Managing Advanced Illness

By James A. Diegel

With advancements in research and improvements in treatment, many people with such potentially life-threatening diseases as cancer will recover or live much longer. Still, millions of people in the United States are living with advanced illnesses that eventually will lead to death. Most people facing advanced illnesses will end up in the hospital at some point, typically at the end of life. Yet, an overwhelming majority — 80 percent — of patients say they wish to avoid hospitalization and intensive care during the terminal phase of illness. And research shows that providing more medical care for terminally ill patients does not necessarily lead to better outcomes.

With advanced illness management, or AIM, health care providers strive to reduce pain, increase quality, improve patient and family satisfaction, and remove some of the inefficiencies of the health care system. Hospitals and systems have been growing AIM program components and improving care for patients with serious illnesses. According to a recent study by the Center to Advance Palliative Care, palliative care programs are now available at more than 80 percent of hospitals with more than 300 beds.

Hospital and health system trustees can provide guidance and support to help their organizations implement best-practice strategies that will integrate AIM into the normal continuum of care and ensure that the wishes of patients and their families are carried out.

Defining AIM

Advanced illness management has four phases: advance directives, palliative care, advanced care planning and hospice care. Successful programs integrate these four phases into one overarching AIM initiative. As a patient progresses through each phase, the nature of care evolves, but the quality remains the same — person-centered, integrated care by a multidisciplinary team of health care professionals adhering to evidence-based, best-practice guidelines. The treatment plan is driven by the personal goals and decisions of the patient and his or her family.

In a second-curve, value-based environment where incentives are aligned, a well-developed AIM program includes these key strategies:

- increasing patient and family access to high-quality AIM services;
- building and training a health care workforce that understands AIM and delivers high-quality care over the continuum of health and decline;
- boosting awareness within the community of the benefits of advanced illness planning.

Successful programs also address cultural sensitivities related to managing advanced illness.

Keys to Success

Large organizations have the opportunity to develop full-scale initiatives for AIM, while smaller hospitals and rural hospitals and systems can partner with other community organizations to achieve the same goals. Trustees can work with administrative and clinical leadership to:

- provide leadership buy-in as multidisciplinary teams are developed;
- ensure that qualifying patients are identified through evidence-based protocols;
- think beyond hospital walls to promote community collaboration with AIM;
- use a performance improvement framework to measure, monitor, evaluate and adapt the program.

In particular, trustees can provide guidance for community collaboration and program evaluation. Organizations must continually analyze the quality of their AIM services for improvement.

The AHA Committee on Performance Improvement report “Advanced Illness Management Strategies” outlines a program framework that hospitals and health care systems can use to coordinate AIM services and increase access. The report also includes examples of successful AIM programs. To access the report, go to www.aha.org/aim-strategies.