

Palliative and End-of-Life Care in Stroke

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AHA SCIENTIFIC STATEMENTS

Palliative and End-of-Life Care in Stroke: A Scientific Statement From the American Heart Association

Claire J. Creutzfeldt, MD, Chair, Julia Bu, MD, Amber Comer, PhD, Susan Enguidanos, PhD, Barbara Lutz, PhD, RN, FAHA, Maisha T. Robinson, MS, MD, Darin B. Zahuranec, MD, FAHA, and Robert G. Holloway, MD, MPH, Vice Chair on behalf of the American Heart Association Stroke Council; Council on Cardiovascular and Stroke Nursing; and Council on Clinical Cardiology

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Keywords: palliative care; stroke; terminal care

Stroke

March 27, 2014

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Check for updates

Palliative and End-of-Life Care in Stroke: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

Robert G. Holloway, MD, MPH, Robert M. Arnold, MD, Claire J. Creutzfeldt, MD, Eldrin F. Lewis, MD, MPH, Barbara J. Lutz, PhD, RN, CRRN, FAHA, FAAN, Robert M. McCann, MD, Alejandro A. Rabinstein, MD, FAHA, ... [SHOW ALL](#) ... on behalf of the American Heart Association Stroke Council, Council on Cardiovascular and Stroke Nursing, and Council on Clinical Cardiology | [AUTHOR INFO & AFFILIATIONS](#)

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Palliative and End of Life Care

Center to Advance PC: <https://www.capc.org/about/palliative-care/>)

- ▶ Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family.

Creutzfeldt et al., 2025, Palliative and End of Life Care in Stroke

- ▶ Palliative care focuses on improving communication about goals of care and quality of life for both patients and their families, emphasizing a holistic, all-person approach. **Palliative care also encompasses hospice and end-of-life care**, with aims to improve the quality of care for people who are dying and their families.

Advances in hyperacute & acute stroke care

Reduced morbidity & mortality

Increased number of stroke survivors

Long-term cognitive & physical disability

Psychosocial and existential distress for stroke survivors & their families

Statement Goals

To provide an update on PC needs and holistic assessment for stroke

To discuss HC disparities specific to stroke and PC

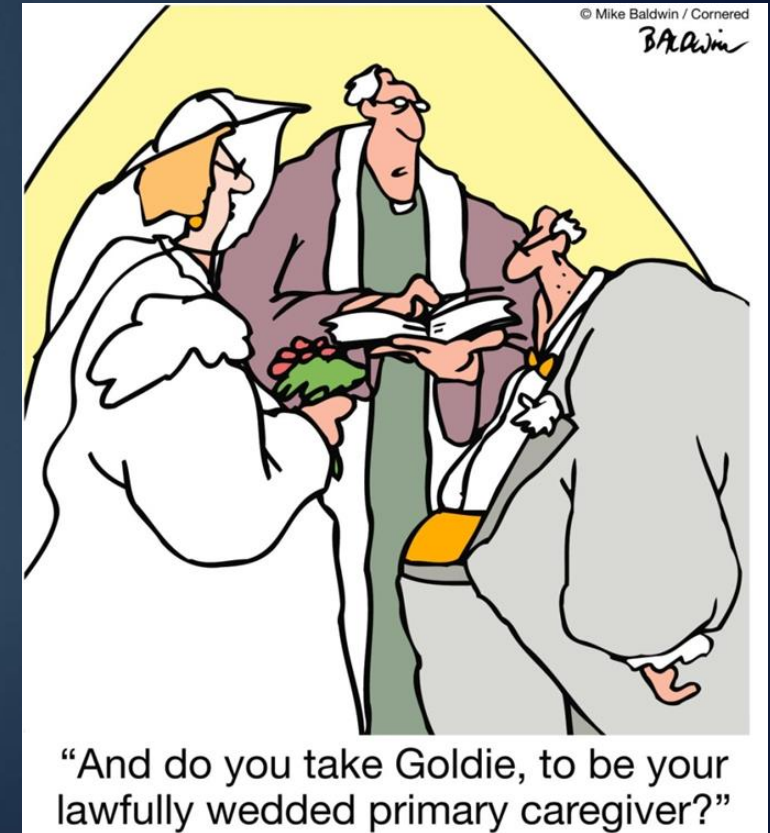
To provide key points for Clinicians and HC systems caring for patients w/ stroke and their families in the post-acute care period and at the EOL.

Racial and Ethnic Inequities in Stroke

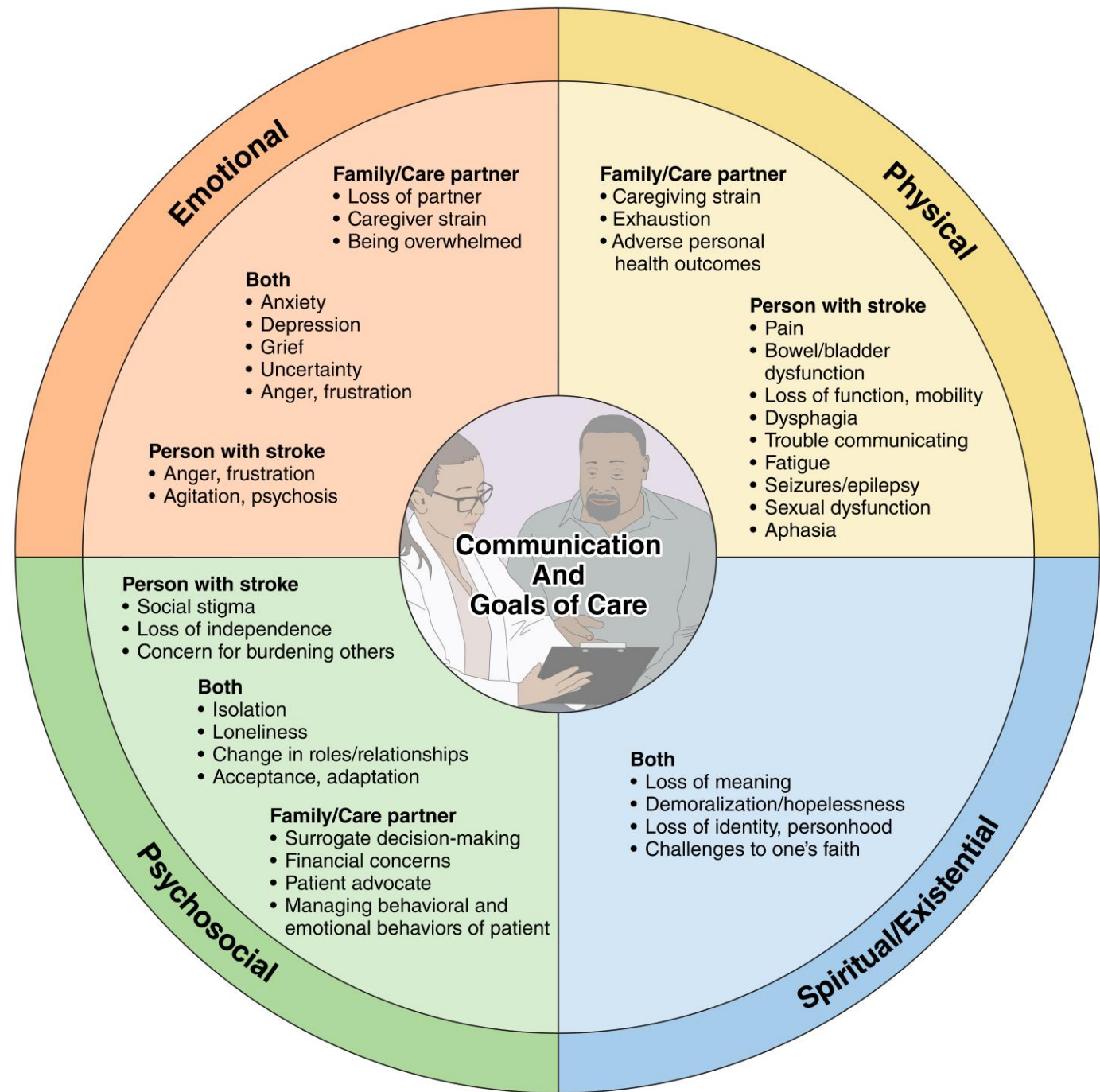
- ▶ Black and Hispanic populations
 - ▶ higher stroke incidence
 - ▶ worse functional outcomes
 - ▶ less frequent receipt of acute stroke treatments
- ▶ Similar patterns of disparities in ACP and patterns of serious illness treatment after stroke
- ▶ Systems-level factors likely contribute to these inequities
- ▶ Systemic tailored interventions may help mitigate these historical inequities

Need for Holistic Assessment at Regular Intervals

- ▶ Focusing on sources of distress
- ▶ Acknowledging the impact on patients and their families, esp. family caregivers
- ▶ Reassessment based on events, symptoms, changes in function, stage of illness

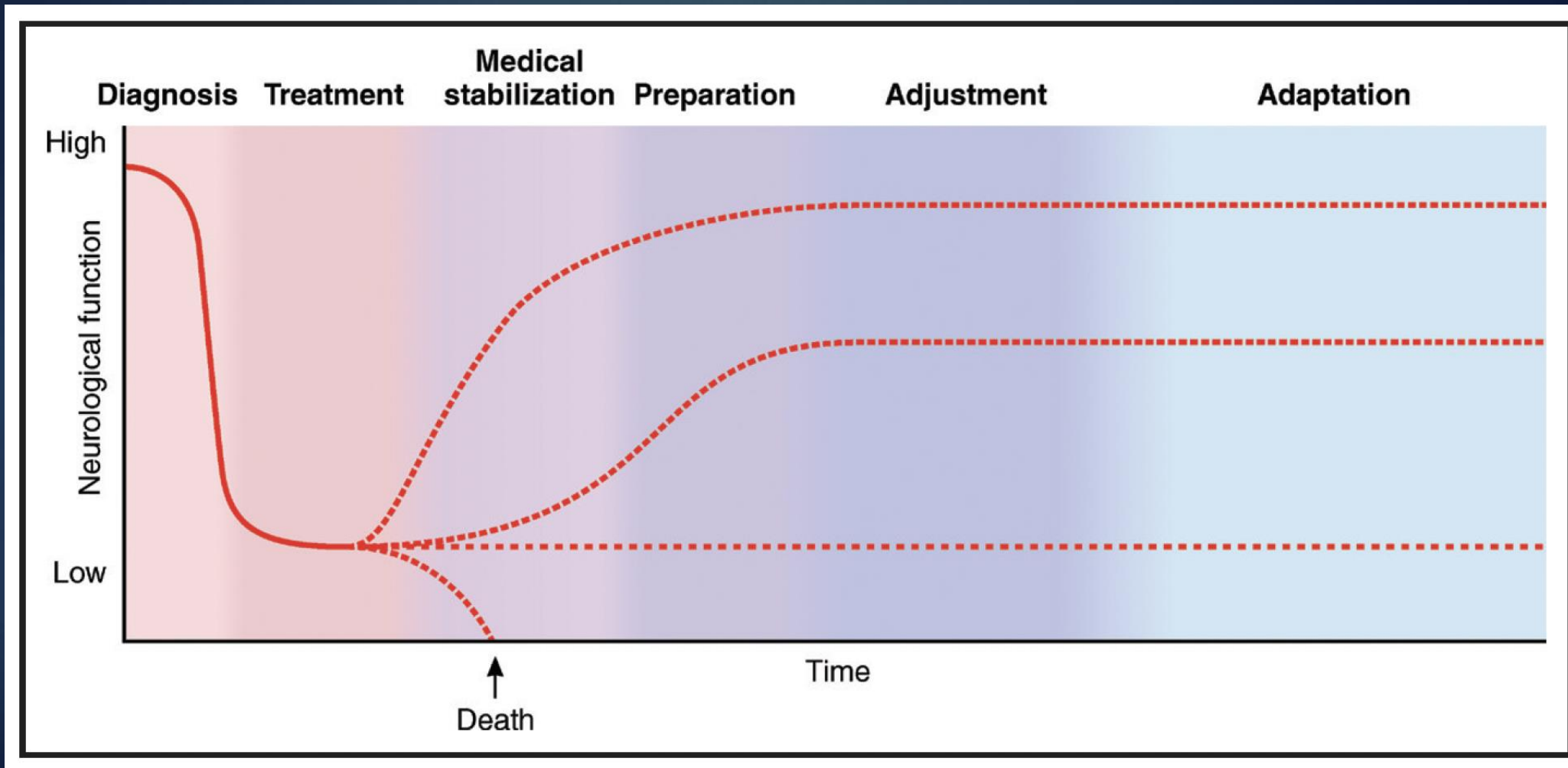


TOTAL PAIN of ILLNESS



Palliative Care Needs

Needs fluctuate over illness trajectory



Examples of PC Needs Assessment Tools

| Tool or trigger | Questions | Action suggestions |
|--|---|--|
| Surprise question ³² (adapted for stroke) | Would you be surprised if this patient: <p>Dies within the next year?</p> <p>Dies during this hospitalization?</p> <p>Does not recover to independence?</p> | If “no,” consider a serious illness conversation (eg, advance care planning, family meeting, referral to palliative care team). |
| SuPPORtT checklist ³³ | Su: Does the patient or family need psychosocial or spiritual support or help with coping? <p>P: Does the patient have pain or other distressing symptoms?</p> <p>PO: Does the patient or family have questions about prognosis or treatment options?</p> <p>rTT: Do we need to readdress goals of care or target treatment to patient-centered goals?</p> | If “yes,” consider a primary palliative care intervention (ie, a conversation with the patient and family focused on the identified needs), change in symptom management, or referral to the respective expert (eg, pain specialist, psychologist, chaplain, palliative care team) for specialist palliative care. |
| End of a time-limited trial ^{34,35} | A time-limited trial is a specified time frame in which to continue life-sustaining treatment to evaluate response and prognosis. | When this specified period has passed, another family meeting is key to assess symptoms and recovery, and to revisit goals of care. |
| Changes in living situation | Changes may include moving from a facility to home, increasing need for assistance with activities of daily living (eg, dressing, meals, toileting), and loss of ability to work or drive. | Any change can be stressful; a change in living situation may also signal a need for revisiting treatment options and goals of care. Referral to social work and support groups may be helpful. |
| Screening for caregiver distress or burnout | Ask care partners specifically about their role as a caregiver, their own wellbeing, and their ability to cope. | Acknowledge the care partner’s role and possible strain, normalize feelings of overwhelm, and recognize burnout. Consider involving social work and peer support groups, and encourage caregivers to engage with their clinicians to address their own health care needs. |
| Screening for spiritual care needs (HOPE instrument) ³⁶ | Explore sources of hope and inquire into organized religion, personal spiritual beliefs, and practices or restrictions that may affect medical care. | Consider referral to spiritual care or personal or community faith leader. |

These tools are meant to help identify needs in a timely and routine manner and trigger certain actions depending on the respective need. This is not a comprehensive list; research in this area is ongoing.

PC for Stroke in the Post-Acute Setting

- ▶ Limited evidence on how to integrate PC into routine stroke care
- ▶ Community-based palliative care models developed for other serious noncancer illnesses could be adapted for stroke
 - ▶ Several models in Heart Failure (Bakitas 2020; Graney et al., 2019; Rogers et al. 2017)
 - ▶ Nurse / Social worker teams with access to other disciplines / specialties (e.g. legal, spiritual, counseling, etc)
- ▶ Recent increase in stroke nurse navigators (Jun-O'Connell et al., 2023; Saragih et al., 2023)
 - ▶ PC assessment / services could be integrated into existing navigation services
- ▶ Preliminary results of current study of stroke caregiver interviews (Creutzfeldt & Zahurnec, PIs)
 - ▶ Single point of contact throughout illness trajectory
 - ▶ Guidance and support tailored to the needs of the patient AND the caregiver / family

AHA Resources for Post Stroke Care

<https://www.stroke.org/en/help-and-support>

Stroke Symptoms Volunteer ShopHeart DONATE

Home / Help and Support / Stroke Resource Library / **Caregiver Resources**

Resources for Caregivers, Family and Friends

Stroke recovery can be difficult and confusing for the survivor and the caregiver. These resources are gathered to help you navigate all aspects of how the stroke has impacted you and your survivor.

- Stroke Resource Library
- Let's Talk About Stroke Fact Sheets
- Lifestyle and Risk Reduction
- Treatment
- Next Steps in Recovery
- Rehabilitation Resources
- Caregiver Resources**
- Community Stroke Prevention Toolkit
- F.A.S.T. Materials
- Spanish Resources for Patients
- Pediatric Stroke Resources

Related Articles

Support Group Finder Stroke Family Warmline

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Home / Life After Stroke / Recovery After Stroke / Managing Your Stroke / **Palliative Care**

Palliative Care

Palliative care is both patient- and family-centered and can help improve quality of life by providing relief from symptoms, stress and suffering. Palliative care is appropriate for patients in any stage of serious illness and in any care setting. It considers the physical, emotional, intellectual, social and spiritual needs.

People recovering from a stroke should have a well-coordinated medical team to personalize their care, optimize their quality of life and focus on what is most important to the patient and family. For a stroke patient and their family, palliative care supports collaboration between patients, families, a stroke team and various other health care professionals, including neurologists, neurosurgeons, primary care providers, nurses and therapists.

As a stroke survivor or family member, you should expect your health care professional to:

- Life After Stroke
- Recovery After Stroke
- Managing Your Stroke
- Compliance and Solutions
- Finances, Insurance and Assistance
- Palliative Care**
- Managing Your Medications Post-Stroke

American Stroke Association
A division of the American Heart Association
Together to End Stroke®

Caregiver Guide to Stroke

Recipes / Food Ideas for
SS w/ dysphagia

Dealing w/
Financial Impact



End of Life Care after Stroke

Most patients die in the hospital or SNF, but proportion of those who die at home is increasing

Most Common S/S at EOL

Dyspnea

Pain

Pain assessment

(Look for verbal & nonverbal cues)

Anticipated Changes @ EOL

Reduced food / fluid intake

Decreased ability to cough

Noisy breathing / changes in breathing

Reduced consciousness / increased agitation

Reduced circulatory / renal function

Consider Hospice

Limited oral intake w/o artificial nutrition

Complications of stroke occur

Imaging indicates poor prognosis

Coma for more than 3 days w/o verbal response, brainstem reflexes, pain response

Other Resources

▶ Canadian Stroke Best Practices

- ▶ <https://www.strokebestpractices.ca/recommendations/acute-stroke-management/palliative-and-end-of-life-care#:~:text=Palliative%20care%20is%20a%20comprehensive,caregivers%2C%20and%20the%20healthcare%20team.>

▶ Stroke Foundation of Australia

- ▶ <https://strokefoundation.org.au/what-we-do/for-survivors-and-carers/after-stroke-factsheets/palliative-care-after-stroke-fact-sheet#:~:text=About%20palliative%20care,support%20from%20palliative%20care%20services.>

The screenshot shows the 'Canadian Stroke Best Practices' website. The navigation bar includes 'Recommendations', 'Quality', 'Resources', 'Events', and 'News'. The main content area is titled '11. Palliative and End of Life Care' with a '2022 update' indicator. It lists 11 items, with the 11th item being 'Palliative and End of Life Care'. The 'Definitions' section for item 11 states: 'Palliative care is an approach that aims to reduce suffering and improve the quality of life for people who are living with life-limiting illness through the provision of: pain and symptom management; psychological, social, emotional, spiritual, and practical support; and support for caregivers during the illness and after the death of the person they are caring for. Palliative care provides comprehensive care throughout a person's illness trajectory and is not solely limited to end of life care. (Adapted from: https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/palliative-care/framework-palliative-care-canada.html#p11)'. It also defines 'In a palliative approach to care' and 'End-of-life care'.

The screenshot shows the 'Stroke Foundation' website. The navigation bar includes 'Our websites', 'InfoMe', 'EradicMe', 'Stroke Foundation', 'StrokeLine', '1800 787 653', and 'Donor'. The main content area is titled 'Palliative care after stroke' and features a 'Download fact sheet' button and a 'Get help' button. Below this, there is a section titled 'What you need to know' with bullet points: 'Palliative care is for people who are nearing the end of their life.', 'It is a specialised treatment that looks at all aspects of care.', and 'It may be provided in the home, a hospital, a residential aged care facility or a hospice.'. There is also an 'About palliative care' section with a paragraph explaining the goal of palliative care.

Other Resources

- ▶ Palliative Care for Stroke Patients and Their Families: Barriers for Implementation.

- ▶ Steigleder T, Kollmar R, Ostgathe C. Front Neurol. 2019 Mar 6;10:164. doi: 10.3389/fneur.2019.00164. PMID: 30894836; PMCID: PMC6414790.

- <https://pmc.ncbi.nlm.nih.gov/articles/PMC6414790/>

Review Front Neurol. 2019 Mar 6;10:164. doi: 10.3389/fneur.2019.00164. eCollection 2019.

Palliative Care for Stroke Patients and Their Families: Barriers for Implementation

Tobias Steigleder¹, Rainer Kollmar², Christoph Ostgathe¹

Affiliations + expand
PMID: 30894836 PMCID: PMC6414790 DOI: 10.3389/fneur.2019.00164

Abstract

Stroke is a leading cause of death, disability and is a symptom burden worldwide. It impacts patients and their families in various ways, including physical, emotional, social, and spiritual aspects. As stroke is potentially lethal and causes severe symptom burden, a palliative care (PC) approach is indicated in accordance with the definition of PC published by the WHO in 2002. Stroke patients can benefit from a structured approach to palliative care needs (PCN) and the amelioration of symptom burden. Stroke outcome is uncertain and outlook may change rapidly. Regarding these challenges, core competencies of PC include the critical appraisal of various treatment options, and openly and respectfully discussing therapeutic goals with patients, families, and caregivers. Nevertheless, PC in stroke has to date mainly been restricted to short care periods for dying patients after life-limiting complications. There is currently no integrated concept for PC in stroke care addressing the appropriate moment to initiate PC for stroke patients, and the question of how to screen for symptoms remains unanswered. Therefore, PC for stroke patients is often perceived as a stopgap in cases of unfavorable prognosis and very short survival times. In contrast, PC can provide much more for stroke patients and support a holistic approach, improve quality of life and ensure treatment according to the patient's wishes and values. In this short review we identify key aspects of PC in stroke care and current barriers to implementation. Additionally, we provide insights into our approach to PC in stroke care.

- ▶ U.S. Department of Veterans Affairs (2024), Management of Stroke Rehabilitation

- <https://www.healthquality.va.gov/guidelines/rehab/stroke/>

U.S. Department of Veterans Affairs

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VA » Health Care » VA/DOD Clinical Practice Guidelines » Clinical Practice Guidelines » Rehabilitation Guidelines » Management of Stroke Rehabilitation (2024)

VA/DOD Clinical Practice Guidelines

Management of Stroke Rehabilitation (2024)

The guideline describes the critical decision points in the Management of Stroke Rehabilitation and provides clear and comprehensive evidence based recommendations incorporating current information and practices for practitioners throughout the DOD and VA Health Care systems. The guideline is intended to improve patient outcomes and local management of patients who have suffered a stroke.

Disclaimer: This Clinical Practice Guideline is intended for use only as a tool to assist a clinician/healthcare professional and should not be used to replace clinical judgment.

Future Directions

- ▶ Develop models to deliver high-quality goal-concordant care for culturally diverse patients with stroke and their families
- ▶ Explore palliative pharmacotherapy specific to stroke
- ▶ Identify appropriate outcome measures
 - ▶ What outcomes are important to patients and families?
- ▶ Consult palliative care teams when
 - ▶ Symptoms are refractory to first-line treatment
 - ▶ Care partners are experiencing distress or burnout
 - ▶ Stroke providers need more in-depth training in goals-of-care and/or prognosis conversations

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“And do you take Goldie, to be your lawfully wedded primary caregiver?”

THANK YOU!

QUESTIONS / DISCUSSION

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Selected References

- ▶ Bakitas, M. A., Dionne-Odom, J. N., Ejem, D. B., Wells, R., Azuero, A., Stockdill, M. L., Keebler, K., Sockwell, E., Tims, S., Engler, S., Steinhauser, K., Kvale, E., Durant, R. W., Tucker, R. O., Burgio, K. L., Tallaj, J., Swetz, K. M., & Pamboukian, S. V. (2020). Effect of an Early Palliative Care Telehealth Intervention vs Usual Care on Patients With Heart Failure: The ENABLE CHF-PC Randomized Clinical Trial. *JAMA Intern Med*, 180(9), 1203-1213. <https://doi.org/10.1001/jamainternmed.2020.2861>
- ▶ Center to Advance Palliative Care (2025). About Palliative Care. <https://www.capc.org/about/palliative-care/>
- ▶ Creutzfeldt, C. J., Bu, J., Comer, A., Enguidanos, S., Lutz, B., Robinson, M. T., Zahuranec, D. B., Holloway, R. G., American Heart Association Stroke, C., Council on, C., Stroke, N., & Council on Clinical, C. (2025). Palliative and End-of-Life Care in Stroke: A Scientific Statement From the American Heart Association. *Stroke*, 56(2), e75-e86. <https://doi.org/10.1161/STR.0000000000000479>
- ▶ Graney, B. A., Au, D. H., Baron, A. E., Cheng, A., Combs, S. A., Glorioso, T. J., Paden, G., Parsons, E. C., Rabin, B. A., Ritzwoller, D. P., Stonecipher, J. J., Turvey, C., Welsh, C. H., & Bekelman, D. B. (2019). Advancing Symptom Alleviation with Palliative Treatment (ADAPT) trial to improve quality of life: a study protocol for a randomized clinical trial. *Trials*, 20(1), 355. <https://doi.org/10.1186/s13063-019-3417-1>
- ▶ Heart & Stroke Foundation of Canada (2025). Candian Stroke Best Practices. <https://www.strokebestpractices.ca/>
- ▶ Holloway, R. G., Arnold, R. M., Creutzfeldt, C. J., Lewis, E. F., Lutz, B. J., McCann, R. M., Rabinstein, A. A., Saposnik, G., Sheth, K. N., Zahuranec, D. B., Zipfel, G. J., Zorowitz, R. D., American Heart Association Stroke Council, C. o. C., Stroke, N., & Council on Clinical, C. (2014). Palliative and end-of-life care in stroke: a statement for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke*, 45(6), 1887-1916. <https://doi.org/10.1161/STR.0000000000000015>

Selected References

- ▶ Jun-O'Connell, A. H., Grigoricic, E., Gulati, A., Silver, B., Kobayashi, K. J., Moonis, M., & Henninger, N. (2023). Stroke nurse navigator utilization reduces unplanned 30-day readmission in stroke patients treated with thrombolysis. *Front Neurol*, 14, 1205487. <https://doi.org/10.3389/fneur.2023.1205487>
- ▶ Rogers, J. G., Patel, C. B., Mentz, R. J., Granger, B. B., Steinhauser, K. E., Fiuzat, M., Adams, P. A., Speck, A., Johnson, K. S., Krishnamoorthy, A., Yang, H., Anstrom, K. J., Dodson, G. C., Taylor, D. H., Jr., Kirchner, J. L., Mark, D. B., O'Connor, C. M., & Tulsy, J. A. (2017). Palliative Care in Heart Failure: The PAL-HF Randomized, Controlled Clinical Trial. *Journal of the American College of Cardiology*, 70(3), 331-341. <https://doi.org/10.1016/j.jacc.2017.05.030>
- ▶ Saragih, I. D., Saragih, I. S., Tarihoran, D., Sharma, S., & Chou, F. H. (2023). A meta-analysis of studies of the effects of case management intervention for stroke survivors across three countries. *J Nurs Scholarsh*, 55(1), 345-355. <https://doi.org/10.1111/jnu.12822>
- ▶ Steigleder, T., Kollmar, R., & Ostgathe, C. (2019). Palliative Care for Stroke Patients and Their Families: Barriers for Implementation. *Front Neurol*, 10, 164. <https://doi.org/10.3389/fneur.2019.00164>
- ▶ Stroke Foundation of Australia (2025). Palliative care after stroke. <https://strokefoundation.org.au/what-we-do/for-survivors-and-carers/after-stroke-factsheets/palliative-care-after-stroke-fact-sheet#:~:text=About%20palliative%20care,support%20from%20palliative%20care%20services>
- ▶ U.S. Department of Veteran's Affairs (2024). Management of stroke rehabilitation. <https://www.healthquality.va.gov/guidelines/rehab/stroke/>