

# FACTS

## Palliative Care

### Reducing Suffering for Patients with CVD & Stroke

#### BACKGROUND

The American Heart Association defines palliative care as patient- and family-centered care that optimizes health related quality of life (HRQOL) by anticipating, preventing, and treating suffering. It focuses on communication, shared decision-making about treatment options, advance care planning, and attention to physical, emotional, spiritual and psychological distress with inclusion of the patient's family and care system.<sup>1</sup> Physicians and palliative care teams, along with families and patients, work together to tailor treatment and care.<sup>1,9</sup> Specialty palliative care team can collaborate with primary managing clinicians regarding the most relevant and current technology and medical management varying by the complexity of the condition.<sup>1</sup> Integral to palliative care is the support structure comprised of a range of key stakeholders and medical professionals (Figure 1).

#### LANDSCAPE

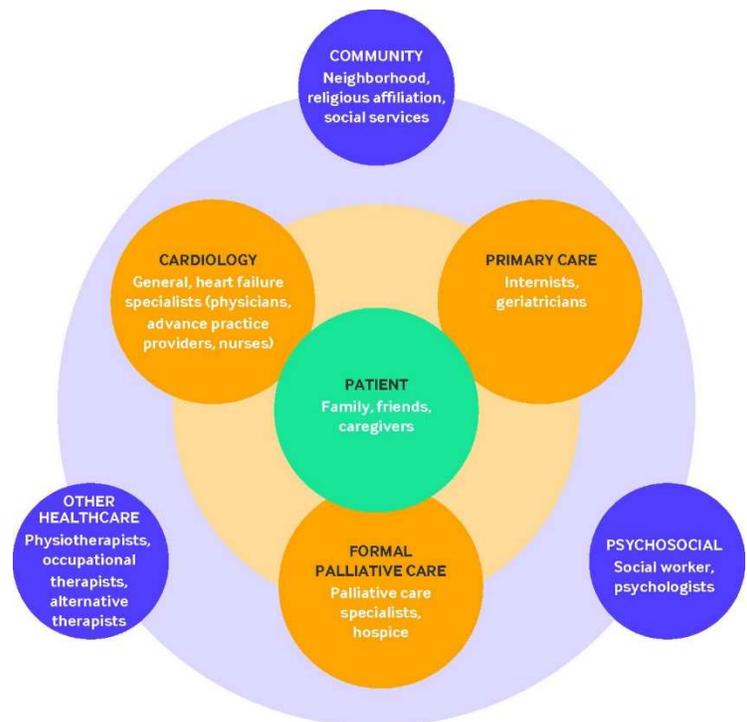
Palliative care helps patients and families face the long-term challenges and burden of advanced cardiovascular disease (CVD) and stroke.<sup>2</sup> It is appropriate for many cardiovascular diseases including heart failure, stroke, congenital syndromes, and congenital anomalies, and their associated symptoms of fatigue, depression,<sup>3</sup> shortness of breath, pain,<sup>4</sup> depression, edema, insomnia, anxiety, confusion, anorexia, constipation and social isolation.<sup>5</sup> Patients with advanced heart failure and stroke survivors, in particular, sometimes experience poor HRQOL as a result of deteriorating health, symptom distress, and complex care regimens.<sup>2,9,12</sup> Family members, who often act as primary caregivers, can experience psychological stress as they deal with physical, emotional, and cognitive changes in their loved one.<sup>2,9</sup> Intended to alleviate symptoms and manage pain at any stage of disease, palliative care should be incorporated early in the disease trajectory by the patient's primary palliative care team or specialty palliative care providers<sup>2</sup> and as an ongoing component of disease-modifying treatment.<sup>6</sup>

#### Benefits of Palliative Care

Integrating palliative care in the management of advanced CVD and stroke patients may provide:

- Improved patient and caregiver understanding of disease, treatment and prognosis<sup>2</sup>
- Improved treatment of symptoms and relief of suffering.<sup>2,7</sup>
- Shared decision making based on patient values, preferences and goals.<sup>2</sup>
- Enhanced patient-clinician communication<sup>2</sup>
- Individual advance care planning based on benefits, risks and burdens of care.<sup>2</sup>
- Improved patient and caregiver outcomes<sup>2</sup>
- Improved preparation for end-of-life and associated care.<sup>2</sup>
- Bereavement support.<sup>2</sup>

Figure 1: Team based palliative care<sup>13</sup>



#### Barriers to Palliative Care

Patients also face barriers to their receipt of palliative care including:

- Reluctance of providers to refer patients to palliative care due to lack of knowledge about benefits or availability of palliative care services.<sup>8</sup>

- Provider discomfort in communicating with patients and families about palliative care<sup>2</sup> and lack of training in communicating need for palliative care.<sup>6</sup>
- Limitations in payment systems for comprehensive palliative care services<sup>2</sup>
- Family dynamics, culture, religion and language differences.<sup>9</sup>

Payment barriers once faced by patients are beginning to be addressed with the Medicare program announcing in October 2015, that beginning January 1, 2016, physicians and other health professionals will be reimbursed for advance care planning discussions.<sup>10</sup> The Medicare Care Choices model,<sup>11</sup> the Centers for Medicare & Medicaid Services' concurrent hospice demonstration project, is testing the ability of patients to maintain curative treatment while also seeking hospice care.

### THE ASSOCIATION ADVOCATES

Awareness of, and access to, palliative care interventions aligns with the AHA/ASA mission and goals. Recognizing that palliative care helps meet the priority needs of patients, better aligns patient care with preferences, supports clinical care best practices and may contribute to improved quality of care and outcomes for patients and families, the AHA advocates for policies that:

- Encourage federal and state agencies to reimburse for comprehensive delivery of palliative care services, inclusive of palliative care treatment for patients with stroke and CVD.
- Support strong payer-provider relationships that involve data sharing in order to identify patients in need of palliative care and support care coordination.
- Identify better care and payment models, and establish quality standards and outcome measurement.
- Address healthcare system policies for the provision of comprehensive palliative care services during hospitalization, including goals of care, treatment decision making, needs of family caregivers, and needs associated with transition to other care settings.
- Promote coordination of care planning, treatment decision-making, and discharge planning processes for patients, as well as feasible care plans that reflect patients' palliative care needs, during transitions and across care settings.
- Respond to the need for health professional education and training in palliative care as part of licensure requirements for those who provide care to CVD and stroke patients, as well as efforts to increase the number of healthcare providers with specialty certification.
- Test and evaluate models of palliative care delivery to improve care for the sickest, most vulnerable beneficiaries.

For more information on specific policy recommendations endorsed by the the American Heart Association / American Stroke Association, please visit, [bit.ly/PalliativeCare\\_CVDandStroke](http://bit.ly/PalliativeCare_CVDandStroke).

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<sup>4</sup> Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J, Claessens MT, Wenger N, Kreling B, Connors AF Jr. Perceptions by family members of the dying experience of older and seriously ill patients: SUPPORT Investigators: Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Ann Intern Med*. 1997; 126: 97-106.

<sup>5</sup> McCarthy, M., M. Lay, and J. Addington-Hall. "Dying from Heart Disease." *Journal of the Royal College of Physicians of London* 30.4 (1996): 325-8. Print.

<sup>6</sup> Barbara Reville. "Utilization of Palliative Care: Providers Still Hinder Access." *Health Policy Newsletter* 24.1 (2011)Print.

<sup>7</sup> Aiken, Leona S., et al. "Outcome Evaluation of a Randomized Trial of the PhoenixCare Intervention: Program of Case Management and Coordinated Care for the Seriously Chronically Ill." *Journal of palliative medicine* 9.1 (2006): 111-26. Print.

<sup>8</sup> Ahluwalia SC, Fried TR. Physician factors associated with outpatient palliative care referral. *Palliat Med*. 2009;23:608-615. doi: 10.1177/0269216309106315.

<sup>9</sup> Allen, L. A., et al. "Decision Making in Advanced Heart Failure: A Scientific Statement from the American Heart Association." *Circulation* 125.15 (2012): 1928-52. Print.

<sup>10</sup> Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 FR 220:70866-71386 (2015).

<sup>11</sup> Centers for Medicare and Medicaid Services. (2015). "Medicare Care Choices Model." Accessed from <http://innovation.cms.gov/initiatives/Medicare-Care-Choices/>. Accessed on July 14, 2016.

<sup>12</sup> Heart Failure Society of America, Lindenfeld J, Albert NM, Boehmer JP, Collins SP, Ezekowitz JA, Givertz MM, Katz SD, Klapholz M, Moser DK, Rogers JG, Starling RC, Stevenson WG, Tang WH, Teerlink JR, Walsh MN. HFSA 2010 comprehensive heart failure practice guideline. *J Card Fail*. 2010;16:e1-e194. doi: 10.1016/j.cardfail.2010.04.004.

<sup>13</sup> McIlvennan, C. K., & Allen, L. A. (2016). Palliative care in patients with heart failure. *bmj*, 353, i1010.