

Strategies for Change— A Collaborative Journey to Transform Advanced Illness Care



Over the next two decades, the number of people age 65 and older will nearly double to more than 72 million, or one in five Americans. Although advanced illness can occur at any age, the vast majority of people with advanced illness will fall in this group. Advanced illness can impair daily activities, reduce mental and physical capabilities, necessitate frequent medical treatments and visits, and increase the risk of death. Care for individuals with advanced illness includes a broad range of services that support families and caregivers, bridging community-based and healthcare services.

CALL TO ACTION

NQP's Advanced Illness Care Action Team issued a national call to action for all stakeholders to ensure that individuals with advanced illness, their families, and caregivers are at the center of care decisions. The Action Team urges healthcare systems, communities, and policymakers to engage individuals, families, and their caregivers as true partners in care planning.

APPROACHES TO ADVANCED ILLNESS CARE

The approach to advanced illness care is undergoing a shift from being geared primarily toward medical or clinical needs to better incorporating the needs of the person as a whole. Person-centered care integrates personal preferences that respond to an individual's medical, functional, social, and emotional needs—preferences that are closely linked to quality of life, yet are often neglected in healthcare decisions. The movement toward person-focused approaches can improve healthcare quality, enhance quality of life, and reduce costs.

NATIONAL QUALITY PARTNERS' (NQP) ADVANCED ILLNESS CARE INITIATIVE

National Quality Partners' (NQP) Advanced Illness Care Initiative connects stakeholders, calling on healthcare systems, communities, and policymakers to take action on this key healthcare priority. Convened by the National Quality Forum (NQF) and co-chaired by The Coalition to Transform Advanced Care and Planetree International, NQP's Advanced Illness Care Action Team includes patients, care providers, physicians, nurses, spiritual advisors, and other experts from the public and private sectors.

INCORPORATING PERSON-CENTERED PREFERENCES

NQP's issue brief, [Strategies for Change – A Collaborative Journey to Transform Advanced Illness Care](#), highlights six key preferences of person-centered advanced illness care, which can form the basis for advance care planning and shared decision making for individuals with serious illness.

Purpose and Connection

Advanced illness can affect self-identity and challenge an individual's sense of purpose and connection to what matters most. Care should go beyond the observable manifestations and clinical symptoms of disease to support what makes a person feel valued and whole and help individuals feel in control of their lives and their future.

Physical Comfort

A person's perception of physical comfort is unique. Most individuals with advanced illness want to be as free from pain as possible, but many other symptoms (e.g., fatigue, nausea) can affect an individual's ability to enjoy life and normal activities. Individuals should work with their care providers to prioritize their goals for symptom management to better understand how certain interventions may affect quality of life.

Emotional and Psychological Well-Being

Care for individuals with advanced illness includes addressing emotional and psychological well-being. Loneliness and isolation from family, friends, and community and a diminished sense of purpose can decrease feelings of joy, happiness, and contentment. Professional psychological support can alleviate fear, anxiety, and stress for both the individual and his or her family, equipping the individual to better cope with life challenges ahead.

Family and Caregiver Support

Caregivers often suffer from physical and psychological stress. Most caregivers are ill-prepared for their role and have little or no support, training, resources, relief, or respite. Many families must balance caregiving with other responsibilities. The physical, psychological, and social needs of caregivers should be a regular consideration in the provision of advanced illness care.

Financial Security

Financial security often drives the choices that individuals and families make around advanced

illness care. Precipitated by out-of-pocket and other expenses, financial concerns can cause significant stress at a time when individuals and families should focus on maximizing quality of life. Individuals and their families may need support navigating complex financial or legal assistance programs.

68% of physicians report feeling inadequately trained to discuss end-of-life care with patients. *JAMA*, 2016

Peaceful Death and Dying

Individuals should experience death and dying on their own terms. Providers and caregivers can help individuals express their wishes about the kind of life they want to lead, how treatments should support these wishes, and how, where, and in whose company they would like to die. Individuals should receive appropriate information about personal rights and choices available to them to allow a person's preferences to tailor care to achieve those goals.

QUESTIONS TO SUPPORT PERSON-CENTERED ADVANCED ILLNESS CARE

Purpose and Connection

- ☐ Did you identify short- and long-term goals that address the individual's primary role(s) in life?
- ☐ Did you discuss religious and spiritual preferences?
- ☐ Did you identify an appropriate team member to work through difficult conversations and assist individuals with goal-setting?

Physical Comfort

- ☐ Have you discussed physical discomfort, including pain, fatigue, loss of appetite, nausea, digestive issues, sleeplessness, and shortness of breath?
- ☐ Have you discussed sources of discomfort and the tradeoffs of different treatment approaches?
- ☐ Have you offered suggestions for medical and nonmedical interventions, if appropriate (e.g., complementary therapies)?

Emotional and Psychological Well-Being

- ☐ Have you identified psychological issues that may be weighing on your patient?
- ☐ Have you discussed feelings of loneliness and isolation from family, friends, and community?
- ☐ Did you help your patient identify resources to cope with life challenges?

- ☐ Did you refer your patient to professional psychological or psychiatric support, if appropriate?

Family and Caregiver Support

- ☐ Do you know who the patient's primary caregiver(s) are at home?
- ☐ Did you provide resources for caregiver support and realistic information about what caregiving may entail?
- ☐ Did you coordinate a meeting to discuss concerns with the patient and caregivers?

Financial Security

- ☐ Has your patient expressed stress, concern, or worry about financial security?
- ☐ Is your patient able to continue to work? If not, does the inability to work add additional stress?
- ☐ Have you shared resources to help the patient and his or her family address financial issues and concerns?

Peaceful Death and Dying

- ☐ Have you provided the patient with information about personal rights and choices?
- ☐ Have you identified the patient's preferences for death and dying?
- ☐ Does the care and treatment plan align with the patient's preferences and goals?