



CANADIAN STROKE BEST PRACTICE RECOMMENDATIONS

Vascular Cognitive Impairment Evidence Tables

7th Edition, Update 2024

Palliative and End-of-Life Care

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on Behalf of the Canadian Stroke Best Practice Recommendations

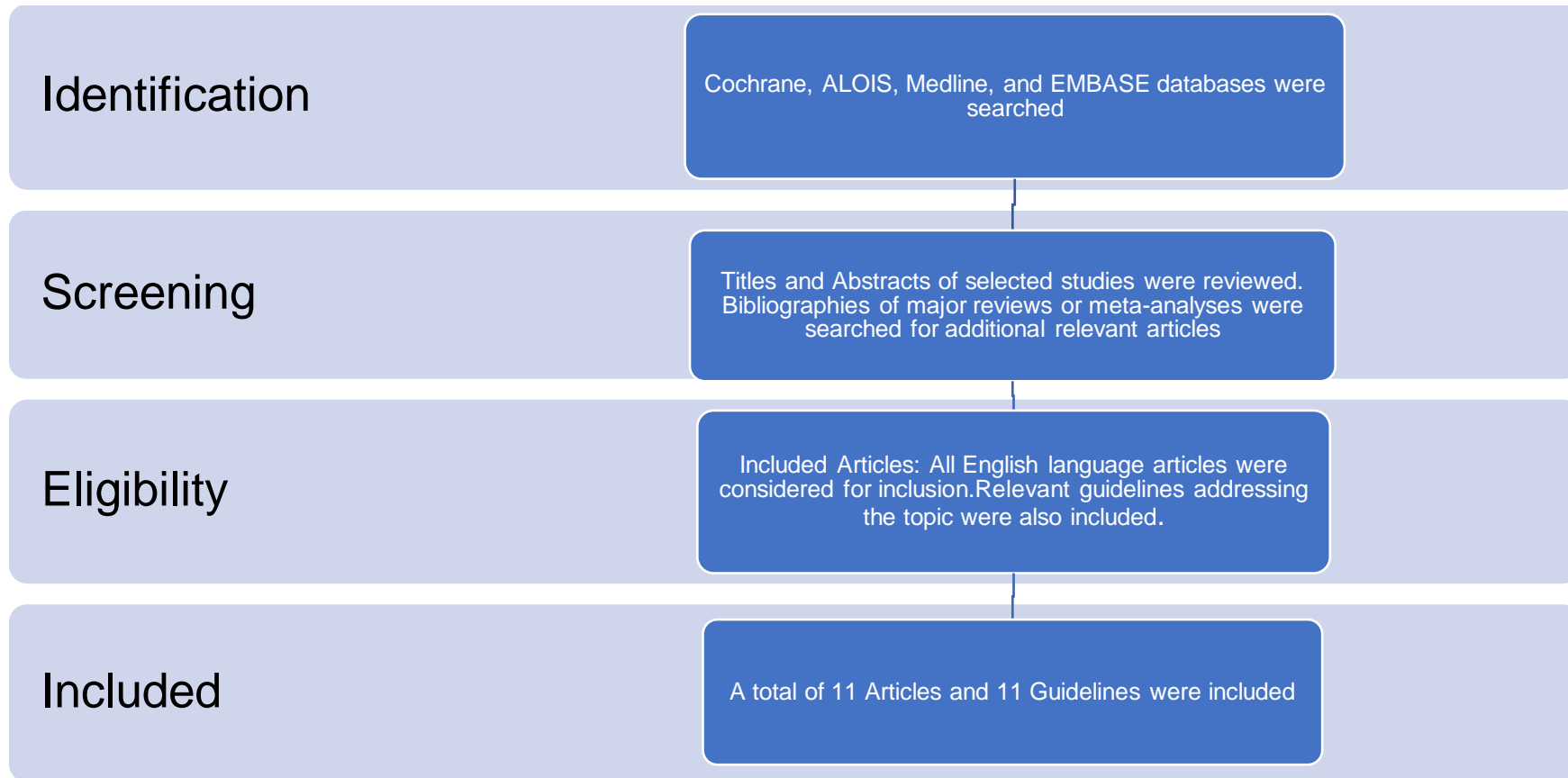
*Vascular Cognitive Impairment Writing Group and in collaboration with the
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Search Strategy



Pubmed, EMBASE and the Cochrane Central Register of Controlled Trials databases were search using the terms vascular dementia OR dementia OR cognitive impairment OR small vessel disease AND advance care planning OR palliative care. Titles and abstract of each article were reviewed for relevance. Bibliographies were reviewed to find additional relevant articles. A total of 12 guidelines and 11 articles were included and were separated into separate categories designed to answer specific questions.

Published Guidelines-Advance Care Planning

Guideline	Recommendations
<p>Scottish Intercollegiate Guidelines Network (SIGN). Assessment, diagnosis, care and support for people with dementia and their carers 2023. (SIGN publication no. 168). [November 2023].</p> <p>Available from URL: http://www.sign.ac.uk</p> <p>(selected)</p>	<p><i>Advance and anticipatory, or future, care planning</i> Offer early and ongoing opportunities for people living with dementia and people involved in their care to discuss: the benefits of planning ahead, lasting power of attorney (for health and welfare decisions and property and financial affairs decisions), an advance statement about their wishes, preferences, beliefs and values regarding their future care, advance decisions to refuse treatment, their preferences for place of care and place of death. Explain that they will be given chances to review and change any advance statements and decisions they have made.</p> <p>At each care review, offer people the chance to review and change any advance statements and decisions they have made.</p> <p>Anticipatory care planning discussions should: • be tailored to the needs, readiness to engage and capacity of the person with dementia • consider the needs of family and carers • consider triggers for discussions, such as diagnosis, change or decline in health status or change in place of residence.</p> <p>Healthcare professionals should ensure that the person with dementia, and their family or carer(s), are aware of the progressive nature of dementia and what to expect at different stages of the illness.</p> <p>Healthcare professionals should be aware that receptivity to anticipatory care planning discussions are increased when the person with dementia and their family have insight into the progressive and terminal nature of dementia.</p> <p>The person with dementia, their family and carers and healthcare professionals should all have the opportunity to initiate, and be involved in, anticipatory care planning discussions.</p> <p>If the person with dementia does not initiate anticipatory planning discussions, healthcare professionals should proactively initiate or enable person-centred anticipatory care planning conversations as soon as possible.</p> <p>The person with dementia, their family and carers and healthcare professionals who are involved in anticipatory care planning discussions should all seek to build trusting relationships.</p> <p>Anticipatory care planning may involve a series of conversations over time to allow clarification, reflection and updates to the plan to reflect any changing needs. Early discussions are beneficial, as the capacity of the person with dementia diminishes as the disease progresses.</p>
<p>McKenzie ED, Couillard P; Canadian Neurological Society.</p> <p>Choosing Wisely: Canadian Neurological Society Recommendations for Advance Care Planning.</p> <p>Can J Neurol Sci. 2023; 50: 351–354.</p>	<ol style="list-style-type: none"> 1. Don't wait for your patient to bring up ACP, initiate the conversation 2. For patients with progressive illness that could impact cognition, initiate ACP conversations as early in the disease course as possible. 3. Encourage family and care partner involvement in ACP. 4. Use clear, direct language when discussing prognosis. 5. Use standardized, specific language to document ACP conversations.

Guideline	Recommendations
	<p>6. Don't recommend or initiate aggressive care without establishing prognosis, preferences, and goals of care.</p> <p>7. Revisit advance care plans regularly and whenever there is significant change in a patient's status.</p> <p>8. Patients who enquire about Medical Assistance in Dying should receive comprehensive information about care options.</p>
<p>Piers R, Albers G, Gilissen J, et al.</p> <p>Advance care planning in dementia: recommendations for healthcare professionals.</p> <p><i>BMC Palliat Care</i> 2018; 17: 88.</p>	<p>Recommendations were based on 67 publications and validation from ten experts, 51 end users and two peer-review groups (24 participants).</p> <p>32 recommendations were developed, covering 8 domains: initiation of ACP, evaluation of mental capacity, holding ACP conversations, the role and importance of those close to the person with dementia, ACP with people who find it difficult or impossible to communicate verbally, documentation of wishes and preferences, including information transfer, end-of-life decision-making, and preconditions for optimal implementation of ACP.</p> <p>Quality of the Recommendations using GRADE were 1C (n=28 studies) or 1B (n=2 studies). 2 recommendations were not assessed.</p>
<p>Holloway RG, Arnold RM, Creutzfeldt CJ, Lewis EF, Lutz BJ, McCann RM, et al.</p> <p>Palliative and end-of-life care in stroke: A statement for healthcare professionals from the American Heart Association/American stroke association.</p> <p><i>Stroke</i> 2014; 45:1887-1916</p> <p>(selected)</p>	<p>Common Preference-Sensitive Decisions in Stroke: Recommendations</p> <ol style="list-style-type: none"> 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) 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) 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) 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). 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) 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)

Guideline	Recommendations
	<p>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)</p> <p>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)</p>
<p>Registered Nurses' Association of Ontario (RNAO). Stroke assessment across the continuum of care 2011 supplement. Toronto (ON): Registered Nurses' Association of Ontario (RNAO); 2011 Aug. 42 p.</p>	<p>Advanced Care Planning</p> <p>Recommendation 4.1</p> <p>Nurses in collaboration with the interprofessional team will assess and support clients (family/substitute decision maker [SDM]) to make informed decisions that are consistent with their beliefs, values and preferences to ensure client wishes are known and incorporated into the plan of care (includes advanced, palliative and end of life care planning).</p> <p>(Level of Evidence = IV)</p>
<p>Royal College of Physicians, British Geriatrics Society, Royal College of Nursing, Royal College of Psychiatrists, Royal College of General Practitioners, British Society of Rehabilitation Medicine, Alzheimer's Society, Help the Aged and the National Council for Palliative Care. Advance care planning. RCP Concise Guidance for Good Practice No. 12. February 2009.</p>	<p>Detailed recommendations were made within the following categories:</p> <p>When and with whom should I be considering ACP discussions?</p> <p>The discussion</p> <p>Will ACP work?</p> <p>Individuals with progressive cognitive impairment</p> <p>Recommendations for training and implementation of ACP</p>
<p>National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 2nd ed. Pittsburgh (PA): National Consensus Project for Quality Palliative Care; 2009. 80 p.</p>	<p>Domain 1: Structure and Processes of Care</p> <p>Guideline 1.1 The timely plan of care is based on a comprehensive interdisciplinary assessment of the patient and family.</p> <p>Guideline 1.2 The care plan is based on the identified and expressed preferences, values, goals, and needs of patient and family and is developed with professional guidance and support for decision making.</p> <p>Guideline 1.3 An interdisciplinary team provides services to the patient and family consistent with the care plan. In addition to nursing, medicine, and social work, other therapeutic disciplines with important assessment of patients and families include physical therapists, occupational therapists, speech and language pathologists, nutritionists, psychologists, chaplains, and nursing assistants. For pediatrics, this should include child-life specialists. Complementary and alternative therapies may be included.</p> <p>Guideline 1.4 The use of appropriately trained and supervised volunteers within the interdisciplinary team is strongly encouraged.</p> <p>Guideline 1.5 Support for education and training is available to the interdisciplinary team.</p> <p>Guideline 1.6 In its commitment to quality assessment and performance improvement, the palliative care program develops,</p>

Guideline	Recommendations
	<p>implements, and maintains an ongoing data driven process that reflects the complexity of the organization and focuses on palliative care outcomes.</p> <p>Guideline 1.7 The palliative care program recognizes the emotional impact on the palliative care team of providing care to patients with life-threatening illnesses and their families.</p> <p>Guideline 1.8 Palliative care programs should have a relationship with one or more hospices and other community resources in order to ensure continuity of the highest-quality palliative care across the illness trajectory.</p> <p>Guideline 1.9 The physical environment in which care is provided should meet the preferences, needs, and circumstances of the patient and family to the extent possible.</p> <p>Domain 2: Physical Aspects of Care</p> <p>Guideline 2.1 Pain, other symptoms, and side effects are managed based upon the best available evidence, with attention to disease-specific pain and symptoms, which is skillfully and systematically applied.</p> <p>Domain 3: Psychological and Psychiatric Aspects of Care</p> <p>Guideline 3.1 Psychological status is assessed and managed based upon the best available evidence, which is skillfully and systematically applied. When necessary, psychiatric issues are addressed and treated.</p> <p>Guideline 3.2 A grief and bereavement program is available to patients and families, based on the assessed need for services.</p> <p>Domain 4: Social Aspects of Care</p> <p>Guideline 4.1 Comprehensive interdisciplinary assessment identifies the social needs of patients and their families, and a care plan is developed to respond to these needs as effectively as possible.</p> <p>Domain 5: Spiritual, Religious and Existential Aspects of Care</p> <p>Guideline 5.1 Spiritual and existential dimensions are assessed and responded to based upon the best available evidence, which is skillfully and systematically applied.</p> <p>Domain 6: Cultural Aspects of Care</p> <p>Guideline 6.1 The palliative care program assesses and attempts to meet the needs of the patient, family, and community in a culturally sensitive manner.</p> <p>Domain 7: Care of the Imminently Dying Patient</p> <p>Guideline 7.1 Signs and symptoms of impending death are recognized and communicated in developmentally appropriate language for children and patients with cognitive disabilities with respect to family preferences. Care appropriate for this phase of illness is provided to patient and family.</p> <p>Guideline 7.2 Postdeath care is delivered in a respectful manner. Cultural and religious practices particular to the postdeath period are assessed and documented. Care of the body postdeath is delivered with respect to these practices, as well as in accordance to both organizational practice and local law.</p> <p>Guideline 7.3 A postdeath bereavement plan is activated. An interdisciplinary team member is assigned to the family in the</p>

Guideline	Recommendations
	<p>postdeath period to help with religious practices, funeral arrangements, and burial planning.</p> <p>Domain 8: Ethical and Legal Aspects of Care</p> <p>Guideline 8.1 The patient's goals, preferences and choices are respected within the limits of applicable state and federal law, within current accepted standards of medical care, and form the basis for the plan of care.</p> <p>Guideline 8.2 The palliative care program is aware of and addresses the complex ethical issues arising in the care of persons with life-threatening debilitating illness.</p> <p>Guideline 8.3 The palliative care program is knowledgeable about legal and regulatory aspects of palliative care.</p>

Published Guidelines-Palliative Care

Guideline	Recommendations
<p>Scottish Intercollegiate Guidelines Network (SIGN). Assessment, diagnosis, care and support for people with dementia and their carers 2023. (SIGN publication no. 168). [November 2023].</p> <p>Available from URL: http://www.sign.ac.uk</p>	<p><i>Palliative Approaches</i></p> <p>From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be. For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process. Involve the person and their family members or carers (as appropriate) as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.</p> <p>Review the person's needs and wishes (including any care and support plans and advance care and support plans) after every transition.</p>
<p>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.</p> <p>Institute for Clinical Systems Improvement (January 2020)</p> <p>Palliative Care for Adults. Updated</p> <p>https://www.icsi.org/wp-content/uploads/2020/01/PalliativeCare_6th-Ed_2020_v2.pdf</p>	<p>13 evidence-based recommendations, including:</p> <ul style="list-style-type: none"> Early intervention Assessing domains of palliative care Informed consent Interdisciplinary care team Care conferences Advance care planning Provider's order for life-sustaining treatment Ethical aspects of care Shared decision making Assessment for hospice referral Care for the dying patient Grief & bereavement <p>Quality of evidence was low for all recommendations. Strength of recommendations was strong for all recommendations.</p>

Guideline	Recommendations
<p>Clinical Guidelines for Stroke Management 2017. Melbourne (Australia): National Stroke Foundation.</p>	<p>Strong Recommendation</p> <ul style="list-style-type: none"> 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. <p>Consensus-based recommendations</p> <ul style="list-style-type: none"> For patients with severe stroke who are deteriorating, a considered assessment of prognosis or imminent death should be made. 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.
<p>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.</p> <p><i>European journal of neurology.</i> 2016;23(1):30-38.</p>	<ul style="list-style-type: none"> Palliative care should be considered early in the disease trajectory, depending on the underlying diagnosis (Level C). 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). 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). 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). 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). Continued and repeated discussion with patients is essential due to changes in function – physical and cognitive – and preferences (Level C). 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).
<p>Guideline Adaptation Committee. Clinical Practice Guidelines and Principles of Care for People with Dementia. Sydney. Guideline Adaptation Committee; 2016.</p> <p>109 Recommendations are included</p>	<p>106. Care for people with advanced dementia should be based on a palliative approach and involve a palliative care service if indicated. Treatment and care should be provided as per the person's Advance Care Plans.</p> <p>107. Health and aged care staff and carers and families should continue to offer people with dementia food and drink by mouth. Assessment of swallowing and feeding from a speech pathologist may be indicated. Professional dietary advice may also be beneficial. Nutritional support, including artificial (tube) feeding, should be considered if dysphagia is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe</p>

Guideline	Recommendations
<p>Dementia-Guideline-Recommendations-WEB-version.pdf (sydney.edu.au)</p>	<p>dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity. Ethical and legal principles should be applied when making decisions about introducing or withdrawing artificial nutritional support. Any decision about rehydration should be made in conjunction with the carer(s) and family after providing them with up-to-date information on the potential benefits and harm.</p> <p>108. If a person with severe dementia has a fever, a clinical assessment should be undertaken. Simple analgesics, antipyretics and mechanical means of cooling the person may suffice. Antibiotics may be considered as a palliative measure in the terminal stages of dementia, but this needs an individual assessment.</p> <p>109. In the absence of a valid and applicable advance directive to refuse resuscitation, the decision to resuscitate should take account of any expressed wishes or beliefs of the person with dementia, together with the views of the carer(s) and family and the multidisciplinary team. The decision should be made in accordance with the guidance developed by the Australian Resuscitation Council and, if the person with dementia lacks capacity, the provisions of state or territory based mental health and guardianship laws. Advance Care Plans must be recorded in the medical notes and care plans and time should be taken to discuss these issues with the carer(s), family and support networks</p> <p>All recommendations represent a practice point (i.e., not evidence-based)</p>
<p>Intercollegiate Stroke Working Party. National clinical guideline for stroke, 5th edition. London: Royal College of Physicians, 2016.</p>	<ul style="list-style-type: none"> • Services providing acute and long-term care for people with stroke should provide high-quality end-of-life care for those who need it. • 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. • 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. • 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. • People with stroke with limited life expectancy, and their family where appropriate, should be offered advance care planning, with access to community palliative care services when needed. • 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.
<p>Holloway RG, Arnold RM, Creutzfeldt CJ, Lewis EF, Lutz BJ, McCann RM, et al.</p> <p>Palliative and end-of-life care in stroke: A statement for healthcare professionals from the American Heart Association/American stroke association.</p> <p>Stroke 2014; 45:1887-1916</p>	<p>Primary Palliative Care: Recommendations</p> <ol style="list-style-type: none"> 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 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 process and getting to know the patient and family in making decision that are in line with their preferences. (Class I; Level of Evidence C)

Guideline	Recommendations
(selected)	<p>Patient and Family-Centered Care: Recommendations</p> <ol style="list-style-type: none"> 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). 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). <p>Estimating Prognosis: Recommendations</p> <ol style="list-style-type: none"> 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). 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). 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). <p>Goal Setting Process: Recommendations</p> <ol style="list-style-type: none"> 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)

Guideline	Recommendations
	<p>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)</p> <p>Approaches to Overcome Challenges with Decision Making in Stroke: Recommendations</p> <ol style="list-style-type: none"> 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) if one's own biases and emotional state to minimize errors in prognostic estimates and goal setting recommendations. (Class IIb, Level of Evidence B) 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). <p>10.</p>
<p>Van der Steen JT, Radbruch L, Hertogh CM, et al.</p> <p>White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care.</p> <p><i>Palliat Med</i> 2014; 28: 197–209.</p>	<p>57 recommendations made across 11 domains, including: Applicability of palliative care, Person-centred care, communication and shared decision making, Setting care goals and advance planning, Continuity of care, Prognostication and timely recognition of dying, Avoiding overly aggressive, burdensome or futile treatment, Optimal treatment of symptoms and providing comfort, Psychosocial and spiritual support, Family care and involvement, Education of the health care team, and Societal and ethical issues</p>

Evidence Table

Advance Care Planning (ACP)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
<i>Dementia +/- other conditions</i>					
Huang et al. 2020 Taiwan Prospective study	NA	40 dyads including persons diagnosed with mild cognitive impairment or mild dementia >55 years of age and their family caregivers, recruited from outpatient clinics, dementia care centers, and community care centers. Mean age of persons with dementia was 77.5 years, 53% were women. Mean age of carers was 56.9 years, 84% were women	The ACP information intervention was conducted in two parts by a senior nurse. The nurse reviewed the contents of an ACP manual, which included topics on the symptoms of end-stage dementia and the common EoL life-sustaining medical treatments, such as CPR, machine ventilation, tube feeding, intravenous infusion, and antibiotics. The nurse later conducted a 60-minute session involved family-centered strategies for developing an ACP. Four weeks after completing the intervention a posttest was conducted using 4 structured questionnaires	Primary outcomes: Changes from baseline in questions related to: knowledge of end-stage dementia (ESD) treatment (scores range from 0-17), knowledge of ACP (scores range from 0-15), Advance Care Planning Attitude (ACPA), and Decisional conflict for EoL care (scores range from 0-100)	<i>Persons with dementia</i> Post intervention, there was significant improvement in mean Knowledge of ESD treatment scores (6.6 vs. 8.8, p=0.008), Knowledge of ACP (2.95 vs. 5.33, p<0.001) and total Decisional conflicts in EoL Care (49.9 vs. 35.1, p<0.001), but not ACPA. <i>Family carers</i> Post intervention, there was significant improvement in mean Knowledge of ESD treatment scores (10.1 vs. 13.1, p<0.001), Knowledge of ACP (6.7 vs. 10.6, p<0.001) and total Decisional conflicts in EoL Care (37.3 vs. 27.7, p<0.001). There was a significant decrease in negative ACPA scores.
Wendrich-van Dael et al. 2020 Belgium Review of reviews	Quality scores of the reviews ranged from 2.5 to 12/13 using the AMSTAR-2 tool and 4 to 6/8 for cross-sectional studies and	19 reviews (163 unique studies) and 11 primary articles, including people with dementia or cognitive impairment and their carers.	Data synthesis	Primary outcomes: Not stated a priori	In quantitative reviews (n=4, 1 primary study) evaluating the effectiveness of ACP interventions, ACP was associated with decreased hospitalizations, increased concordance between care received and prior wishes and increased completion of ACP documents. In qualitative studies, views of ACP clustered around 6 themes; 1) timing and tailoring, 2) willingness to engage, 3) roles and responsibilities of healthcare professionals, 4) relationships, 5)

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
	5 to 8/10 for qualitative studies using Joanna Briggs Institute criteria				training and 6) resources needed. Diminishing decision-making capacity over time is a key overarching feature.
Bryant et al. 2019 Australia Systematic review	Risk of bias was high or unclear in 3 studies	4 studies (2 RCTs, 1 cluster RCT and 1 controlled trial) including persons with dementia and/or a carer/ family member. Studies were conducted in hospitals, nursing homes and day care centres.	The effectiveness of interventions to increase participation in ACP was evaluated. Three interventions used varied structured one-on-one family meetings or consultations with caregivers to deliver education and provide an opportunity to complete an ACP, and the final study used face-to-face group sessions with caregivers, aimed to enhance knowledge, self-efficacy and behavioural skills to make end-of-life treatment plan.	Primary outcomes: ACP outcomes	In the 1 st study, only 32% of caregivers developed an ACP after the intervention. In the 2 nd study, a greater proportion of caregivers in the intervention group than in the control group changed their decision regarding the use of CPR, mechanical ventilation and tube feeding postintervention. In the 3 rd study, caregivers in the intervention condition were more likely to have had a Medical Order for Life-Sustaining Treatments (MOLST) added to their relative's chart over the course of the study, and to have decided on medical options (DNR, DNI, DNH, no feeding tube) to be listed in the person with dementia's advance directive. In the last study, where caregivers reviewed a draft advance care plan, no significant effects were found for completion of do not resuscitate orders between the intervention and the control group.
Brazil et al. 2018 UK Cluster RCT	CA: <input checked="" type="checkbox"/> Blinding: Participant <input checked="" type="checkbox"/> Assessor <input checked="" type="checkbox"/> ITT: <input checked="" type="checkbox"/>	24 nursing homes (12 homes in each group) that included residents with dementia.	The family members most responsible for care of residents who did not have decisional capabilities were identified and randomized to participate in up to two family meetings with the ACP facilitator (n=80), or to usual care (n=117)	Primary outcome: 16-item Decisional Conflict Scale (DCS) Secondary outcomes: 25-item Family Perceptions of Care Scale (FPCS), 12-item General Health Questionnaire (GHQ)	6 weeks after the intervention, the mean DCS scores in the intervention group were significantly lower (18.3 vs. 30.7, mean difference=-10.5, 95% CI -16.4 to -4.7, <0.001). All 5 subscores of the DCS were significantly lower in the intervention group. At 6 weeks, total mean FPCS scores were significantly higher in the intervention group (144.6 vs. 133.6, mean difference=8.6, 95% CI 2.3- 14.8, p<0.01). There was no significant difference in GHS scores between groups
Hickman et al. 2016	NA	2,709 long-term nursing home residents believed to be most in need of an	The outcomes of residents who engaged in ACP discussions with	Primary outcome: Preliminary outcomes	The average number of discussions per resident in those who engaged in ACP conversations was 1.6; their average duration of time was 40 minutes.

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
USA Prospective study		ACP conversation, recruited between August 1, 2013, and December 31, 2014, from 19 nursing homes. Mean age was 78.5 years, 67.1% were women. 63% of residents had dementia.	pecially trained nurses (n=731) were compared with those of residents who did not (n=1,978).		69% of residents who had engaged in ≥1 ACP discussions experienced a change in documented care preferences. The generation of a Physician Orders for Scope of Treatment form was the most common change (87.1%). The most common item on the form was the addition of a DNR.
Houben et al. 2014 The Netherlands Systematic review & meta-analysis	31 trials (55.4%) were classified as low quality, based on the PEDro scale, with scores <6/10.	55 RCTs including adults with a variety of medical conditions and healthy individuals.	Interventions were focused on advanced directives in 26 trials and communications in addition to advanced directives in 30 trials.	Primary outcome: Completion of advance directives and occurrence of end-of-life discussions	Overall, the intervention group showed an increased likelihood for the completion of advance directives compared to usual care (OR= 3.26; 95% CI 2.00-5.32). The results were similar in the trials focusing on advance directives (OR=3.31; 95% CI 1.69-6.50) and those also including communication (OR= 2.76; 95% CI 1.41-5.37). The occurrence of discussions about end-of-life preferences between patients and healthcare professionals following an intervention was significantly higher compared with control groups (OR= 2.82; 95% CI 2.09-3.79). 9 trials explored whether interventions can be used to improve knowledge of ACP. Among them, 5 trials reported significant results in favor of the intervention and 4 found no effect of interventions on knowledge of ACP.

Palliative Care in Dementia

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
Walsh et al. 2021 Ireland Cochrane review	Overall risk of bias was low in 4 studies and high in 2.	9 studies (8 RCTs/cluster RCTs) including 2,122 participants, who were composed of people with advanced dementia, their family members, clinicians or paid care	Intervention and control conditions were: 1) efficacy of a facilitated approach to family case conferencing vs. usual care; 2) palliative team care vs. primary care	Primary outcomes: Comfort in dying, symptom management	All studies were conducted in hospitals or long-term care facilities. <i>Organization of care</i> The mean comfort in dying score was 33.38. The mean difference in scores between groups from baseline was 1.49, 95% CI 0.34 to 2.64, favoring

Study/Type	Quality Rating	Sample Description	Method	Outcomes	Key Findings and Recommendations
		staff.	team; 3) generic vs. specific feedback of relatives of patients who had died; 4) Namaste Care vs. usual care; 5) palliative care aimed at dyads vs. information only; 6) a multidimensional intervention (before/after); 7) decision aid vs. information provision; 8) decision aid vs. usual care; 9) advance care planning (ACP) video vs. reading of same material to proxies, to determine level of care for patients.		<p>the intervention group, based on 5 studies, 335 participants. Very low certainty of evidence.</p> <p>Two studies assessed symptom management, both using the SM-EOLD scale. The results conflicted. One trial showed a non-significant difference favouring usual care, the other reported a significant benefit of the intervention.</p> <p>Changes to organization of care may increase the likelihood of having a palliative care plan in place (RR=5.84, 95% CI 1.37 to 25.02; 1 study, 99 participants). Very low certainty evidence</p> <p><i>Advance care planning</i> A decision aid to improve symptom management, measured by family members was not effective (MD= -1.80, 95% CI -6.49 to 2.89; 1 study, 67 participants). Very low certainty of evidence.</p> <p>Participants who received an advance care planning intervention were more likely to have a goals of care discussion compared to those in the control group (RR=1.33, 95% CI 1.11 to 1.59; 2 studies, 384 participants). Moderate certainty of evidence. They also increased concordance with goals of care (RR=1.39, 95% CI 1.08 to 1.79; 1 study, 63 participants). Low certainty evidence.</p>
Ouellet et al. 2021 USA Cross sectional study	NA	15,217 nursing home residents with advanced dementia and AF who had at least moderate stroke risk (CHA ₂ DS ₂ VASC score ≥2), and who died between January 1, 2014, and December 31, 2017. Mean age was 87.5 years, 68% were women.	The associations between anticoagulant use and patient characteristics were examined using multiivariable logistic regression	Primary outcome: Patient characteristics	<p>5,033 (33.1%) residents received an anticoagulant in the last 6 months of life.</p> <p>Independent predictors of anticoagulant use were CHA₂DS₂VASC score >7, (OR= 1.38, 95% CI, 1.23-1.54) and ATRIA score >7, (OR, 1.25, 95% CI, 1.13-1.39), nursing home length of stay of at least 1 year (OR= 2.68, 95% CI, 2.48- 2.89), not having Medicaid (OR= 1.59, 95% CI, 1.45-1.69), weight loss (OR=1.09, 95% CI, 1.01-1.18), pressure ulcers (OR=1.37, 95% CI, 1.27-1.48), and difficulty swallowing (OR=1.12, 95% CI, 1.02-1.22).</p>

Abbreviations

CA: concealed allocation	CI: confidence interval	ITT: intention-to-treat
OR: odds ratio	RR: relative risk	

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