Canadian Stroke
Best Practices™

# CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

# Acute Stroke Management Evidence Tables

## *Palliative and End of Life Care*

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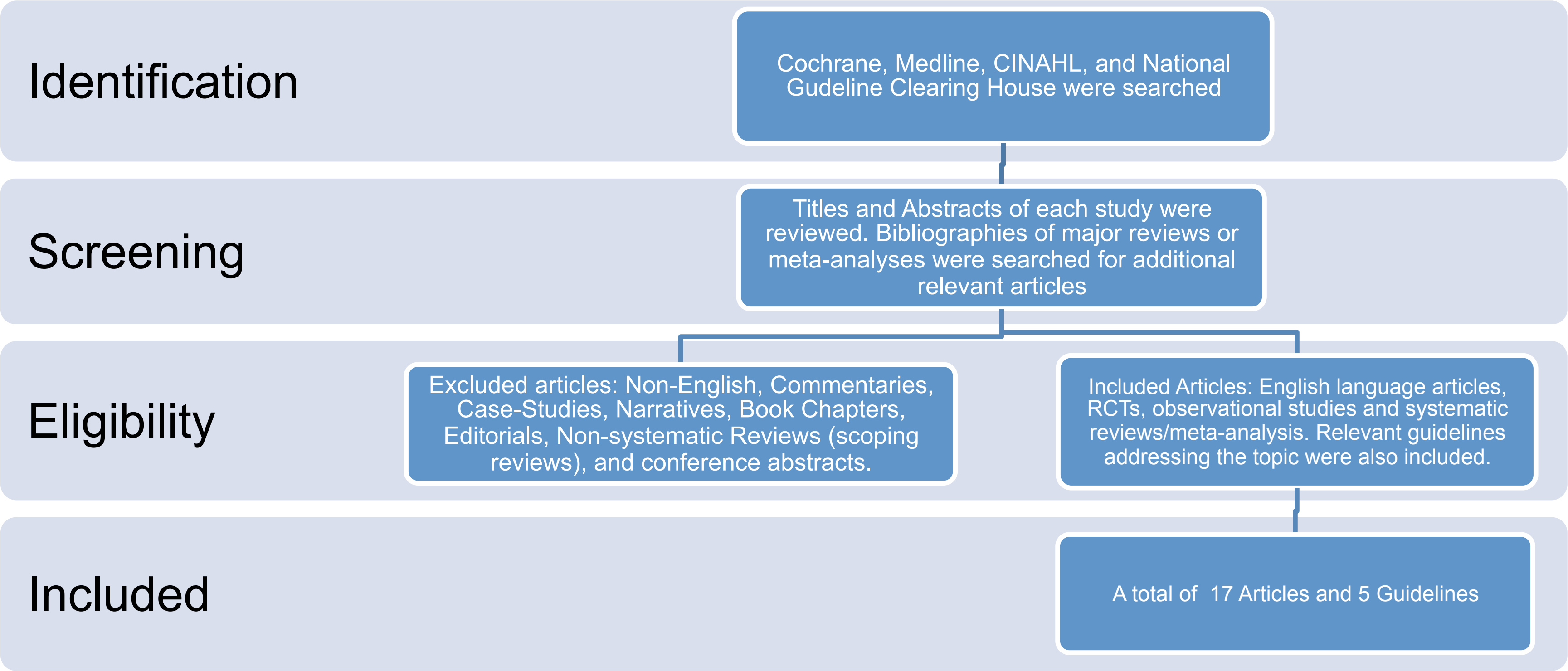
# Search Strategy



Cochrane, Medline, CINAHL, and National Guideline Clearing House were search using the terms (“Stroke” and “palliative” or “end-of-life”). Titles and abstract of each article were reviewed for relevance. Bibliographies were reviewed to find additional relevant articles. Articles were excluded if they were: non-English, commentaries, case-studies, narrative, book chapters, editorials, non-systematic review, or conference abstracts. Additional searches for relevant best practice guidelines were completed and included in a separate section of the review. A total of 17 articles and 5 guidelines were included and were separated into separate categories designed to answer specific question

# Published Guidelines

| Guideline | Recommendations |
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| **Clinical Guidelines for Stroke Management 2017. Melbourne (Australia): National Stroke Foundation.** | Strong Recommendation<br>• Stroke patients and their families/carers should have access to specialist palliative care teams as needed and receive care consistent with the principles and philosophies of palliative care.<br>Consensus-based recommendations<br>• For patients with severe stroke who are deteriorating, a considered assessment of prognosis or imminent death should be made.<br>• A pathway for stroke palliative care can be used to support stroke patients and their families/carers and improve care for people dying after stroke. |
| **Oliver DJ, Borasio GD, Caraceni A, et al. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease.**<br>***European journal of neurology.* 2016;23(1):30-38.** | • Palliative care should be considered early in the disease trajectory, depending on the underlying diagnosis (Level C).<br>• The assessment and care should be provided by a multidisciplinary team approach consisting of at least three different professions: physician, nurse, and social worker or psychologist/counsellor (Level C). Patients should have a multidisciplinary palliative care assessment and access to specialist palliative care for ongoing management (Level B).<br>• Communication with patients and families should be open, including the setting of goals and therapy options, and should be structured following validated models (Level C). Early advance care planning is strongly recommended, especially when impaired communication and cognitive deterioration are possible as part of disease progression (Level C).<br>• Physical symptoms require thorough differential diagnosis, pharmacological and non-pharmacological management and regular review (Good Practice Point). Proactive assessment of physical and psychosocial issues is recommended to reduce the intensity, frequency and need for crisis intervention (unplanned care) (Level B). The principles of symptom management, as part of the wider palliative care assessment, should be applied to neurological care (Level B).<br>• The needs of carers should be assessed on a regular basis (Level C). The support of carers – before and after death – is an indispensable part of palliative care as it may reduce complicated bereavement and improve patients' quality of life (Level C). Professionals involved in the care of progressive disease should receive education, support and supervision to reduce the risks of emotional exhaustion and burnout (Level C).<br>• Continued and repeated discussion with patients is essential due to changes in function – physical and cognitive – and preferences (Level C).<br>• Encourage open discussion about the dying process and explain that most patients will die peacefully with appropriate care (Level C). Encourage open discussion of wishes to restrict treatment and interventions and the wish for hastened death, and assess regularly (Level C). Recognition of deterioration over the last weeks and months is relevant for the appropriate management (Level C). The diagnosis of the start of the dying phase, although this may not always be possible, is relevant for the appropriate management, including the use of appropriate medication and intervention and care and support of families and carers (Level C). |
| **Intercollegiate Stroke Working Party. National clinical guideline for stroke, 5th edition. London: Royal College of Physicians, 2016.** | • Services providing acute and long-term care for people with stroke should provide high-quality end-of-life care for those who need it.<br>• Staff caring for people dying of stroke should be trained in the principles and practice of end-of-life care, including the recognition of people who are approaching the end of life.<br>• Decisions to withhold or withdraw life-prolonging treatments after stroke including artificial nutrition and hydration should be taken in the best interests of the person and whenever possible should take their prior expressed wishes into account.<br>• End-of-life (palliative) care for people with stroke should include an explicit decision not to impose burdensome restrictions that may exacerbate suffering. In particular, this may involve a decision, taken together with the person with stroke, those close to them and/or a palliative care specialist, to allow oral food and/or fluids despite a risk of aspiration.<br>• People with stroke with limited life expectancy, and their family where appropriate, should be offered advance care |

| Guideline | Recommendations |
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| | planning, with access to community palliative care services when needed.<br>- People dying of stroke should have access to specialist palliative care, including the timely transfer of care to their home or to a hospice or care home according to the wishes of the person and their family/carers. This should also include timely communication and involvement of the primary care team. |
| **Holloway RG, Arnold RM, Creutzfeldt CJ, Lewis EF, Lutz BJ, McCann RM, et al.**<br>**Palliative and end-of-life care in stroke: A statement for healthcare professionals from the American Heart Association/American stroke association.**<br>***Stroke 2014*; 45:1887-1916** | Primary Palliative Care: Recommendations<br>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)<br>2. Stroke systems of care should support a well-coordinated and integrated healthcare 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 proves and getting to know the patient and family in making decision that are in line with their preferences. (Class I; Level of Evidence C)<br>Patient and Family-Centered Care: Recommendations<br>1. The stroke community of providers, researchers, educators, payers and policymakers should promote patient- and family-centred care as its own quality dimension that requires measurement and improvement (class I; Level of Evidence C).<br>2. It is reasonable that the stroke community support interventions, evaluation methods, and resources to encourage providers to focus on improving and refining patient-centred communication skills through-out their careers (Class IIa; Level of Evidence C).<br>Estimating Prognosis: Recommendations<br>1. Before making a prognostic statement, to the extent possible, clinicians should obtain a thorough understanding of what aspects of recovery (eg, 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).<br>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)<br>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).<br>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).<br>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)<br>6. Explicit disclosure of prognostic uncertainty to patients and family members may be reasonable. (Class IIb, Level of Evidence C). |

| Guideline | Recommendations |
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| | **Goal Setting Process: Recommendations**<br>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)<br>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)<br>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)<br>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)<br>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)<br>**Approaches to Overcome Challenges with Decision Making in Stroke: Recommendations**<br>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)<br>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)<br>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)<br>4. It might be useful for providers to practice self-awareness strategies (prognostic time out, self-reflection) if one's own biases and emotional state to minimize errors in prognostic estimates and goal setting recommendations. (Class IIb, Level of Evidence B)<br>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)<br>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)<br>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).<br>**Common Preference-Sensitive Decisions in Stroke: Recommendations**<br>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) |

| Guideline | Recommendations |
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| | 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)<br>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)<br>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)<br>5. 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)<br>6. 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).<br>7. 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)<br>8. 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)<br>9. 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)<br>10. 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)<br>**Pain: Recommendations**<br>1. For the treatment of CPSP, pharmacological treatment with amitriptyline or lamotrigine is reasonable, although studies have been small. 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 on the basis of 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).<br>2. FO patients with poststroke 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 intra-articular steroid injections (Class IIb; Level of Evidence C), intramuscular Botox injections in the base of local spasticity (Class IIb; Level of Evidence A), intramuscular electrical stimulation (Class IIb; Level of Evidence B), and slow-stroke back massage (Class IIb; Level of Evidence B). |

| Guideline | Recommendations |
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| | **Non-pain Physical Symptoms: Recommendations**<br>1. In patients with primary poststroke fatigue, the usefulness of pharmacological treatment such as modafinil, amantadine, or methylphenidate is not well established (Class IIb; Level of Evidence C).<br>2. Poststroke epilepsy should be treated similarly to epilepsy from any other pathogenesis (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)<br>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)<br>4. Patients with stroke who have excessive daytime somnolence should be referred to an accredited sleep center or an evaluation. (Class I, Level of Evidence B)<br>**Psychological Symptoms: Recommendations**<br>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)<br>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)<br>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)<br>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)<br>**Social Suffering: Recommendations**<br>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)<br>2. Providers should try to anticipate, recognize, and help manage grief in patients and families with stroke. (Class I, Level of Evidence C)<br>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)<br>**Addressing Requests for Hastened Death: Recommendations**<br>1. Providers may consider developing a strategy for evaluating and responding to requests for hastened death in |

| Guideline | Recommendations |
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|  | patients with stroke, including assessment of suicide and searching for remedies for the underlying problem (Class IIb; Level of Evidence C).<br>**Palliative Treatments and Options at the End of Life: Recommendations**<br>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)<br>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)<br>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)<br>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).<br>**Role of Palliative Care Specialists: Recommendation**<br>1. Although not an exhaustive list, in patients with stroke, a formal palliative care consultation may be reasonable in the following situations: (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. (Class IIb; Level of Evidence B).<br>**Role of Hospice: Recommendation**<br>1. In patients with stroke, referral to hospice should be considered if survival is expected to be ≤6 months and when the patient's goals are primarily palliative (Class I; Level of Evidence B).<br>2. 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)<br>**Education: Recommendation**<br>1. 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)<br>**Quality Improvement and Research: Recommendation**<br>1. Stakeholders with an interest in improving the quality of care and quality of life for patients and families with stroke |

| Guideline | Recommendations |
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| | 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) |
| **McCusker M, Ceronsky L, Crone C, Epstein H, Greene B, Halvorson J, Kephart K, Mallen E, Nosan B, Rohr M, Rosenberg E, Ruff R, Schlecht K, Setterlund L. Institute for Clinical Systems Improvement. Palliative Care for Adults. Updated November 2013.** | Palliative care planning should begin early in the patient's journey of a progressive, debilitating illness. A key question for providers is "Would you be surprised if the patient died within two years?" Or for pediatric patients, "Would you be surprised if the patient didn't live into adulthood?" (Annotations #1, 3; Aim #1)<br>• Where palliative care consultation is available, referral to this service should be done early on in the patient's care.<br>• Where palliative care services are not available, primary care providers should begin palliative care planning early.<br>• Health care providers should initiate palliative care conversations with their patients. (Annotation #3; Aim #2)<br>• Health care providers should complete a systematic review and document patients' goals for care and advance directives. (Annotations #4, 10; Aim #6)<br>• Suffering is common in this patient population. It commonly presents itself in physical symptoms; thus, controlling symptoms to maximize patient comfort is a cornerstone function of palliative care. Also important are the recognition, assessment, and management of non-physical areas of suffering that are important to the patient. These include cultural, psychological, social, spiritual, religious, existential, financial, ethical and legal issues. (Annotations #5 to 11; Aim #3)<br>• The ability to address these issues depends on the quality of communication with patients and families. Communication difficulties among health care providers, patients, and families can hamper quality of care and patient well-being. Setting realistic goals of care and providing realistic hope are essential. (Annotation #3; Aim #2)<br>• In the delivery of palliative care, aggressive interventions may continue with an increased focus on symptom management. (See the Introduction section in the original guideline document.)<br>• Hospice is a form of palliative care. However, unlike hospice, palliative care is not limited by the clinical or reimbursement perspective. (See the Introduction section in the original guideline document, Annotation #13.)<br>• Health care providers play an important role in the grief and bereavement processes by supporting the patient and family throughout the course of illness and following the patient's death. (Annotation #22)<br>**Recommendations**<br>• Clinicians should discuss the likelihood of disease progression to death with patients and/or their families.<br>• Clinicians should initiate or facilitate advance care planning for all adult patients and their families with regular review as the patient's condition changes.<br>• Clinicians should use a validated assessment tool to assess palliative care needs.<br>• Care conferences with the patient, family and an interdisciplinary health care team are recommended on an ongoing basis to discuss patient's condition, course of illness, treatment options, goals and plan of care.<br>• Clinicians should engage in ongoing communication with the patient and/or family regarding the dying process and the treatment plan.<br>• A cultural assessment should be an integral component of the palliative care plan. |

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| | • Palliative care should begin at the time of diagnosis of a serious condition and continue through cure, or until death and then into the bereavement period.<br>• Clinicians should recognize those patients who are receiving non-beneficial, low-yield therapy.<br>• Informed consent should be obtained for any treatment or plan of care from either a patient with decision-making capacity or an appropriate surrogate decision-maker.<br>• The physical aspects of the patient’s serious illness should be an integral component of the palliative care plan.<br>• Clinicians should follow the established best practices of utilizing professional medical interpreters when English is not a patient's first language or when there are gaps in understanding English.<br>• A psychological assessment should be an integral component of the palliative care plan.<br>• Palliative care discussion or referral should be considered whenever the patient develops a serious illness.<br>• Palliative care discussions should be included whenever a patient with a life-limiting or life-threatening illness presents, including the hospital ICU or emergency department.<br>• A social assessment should be an integral component of the palliative care plan.<br>• A spiritual assessment should be an integral component of the palliative care plan.<br>• Clinicians should utilize clinically trained chaplains as members of the interdisciplinary health care team to provide patient-centered spiritual care and support. |

# Evidence Tables

## Transition to Palliative Care

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
|---|---|---|---|---|---|
| **San Luis et al. 2013**<br>**USA**<br>**Retrospective Study** | NA | 236 patients admitted to hospital with a confirmed diagnosis of stroke (middle cerebral artery, MCA) and dysphagia.<br>Exclusion criteria: pre-existing dysphagia, delayed admission to hospital or delayed dysphagia screen. | Patients were classified as either "not transitioned to palliative level of care" (n=157) or "early transition to palliative level of care" (n=79). | **Primary outcome:** Independent predictors of transition to palliative care. | Patients transitioned to palliative care were more likely to be older, have atrial fibrillation, have more severe dysphagia on the first swallowing evaluation, left MCA stroke, higher initial stroke severity, receive tPA, and admitted on a weekday.<br>All variables remained significant in multivariable analysis except for weekday admission to hospital.<br>Age: OR= 1.105, 95% CI 1.056-10155, p<0.001<br>Right vs. Left MCA Stroke: OR= 0.417, 95% CI 0.182-0.956, p=0.039<br>Admission NIHSS score: OR= 3.038, 95% CI 1.222-7.555, p=0.017<br>Received tPA: OR= 7.106, 95% CI 2.541-19.873, p<0.001<br>Assessed on first swallow: OR= 0.053, 95% CI 0.022-0.131, p<0.001 |
| **Gott et al. 2013**<br>**UK**<br>**Prospective Survey** | NA | 514 inpatients from two hospitals were included. 183 patients had palliative care needs and 61 had evidence for transfer to palliative care.<br>Median Age was 80 years (for those who made a transition to palliative care), 76 years (for those who had not made transition)<br>Presence of stroke: 19.7% of patients had stroke (for those who made a transition), 4.1% (for those who had not | Hospital case notes were reviewed for evidence of palliative care need, demographic information, medical history, and evidence for the adoption of palliative care.<br>Patients were classified as having palliative care need, and if so, they were then further classified as having evidence for the transition to palliative care or having no evidence for the transition to palliative care.<br>Logistic regression was | **Primary outcome:** Factors associated with transition to palliative care, defined as having in a patient's clinical notes at least one of the following: presence of a do-not-attempt resuscitation order, referral to specialist palliative care, placed on the Liverpool care pathway, long term prescription of opiates or a documented advanced care plan. | Patients with cancer, heart disease and stroke were more likely to be transferred to palliative care.<br>Those of higher age and living in a nursing home or residential care facility were also more likely to be transferred to palliative care.<br>Controlling for other factors, patients with a diagnosis of cancer (OR= 5.1, 95% CI 2.2-12.1, p<0.001), dementia (OR= 2.6, 95% CI 1.0-6.3, p=0.039) and stroke (OR= 8.0, 95% CI 2.5-25.9, p=0.001) were more likely to be transitioned to palliative care. Older patients were also more likely to receive a palliative care approach (OR= 1.03, 95% CI 1.00-1.06, p=0.038). |

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
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| | | made the transition) | used to assess the relationship between potential predictor variables and the transition to palliative care. | | |
| **Burton et al. 2010**<br>**UK**<br>**Retrospective study** | NA | 191 acute stroke patients admitted to an acute care hospital. 25.7% < 65 years, 23.6%> 85 years of age. The mean time since admission was 7.8 days. | Medical records were reviewed (demographic information, medical history, and stroke related information) to estimate the need for palliative care, using the Sheffield Profile for Assessment and Referral to care (SPARC).<br>SPARC domains include: physical, psychological, religious and spiritual, independence and activity family and social. Patients were also asked about mobility and fear of falling. | **Primary outcome:**<br>Prevalence of SPARC domains and predictors of the need for palliative care | **Prevalence of SPARC Domains:**<br>Communication problem – 80%<br>Fatigue-related problem – over 50%<br>Pain, Memory, Headache, Restlessness of Bladder problems – 50%<br>Fear of falling (moderate to severe) – 40%<br>Feeling that everything is an effort – 70%<br>Psychological distress – 50%<br>Religious and Spiritual concerns – Low<br>Concerns about death or dying – 25%<br>Worried about effects of stroke on others – 50%<br>Felt that help outside of family was needed – 25%<br>**Predictors of Palliative Care Need:**<br>Patient dependence, age, gender and number of comorbidities were significant predictors of the need for palliative care among the SPARC domains.<br>Age and dependency were independent predictors of palliative care need. The interaction between age, dependency and co-morbidities was significant (P=0.026). |
| **Holloway et al. 2010**<br>**US**<br>**Retrospective Study** | NA | 101 stroke patients who were admitted to acute care and received a palliative care consult. | Palliative consults for stroke patients were compared to those for patients with other conditions, including cancer, congestive heart failure, chronic obstructive pulmonary disease, and dementia. | Referral to palliative care | Only 6.5% of the 1551 stroke patients admitted to hospital during the study period were referred for a palliative care consult.<br>Compared to patients with other conditions, stroke patients who received a palliative care consult were more often referred for end-of-life issues and more likely to die in hospital (all at $p<0.05$, as compared to all 3 other conditions).<br>Approximately 50% of stroke patients who died in palliative care died following the withdrawal of a |

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| | | | | | life-sustaining intervention. |
| **Blacquiere et al. 2009**<br>**Canada**<br>**Retrospective Study** | NA | 104 acute stroke patients who died in an acute care unit. | Medical records were examined for all patients who died over a 2-year period, during which time a locally developed palliative care guideline was in place on the unit. | Information abstracted from medical records included the time interval and rationale for transfers to palliative care, the cessation of feeding/intravenous fluids, and any documented family conflicts. | Of the 16% of patients who died in the acute stroke unit, 90.4% had been transferred to palliative care.<br>Patients were palliated a median of 3.6 days and died a median of 8.5 days following admission. For the majority of patients, vital sign monitoring, non-palliative medication, investigations, nasogastric feeding, and intravenous fluids were discontinued or never begun (98.9%, 95.7%, 100%, 96.8%, 87.2%, respectively).<br>Family conflicts most commonly related to the transfer to palliative care (19.2%) and the cessation of feeding/fluids (20.2%). |

## Palliative Care Needs of Patients and Families

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
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| **Ntlholang et al. 2016**<br>**Ireland**<br>**Retrospective study** | NA | 54 consecutively-admitted patients who died following acute stroke, over a 2-year period at a single hospital. Mean age was 79.3 years, 61.1% were female | Charts were reviewed for references to symptomatology, interventions and Do Not Attempt Resuscitation (DNAR) orders | Palliative care needs | Death was attributed to the brain lesion in 24 (44.4%) patients and medical complications in 20 (37.0%). Death was unrelated to stroke in 10 cases (18.5%).<br>The median interval between stroke onset and death was 20 days.<br>Palliative care expertise was sought in 13 cases (24.1%).<br>Palliative care needs identified included pain 17 (31.5 %), respiratory secretions 17 (31.5 %), dyspnea 21 (38.9 %), agitation 14 (25.9 %), and psychological distress 1 (1.9 %).<br>Do Not Attempt Resuscitation (DNAR) orders were in place in 86.8 % of patients at time of death. |

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
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| **Blacquiere et al. 2013**<br>**Canada**<br>**Prospective Study** | NA | 15 patients and their families were recruited from a neurological service ward with a diagnosis of stroke or non-traumatic hemorrhage. | Patients' families were contacted 4 to 6 weeks after the patient's death. Service satisfaction surveys were administered over the phone. | **Primary outcome:**<br>Family satisfaction with individual symptoms and specific domains were assessed (feeding, hydration and communication, coordination of care, attention to family needs, focus on individual, advanced care planning etc.). The family's satisfaction with the overall palliative care approach was also assessed. | **Satisfaction with care received for individual symptoms and specific domains (0-1):**<br>Least satisfied with feeding, hydration, and communication, anxiety/depression treatment and information to family regarding analgesia. Most satisfied with the analgesia given.<br>**Overall satisfaction with the process of care (0-10):** Highest score achieved for being satisfied with the communication with the patient. Least satisfied with symptom control and emotional support for the families. |
| **Mazzocato et al. 2009**<br>**Switzerland**<br>**Retrospective study** | NA | 42 patients referred to a palliative care team (PCT) from 2000-2005, following admission to hospital for stroke. Mean age was 84 years, 40% were male | Charts were reviewed and information collected related to symptoms, use of medications, ability to communicated and primary cause of death. For patients unable to communicate, evidence of pain and dyspnea were based on behavioural symptoms | **Primary outcome:**<br>Symptoms, medications, immediate causes of death | Median time from admission to death was 12 days.<br>90% of referrals were from the stroke unit.<br>The median NIHSS score on admission was 21. At the time of admission, 5 (12%) of patients had a mild deficit (NIHSS < 10).<br>At the first visit by the PCT, 2 (5%) patients were able to communicate normally, 14 (33%) were aphasic or somnolent, and 26 (62%) were in stupor or coma.<br>The most common symptoms were dyspnea (34, 81%), pain (29, 69%) and mouth dryness (26, 62%).<br>The most commonly used drugs for management of dyspnea were anti-muscarinic agents and opioids. The most commonly used drugs for management of pain were opioids and acetaminophen.<br>The main immediate causes of death were neurological complications, pneumonia, acute heart failure and ischemic heart disease. |
| **Stevens et al. 2007** | NA | 7 studies that attempted to identify the palliative care needs of stroke | The palliative care needs of patients and caregivers were examined in studies | Not specified in advance | Findings:<br>Symptom and psychological management is insufficient for stroke patients who die in hospital. |

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
|---|---|---|---|---|---|
| **UK**<br>**Review** | | patients through surveys and interviews | that used case notes, n=1, observational studies n=1, prospective study using interviews & questionnaires, n=1, survey of symptoms n=1, postal survey, n=1 interview surveys based on proxy viewpoints, n=2. | | In one study, 43% of proxy respondents reported that patients required more assistance with personal care in their last year of life.<br>Only one intervention study (n=20) was identified that described the implementation of a palliative care pathway on an acute stroke unit. Following a before and after comparison, it was reported that Implementation lead to 'marked' improvement in the documentation of 6/7 areas of palliative care. |
| **Steinhauser et al. 2000**<br>**USA**<br>**Survey** | NA | 340 seriously ill patients, 332 recently bereaved family members, 361 physicians and 429 care providers (nurses, social workers, chaplains and volunteers) | A cross-sectional, randomly-selected, stratified, nationally representative survey was conducted by mail. Respondents were asked to rate the importance of 44 attributes of the experience of end-of-life care, using a 5-point scale. Responses were also compared among the 4 groups. Respondents were also asked to rate the importance of 9 preselected attributes. | **Primary outcome:** Importance of 44 attributes, ranking of 9 preselected attributes, | Response rates among the 4 groups varied from 71% to 96%.<br>Of the 44 attributes, 26 were rated as important by more than 70% of all respondents. Of these, the top 10 were: to be kept clean, name a decision maker, have a nurse with whom one feels comfortable, have someone who will listen, maintain one's dignity, trust one's physician, have financial affairs in order, to be free of pain and to maintain a sense of humour.<br>8 attributes were rated as important by patients, but not by physicians including being mentally aware, not being a burden on family and having funeral arrangements planned.<br>Among the preselected attributes, all groups ranked freedom from pain as #1. Patients and bereaved family members ranked being at peace with God as #2 (ranked #3 by physicians and other care providers). Physicians and other caregivers ranked presence of family as #2, while patients and bereaved family members ranked it as #3.<br>The least important of the 9 attributes, ranked by patients, bereaved family members and physicians was dying at home. |

## End of Life Care

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
|---|---|---|---|---|---|
| **Eriksson et al. 2016**<br>**Sweden**<br>**Retrospective study** | NA | 1,626 patients included in a national quality register for end-of-life care who had died of stroke in a hospital or nursing home, and in which death was the expected outcome and 1,626 patients in the same register who died of cancer, matched for place of death, age and sex. | End-of-life care during the last week of life were compared between stroke and cancer patients. The registry included 30 questions, 24 of which were analyzed. | Place of death, main cause of death, symptom management during last week of life | The odds of experiencing dyspnea, anxiety and severe pain were significantly lower for patients with stroke (OR=0.69, 95% CI 0.58-0.82 and 0.37, 95% CI 0.31-0.43 and OR=0.15, 95% CI 0.12-0.20, respectively).<br>Family members of stroke patients were less likely to be offered bereavement follow-up (OR=0.67, 95% CI 0.57-0.80). Patients were less likely to be informed about transition to end-of-life care (OR=0.09, 95% CI 0.08-0.11) |
| **Chan et al. 2016**<br>**Australia**<br>**Cochrane Review** | NA | Patients and families who had received care guided by an end-of-life care pathway. There were no restrictions on age of the patient, diagnosis or setting (hospital, home, nursing home). | RCTs, quasi randomized trials, or high quality controlled before and after studies that examined the use of an end-of-life care pathway vs. care as usual in the management of care for the dying were sought.<br>One cluster RCT was included (n=16 hospital wards), comparing an Italian version of the Liverpool Care Pathway (LCP-I), a continuous quality improvement programme of end-of-life care vs. usual care.<br>232 family members of 308 patients who died from cancer were interviewed. | **Primary Outcomes**: Physical symptom severity, psychological symptom severity, QoL, adverse events<br>**Secondary outcomes:** Advance care planning, communication between healthcare teams and families, carers' well-being, cost | Outcomes were assessed during face-to-face interviews of family members 2–4 months after the patient's death.<br>Only 34% of the participants were cared for in accordance with the care pathway as planned.<br>The odds of adequate pain control and control of nausea or vomiting were not significantly higher in the LCP-I group (OR= 1·3, 95% CI 0.7-2.6, p-0.46 and OR=1·5, 95% CI 0.7-3.2, p=0.25, respectively).<br>The odds of control of breathlessness were significantly higher in the LCP-I group (OR= 2·0, 95% CI 1.1-3.8, p=0.026).<br>No other outcomes of interest were assessed. |
| **Gardiner et al. 2013**<br>**UK** | NA | 66 health professionals (nurses, registrars, physiotherapists, occupational therapists etc.) from various | Focus groups and individual interviews each for 1 hour in length. | Core themes | Three themes were identified:<br>1. **Palliative care as a recognized component of stroke care**: all professionals cited it as an important component. Designated palliative care beds existed in some cases. A marker for |

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
|---|---|---|---|---|---|
| **Qualitative Study** | | hospital-based settings (hyper-acute, acute, rehabilitation and combined acute/rehabilitation stroke units). | | | successful palliative care was the ability of a patient to die at home.<br>2. **Uncertainty in making transitions to palliative care**: Recognition that some patients could be identified earlier in their disease pathway as benefiting from palliative care services.<br>3. **Issues integrating acute stroke care and palliative care:** Unsure if palliative and acute care can exist simultaneously. |
| **Hall et al. 2011**<br>**UK**<br>**Cochrane Review** | NA | 2 RCTs and 1 controlled before and after study, presenting data for 735 nursing care home residents. | The effectiveness of palliative care interventions in care homes were evaluated. | No primary or secondary outcomes were specified. All measures reported as outcomes were abstracted.<br>The number needed to treat was calculated for dichotomous outcomes whereas Cohen's *d* was calculated for differences in means. | Of the 2 studies that reported outcomes for residents, palliative care interventions were associated with improved quality of care (as assessed by proxy; $\chi^2$=2.1, 95% CI 0.69 to 5.97) and reduced discomfort (*d*=0.01). No differences were observed with respect to physical complications (*d*=0.01), dementia-related behaviours (*d*=0.37), or 6-month mortality ($\chi^2$=1.22, 95% CI -2.67 to 14.38).<br>In terms of processes of care, palliative care interventions were found to be associated with increased referral to hospice (NNT=6, 95% CI 3.8-9.2), fewer hospital admissions/ hospital length of stay (both at *p*<0.05), and the proportion of patients with do-not-resuscitate orders (NNT=5, 95% CI 3.2 to 9.7) and documented advance care plans (NNT=8, 95% CI 5.5 to 14.0).<br>Given the small number and methodological limitations of identified trials, the authors concluded that there is little evidence that palliative care interventions are associated with improved resident outcomes. |
| **Jack et al. 2004**<br>**UK**<br>**Retrospective Study** | NA | 40 patients admitted to an acute stroke unit. | A chart review was conducted before (n=20) and after (n=20) the implementation of the Liverpool Care Pathway (LCP). The LCP provides | Proportion of patients for whom documentation indicated that the "standard" of care was achieved. | Following implementation of the LCP, the authors reported improved documentation for the appropriate use of comfort measures (75%-100% vs. 5%-40%), assessment of religious/spiritual needs (80% vs. 8%), and communication with family (90%-100% vs. 1%-80%) of each of the |

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
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| | | | guidance in seven areas of end-of-life care. | | seven areas assessed. |

## Withdrawal of Care

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
|---|---|---|---|---|---|
| **Alonso et al. 2016**<br>**Germany**<br>**Retrospective study** | NA | 117 patients admitted to a 29 bed Stroke Unit with ischemic or hemorrhagic stroke between January 2011 and December 2014, who died during the course of hospital treatment. Mean age 81.1 years, 41.8% male. The mean NIHSS score on admission was 19. | Charts were reviewed for do-not-resuscitate-orders (DNRO), and therapy goal modifications with transition to symptom control. | **Primary outcome:** Factors that contributed to the decision to limit life-sustaining therapies | A DNRO was made in 101 (86.3%) patients, usually within 48 hours of admission.<br>40 patients were transferred to palliative care after a mean of 5 days. 38 patients were not able to communicate at the time of decision making.<br>Following transfer, monitoring of vital parameters (95%) and diagnostic procedures (90%) were discontinued. Antibiotic therapy (86%), nutrition (98%) and oral medication (88%) were never ordered or withdrawn. Low-dose heparin was withdrawn in 23% cases. All patients were maintained on IV fluids until death.<br>Disturbance of consciousness at presentation, dysphagia on day 1 and large supratentorial strokes were independent predictors of decisions to withdrawing/ withholding further treatment. Patient died an average of 2.6 days following therapy restrictions. |
| **Helvig et al. 2015**<br>**Norway**<br>**Retrospective study** | NA | 2,506 patients consecutively admitted to a stroke unit from 2006-2011 with ischemic or hemorrhagic stroke. | Chart review was conducted to determine the timing of death following stroke. Comparisons were performed between patients who died with (n=50) or without withdrawal (n=134) of life-sustaining treatment. | **Primary outcome:** Number of days from withdrawing all life-sustaining treatment to death because of poor prognosis after a written joint decision with the family. | Among patients who died after withdrawal of life-sustaining treatments, the mean number of days from stroke onset to death was 9.8 days. The mean number of days to death after withdrawal of treatment was 4.7 days (range 1-11). Independent predictors of a shorter time to death were older age, male sex and high serum CRP.<br>Among patients who died and where treatments wee continued, the mean number of days from |

| Study/Type | Quality Rating | Sample Description | Method | Outcomes | Key Findings and Recommendations |
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| | | | | | stroke onset to death was 6 days, which was significantly shorter compared with patients whose treatments were stopped (p<0.01). |

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