Post-stroke sexual dysfunction should be acknowledged and periodically screened for, and when present, a referral to necessary resources provided. **(Class I, Level of Evidence C)**
4. Patients with stroke who have excessive daytime somnolence should be referred to an accredited sleep center for an evaluation. **(Class I, Level of Evidence B)**

Psychological Symptoms

1. Stroke survivors should be periodically screened for and evaluated for the presence of depression and, if present, treated with antidepressant therapy, especially SSRIs. **(Class I, Level of Evidence B)**
2. In patients with stroke and generalized anxiety, antidepressant medications can be useful. **(Class IIa, Level of Evidence B)** Benzodiazepines are recommended only for short-term treatment, particularly in patients receiving end-of-life measures, or if symptoms are severe. **(Class I, Level of Evidence C)**
3. All stroke patients with delirium should be evaluated for reversible causes, such as toxic and metabolic derangements; specific treatment of the causes and behavioral approaches is recommended for management. **(Class I, Level of Evidence C)** Antipsychotic agents may be considered for short-term treatment **(Class IIb, Level of Evidence B)**, but benzodiazepines are not recommended. **(Class III, Level of Evidence B)**
4. In stroke patients with emotional lability, the use of antidepressants may be considered if symptoms are troubling or co-exist with depression. **(Class IIb, Level of Evidence B)**

Social Suffering

1. To prevent caregiver burnout, education about the nature of the stroke, stroke management, and outcome expectations, including their roles in those processes, is useful. Caregivers should be provided information on supportive resources **(Class I, Level of Evidence C)**. Caregiver training may be considered. **(Class IIb, Level of Evidence C)**
2. Providers should try to anticipate, recognize, and help manage grief in patients and families with stroke. **(Class I, Level of Evidence C)**
3. Providers should develop self-care strategies to monitor for symptoms and to manage burnout while providing care to patients with serious and life-threatening stroke. **(Class I, Level of Evidence C)**

Spiritual Needs

- It is reasonable for providers caring for stroke patients and their families to consider asking their patients about possible spiritual or religious beliefs and offering referral to a chaplain or spiritual care provider. (**Class IIa, Level of Evidence C**)

Addressing Requests for Hastened Death

1. Providers may consider developing a strategy for evaluating and responding to requests for hastened death in patients with stroke, including assessment of suicide and searching for remedies of the underlying problem. (**Class IIb, Level of Evidence C**)

Palliative Treatments and Options at the End of Life

1. In patients with severe brain injury, withdrawal of life-sustaining treatments and the institution of intensive comfort measures is an appropriate treatment plan that should be made in collaboration with identified surrogate decision makers. (**Class I, Level of Evidence C**)
2. Patients undergoing palliative extubation should be closely monitored for symptoms of discomfort and air hunger and treated appropriately with opioids or benzodiazepines. (**Class I, Level of Evidence C**)
3. Patients who have intractable physical symptoms (eg, dyspnea and pain) at the end of life should be provided with the minimally effective amount of sedation necessary to relieve refractory symptoms (proportionate palliative sedation). Only rarely will patients require progressive increases in sedation to the point of unconsciousness to achieve this goal. (**Class I, Level of Evidence B**)
4. Physicians should work closely with representatives from the local organ procurement agency to ensure that the option of organ donation is offered to the family of every patient declared brain dead. (**Class I, Level of Evidence C**)

Role of Palliative Care Specialists

(Class IIb, Level of Evidence B)

1. Management of refractory pain, dyspnea, agitation or other symptoms, particularly near the end of life.
2. Management of more complex depression, anxiety, grief, and existential distress.
3. Requests for hastened death.
4. Assistance with goals and methods of treatment, particularly pertaining to options for long-term feeding and methods of ventilation.
5. Assistance with managing the process of palliative extubation.
6. Assistance with addressing cases of near futility and in families who —want everything.
7. Assistance with conflict resolution whether it be within families, between staff and families, and among treatment teams introducing and transitioning to hospice care.

Hospice Criteria for Stroke and Coma

Patients will be considered to be in the terminal stages of stroke or coma (life expectancy of 6 months or less) if they meet the following criteria:

Acute Stage of Stroke:

- Comatose patients with any 3 of the following on day three of coma:
- abnormal brain-stem response;
- absent verbal response;
- absent withdrawal response to pain;
- serum creatinine > 1.5 mg/dL.

Chronic Stage of Stroke

- Karnofsky Performance Status (KPS) < 50% or Palliative Performance Scale (PPS) of < 40% .
- Inability to maintain hydration and caloric intake with one of the following:
- Weight loss >10% in the last 6 months or >7.5% in the last 3 months;
- Serum albumin < 2.5 gm/dL;
- Current history of pulmonary aspiration not responsive to speech language pathology intervention;
- Sequential calorie counts documenting inadequate caloric/fluid intake; and
- Dysphagia severe enough to prevent patient from continuing fluids/foods necessary to sustain life and patient does not receive artificial nutrition and hydration.

Hospice Criteria for Stroke and Coma

- Documentation of the following factors will support eligibility for hospice care
- Medical complications, in the context of progressive clinical decline, within the previous 12 months, which support a terminal prognosis:
 - Aspiration pneumonia;
 - Upper urinary tract infection (pyelonephritis);
 - Refractory stage 3-4 decubitus ulcers;
 - Fever recurrent after antibiotics.
- Documentation of diagnostic imaging factors which support poor prognosis after stroke include:
 - For non-traumatic hemorrhagic stroke:
 - Large-volume hemorrhage on CT:
 - Infratentorial: ≥ 20 mL.;
 - Supratentorial: ≥ 50 mL.
 - Ventricular extension of hemorrhage;
 - Surface area of involvement of hemorrhage $\geq 30\%$ of cerebrum;
 - Midline shift ≥ 1.5 cm.;
 - Obstructive hydrocephalus in patient who declines, or is not a candidate for, ventriculoperitoneal shunt.
 - For thrombotic/embolic stroke:
 - Large anterior infarcts with both cortical and subcortical involvement;
 - Large bihemispheric infarcts;
 - Basilar artery occlusion;
 - Bilateral vertebral artery occlusion.

Role of Hospice

- In patients with stroke, referral to hospice should be considered if survival is expected to be 6 months or less and when the patient's goals are primarily palliative. (**Class I, Level of Evidence B**)
- When introducing and discussing hospice with patients and families, providers may consider adopting strategies of communication used in other —” bad news” settings, and frame the discussions around setting benefits and burdens hospice in achieving the patients and families overall goals of care. (**Class IIb, Level of Evidence C**)

Education and Quality Improvement Research

- The teaching of critical core competencies in palliative and end-of-life care should be integrated within training programs and continuous educational offerings for all professionals who care for patients with stroke and their families. (**Class I, Level of Evidence C**)
- Stakeholders with an interest in improving the quality of care and quality of life for patients and families with stroke should develop and implement an aggressive palliative and end-of-life research and quality improvement agenda for this population. (**Class I, Level of Evidence C**)

Summary

1. Stroke care is dominated by clinically challenging, emotionally intense, and ethically complex medical choices.
2. Palliative should be integrated into all stroke systems of care and managed by the primary stroke team.
 - It should be viewed not as an alternative to offering life-sustaining therapies, but as an important supplement that can enhance care delivery for patients, families, and providers alike.