

ISSUE BRIEF

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



NATIONAL
QUALITY FORUM

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INTRODUCTION

Atul Gawande's *Being Mortal* and Paul Kalanithi's *When Breath Becomes Air*—both *New York Times* bestsellers authored by physicians—have engaged citizens, clinicians, and caregivers across the United States in thinking about life-threatening illness, disease, and death—often taboo subjects in our culture. Through personal stories, the authors have inspired the nation to think about mortality, what matters most in life, and why personal preferences are so often neglected in healthcare decisions.

The healthcare system is beginning to undergo a shift from care geared primarily toward medical or clinical needs to care that addresses the needs of the person as a whole. Person-centered care integrates the preferences of the individual and responds to medical as well as functional, social, and emotional needs. Driving this change is a consumer-focused movement along with the recognition that better patient engagement improves healthcare quality and lowers costs.¹ This pivot is critical given the increasing number of older Americans facing advanced or serious illness and the growing cultural diversity of the United States population. Advanced illness may result in impairment of daily activities, reduced mental and physical capabilities, frequent medical treatments and visits, and a higher risk of death—all of which can cause an overall decline in health and quality of life.

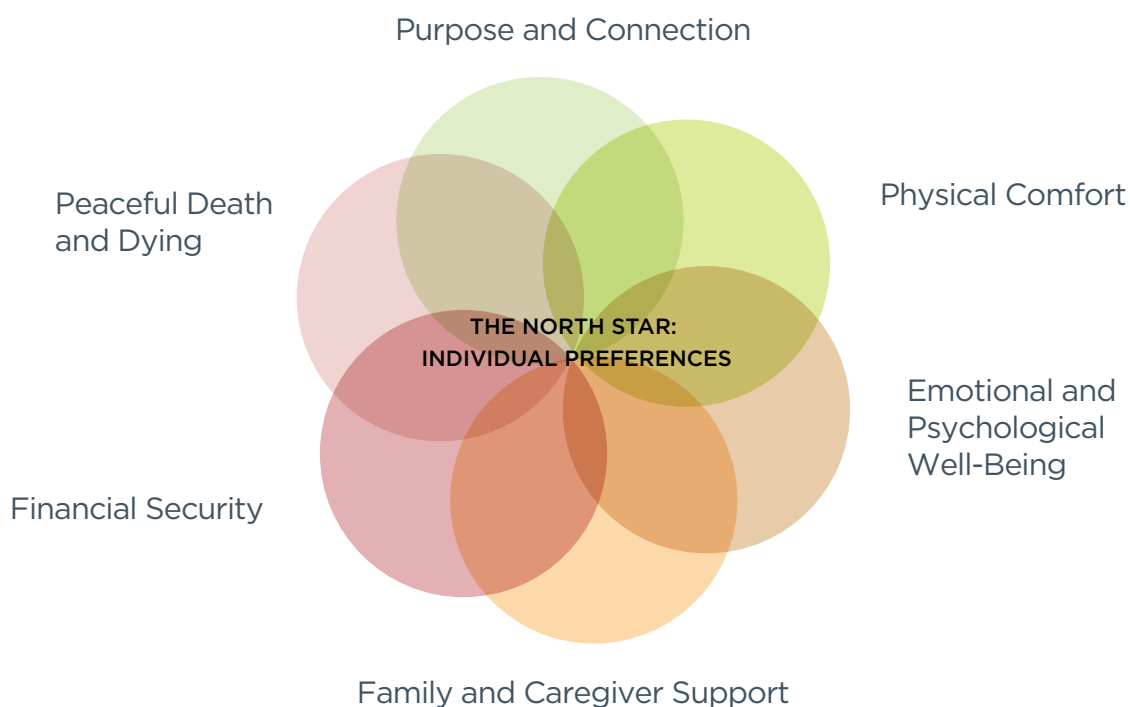
Advanced illness care encompasses a broad range of services that bridges families and caregivers, communities, and the healthcare system. People with complex medical needs benefit from palliative care in various settings (including home, community, hospital, hospice, nursing homes, and other long-term care facilities) especially at the end of life which in

many cases, but not always includes hospice care. By integrating individual preferences, advanced illness care should empower people to participate in healthcare decisions to the greatest extent possible. Over the past 30 years, the hospice and palliative care movements have introduced interdisciplinary, team-based approaches to care. Care teams often include physicians, nurses, chaplains, pharmacists, and social workers. Building on these and other efforts, the National Quality Forum (NQF) launched an initiative to improve healthcare quality for individuals with advanced illness through measurement, policy, and practice. The Advanced Illness Care Initiative is spearheaded by National Quality Partners (NQP), an effort at NQF to engage its members to collaborate on healthcare quality issues of national importance. Guided by a diverse Action Team co-led with The Coalition to Transform Advanced Care and Planetree, this initiative convenes and connects stakeholders to spur national dialogue and action. With the individual in mind as the guiding “North Star,” the Action Team is issuing a call to action for healthcare systems, communities, and policymakers to work together to improve the lives of those with advanced illness.

PERSON-CENTERED PREFERENCES TO GUIDE ADVANCED ILLNESS CARE

The Advanced Illness Care Action Team along with key contributors identified six person-centered preferences to help guide thinking and approaches on advanced illness care. In addition to describing the preferences, the issue brief highlights selected exemplars or “snapshots” to illustrate each, recognizing that many other organizations are doing innovative work in this area.

Person-Centered Preferences to Guide Advanced Illness Care



CALL TO ACTION

The National Quality Partners’ Advanced Illness Care Action Team is leading the way to create a shared sense of urgency to address the needs of individuals with advanced illness and their families and caregivers. The Action Team is calling for bold action from all stakeholders to transform advanced illness care.

Please join us—the time for change is now.

Purpose and Connection

With advanced illness, the structure and flow of life naturally changes. As functional abilities decline and illness worsens, individuals may find themselves confined to their homes, more engaged with the healthcare system than with their loved ones, and increasingly disconnected from their everyday lives. These scenarios can profoundly affect self-identity—whether as a person, caretaker, employee, family member, friend, or contributor to society—which, in turn, may challenge an individual's sense of purpose and connection to what matters most.

Advanced illness care supports the identification and integration of goals that emphasize individuals as human beings—goals that vary greatly from person to person—and that depend on how and with whom people prefer to spend their time. Whereas some goals may be relatively simple and shorter-term, such as attending a wedding or cooking a family dinner, others may be more complex and longer-term, such as coping with loneliness or working on family reconciliation. People may want to improve the control they have in shaping their future, build confidence to cope with their health issues, face fears of the unknown, or contemplate their legacy or mark on society.

A person's spirituality and religion can play an important role in supporting sense of purpose and connection. Studies suggest that spiritual well-being helps individuals facing an advanced illness cope with disease symptoms, improves quality of life, and affects medical decision making near end of life. Unfortunately, a Coping with Cancer study concluded that more than 70 percent of advanced cancer patients' spiritual needs were minimally or not at all supported by the medical system.² By employing a team-based interdisciplinary approach that includes access to faith leaders, in addition to advanced illness care is better positioned to integrate personal preferences for spiritual or religious support.

Integrating other disciplines into the care team—such as rehabilitation specialists and counselors—may be helpful to work through difficult conversations, assist individuals in setting realistic goals related to their life purpose and connection to others, and offer supporting services to achieve these goals. By going beyond the observable manifestations of disease and clinical symptoms, and emphasizing with what makes a person feel valued and whole, advanced illness care encourages a consideration of purpose and connection at a very important time in life.

80% of advanced cancer patients cite religion and spirituality as essential to coping with illness, yet 70% say these needs are not being met by the medical system.

Journal of Clinical Oncology, 2007; Journal of Supportive Oncology, 2012^{a,b}

90% of patients vs. 65% of physicians feel a sense of completion is important at end of life.

JAMA, 2000^c

Snapshot

HEALTHCARE CHAPLAINCY NETWORK

The California State University Institute for Palliative Care and HealthCare Chaplaincy Network (HCCN) has defined **11 competencies for professional chaplains** who provide palliative and end-of-life care. These competencies were established in direct response to the **National Consensus Project for Quality Palliative Care Clinical Practice Guidelines**, which calls for a board certified chaplain to be a member of the interdisciplinary palliative care team. The competencies address palliative care knowledge related to communication, counseling skills, teamwork and collaboration, spiritual assessment and documentation, ethics, delivery of care and continuity of care, cultural competence that incorporates inclusion and marginalized populations, care for other members of the team, and continuous quality improvement and research.

DIGNITY THERAPY AT SAN DIEGO HOSPICE

Dignity therapy is a psychotherapy intervention which strives to “conserve the dying patient’s sense of dignity by addressing sources of psychosocial and existential distress.” The intervention involves interviewing the patient about his or her life, and then producing a document (or “legacy”) to share with family and friends as desired. Early studies show high satisfaction with dignity therapy which both patients and their families see as helpful. The Institute for Palliative Medicine at the San Diego Hospice implemented a **dignity therapy toolkit** to determine the “pragmatic aspects” of delivering such care to hospice patients. A study of this intervention found that all participants chose to discuss their autobiographical information, love, and the lessons they learned in life. Other common themes included defining the roles in their lives, their accomplishments, regrets with perceptions of “unfinished business,” and their “hopes and dreams for others.”

Source: Montross L, Winters KD, Irwin SA. Dignity therapy implementation in a community-based hospice setting. J Palliat Med. 2011;14(6):729-734.

Physical Comfort

Physical comfort is an important aspect of advanced illness care, and most individuals with advanced illness want to be as free from pain as possible. While pain is one symptom of illness, many others can markedly affect the ability to enjoy life or go about normal work or social activities. People with cancer have ranked fatigue and loss of appetite as the top two reasons for physical distress, followed by pain, nausea and vomiting, constipation, delirium, and shortness of breath.³ Frailty, insomnia, malnourishment, dehydration, and general malaise can also cause significant discomfort and unease.

A person's perception of physical comfort is unique, and signs of discomfort may be difficult for providers to identify without specific conversations about a range of possible symptoms. Working in concert with their care providers, individuals need to prioritize their goals for symptom management, with an understanding of how certain interventions may affect their quality of life. Because individuals often have a constellation of complex and interrelated symptoms, and treatments can have profound side effects, providers must engage in earnest discussions about sources of discomfort

and tradeoffs of treatment. As an example, pain medications may cause constipation or grogginess, and different individuals have different levels of tolerance for each. One person may choose to accept a higher level of pain in order to remain conscious and lucid, while another may want to minimize pain and experience a lower level of alertness. Many of these tradeoffs may evolve over the course of an illness, and therefore symptoms need to be regularly assessed and addressed.

Options for improving physical comfort can include a variety of medical and nonmedical interventions to manage symptoms and associated side effects of treatment. Hospice and palliative care teams offer the services of medical doctors, nurses, pharmacists, and nutritionists, who can suggest options for symptom management. Complementary therapies such as music, massage, and aromatherapy may offer additional support and relief from symptoms such as pain, anxiety, and sleeplessness. Importantly, simple environmental stimuli, such as lighting, noise, or smells, can also be modified to support a person's level of comfort and sense of well-being.

Physical symptoms of advanced illness can include:

fatigue, loss of appetite, pain, nausea, vomiting, constipation, delirium, shortness of breath, frailty, insomnia, malnourishment, dehydration, general malaise.

93% of seriously ill patients & 99% of physicians believe it is important to be pain-free at the end of life.

JAMA, 2000^d

Snapshot

COMMUNITY-BASED PALLIATIVE CARE: BROOKDALE-CORNELL PALLIATIVE CARE CONSORTIUM

A partnership between the Brookdale Center for Healthy Aging at Hunter College, Weill Cornell Medical Center, and the East and Central Harlem community conducted a community needs assessment with outreach to social service agencies and faith-based organizations, including face-to-face interviews with agency and church leaders as well as clients and parishioners. The results revealed a significant symptom burden among respondents, with 79 percent reporting pain and 76 percent reporting tiredness. Additionally, 53 percent of respondents reported difficulty sleeping and 49 percent reported depression as problems. One respondent commented, “The spirit is willing, it’s the flesh that is weak. My spirit is very happy, but my flesh is very weak and painful. I am sitting here talking to you, but I am in pain. I am in pain.” Nearly two-thirds of community-based providers in this area offer aspects of person-centered services, such as alternative strategies for pain reduction and spiritual support. Most are interested in partnering together to address person-centered needs.

Source: C-TAC. Webinar presented on spreading community-based models: spotlighting a community-academic partnership in east and central Harlem; March 30, 2016. <https://attendee.gotowebinar.com/recording/3425526650908662532>. Accessed November 2016.

HOSPICE & PALLIATIVE CARECENTER

The **Hospice & Palliative CareCenter of North Carolina** offers patients complementary therapies to nurture the mind, body, and spirit in addition to more traditional therapies. These services are used “to promote comfort and wholeness for both patients and their families.” Gentle touch therapies (e.g., massage, reflexology, Reiki) help address pain, anxiety, sleeplessness, and other issues. The program also uses music therapy as a tool to address anxiety and pain, among other symptoms. Complementary therapies such as these do not substitute for medical, social, or spiritual care. Instead, these therapies are part of a comprehensive approach to patient care and can help comfort patients and families during an advanced illness and end of life.

Emotional and Psychological Well-Being

Care for individuals with advanced illness includes addressing emotional and psychological well-being. Advanced illness can result in emotional distress in the form of mental or behavioral symptoms, including depression.

Unmet psychological needs can place additional stress on individuals and their families. Dementia, delirium, depression, cognitive loss, anxiety, stress, shame, guilt, and emotional distress all can adversely affect a person's ability to cope with illness and to live life to the fullest. Furthermore, loneliness and isolation from family, friends, and community and a diminished sense of purpose can take a toll on a person's quality of life and diminish feelings of joy, happiness, or contentment. A fragmented and confusing health system can further worsen quality of life, creating uncertainty and fear, particularly as an illness progresses.

Professional psychological or psychiatric support in advanced illness care can help alleviate fear, anxiety, and stress, whether they stem from the original diagnosis, an uncertain prognosis, the anticipated progression of disease, the burden of treatment, or the need to prepare for death. Members of the care team as well as families and caregivers should be aware of emotional or psychological issues that may arise during advanced illness and should support

individuals' ability to understand their condition and prognosis, implications for treatment, and realistic plans for the future. Professionals can also support patients and families with their ability to cope with the life changes they face, and can rely on tools that assess mood, anxiety, and mental status as well as person-reported outcomes—information on health conditions reported directly by the individual—to determine the most pressing needs. Although advanced illness can have a negative impact on a person's emotions and psyche, care should focus on maximizing well-being to the greatest extent possible.

Patients with advanced illness

are twice as likely to be potentially depressed as other patients, but less likely to receive antidepressants.

Palliative Support Care, 2005^e

5-15% of patients with cancer have major depressive disorder.

Handbook of Psychiatry in Palliative Medicine, 2000^f

Snapshot

THE COLEMAN PALLIATIVE MEDICINE TRAINING PROGRAM

Since 2012, the [Coleman Palliative Medicine Training Program](#) has offered an educational initiative for physicians, nurses, social workers, and chaplains across the Chicago area to improve the quality of and access to palliative care for patients with cancer and other life-limiting illnesses. Run by regional leaders in palliative care, the training offers interdisciplinary fellows a two-year training, including bi-annual conferences, self-directed web-based learning, one-on-one mentoring, and practice improvement projects. The trainings cover a range of topics, including ethical issues, psychological assessment, communication skills development, evaluating and responding to psychological distress, spiritual and psychosocial assessment, conflict resolution for families, and many other important issues critical to improving quality in palliative care.

NATIONAL COMPREHENSIVE CANCER NETWORK DISTRESS THERMOMETER

The emotional effects of cancer may be less obvious than the physical effects. The [National Comprehensive Cancer Network Distress Thermometer](#) measures emotional distress in an approach similar to assessing pain—on a scale of 0 to 10, with 10 being the worst. This tool makes it easier for people to talk to their doctors about the emotional effects caused by the diagnosis, symptoms, and treatment of cancer and other issues, such as family, emotional, spiritual, and physical problems.

Family and Caregiver Support

In the U.S., an estimated 44 million people provide unpaid care to older people and adults with disabilities in the community.⁴ During the last year of an ill person's life, family caregiving averages 66 hours per week,⁵ and many caregivers provide an intense level of care while suffering from poor health themselves.⁶ Most caregivers are ill-prepared for their role and have little or no support, training, relief, or respite. Caregivers often suffer from physical and psychological stress, including injuries, arthritis, high blood pressure, gastric ulcers, headaches, and depression.⁷ As the population ages and as people work and live longer, this phenomenon is likely to intensify.

Financial considerations and the availability of support services often drive the choices families make about caregiving. Many family members do not feel they have a choice about stepping into the role of caregiver. Many people must balance caregiving with other responsibilities, including their own families and work, which can result in having to cut back on or leave work entirely, causing even greater stress. Caregivers may find themselves in the middle of conflicts between family members, may feel personally neglected, and may experience strains on their own relationships. Family members or caregivers may need to take the lead in initiating difficult conversations and make hard decisions about

care and end-of-life plans without feeling prepared. Further, caregiver survivors may continue to experience stress or negative feelings such as guilt or shame after the death of their loved one.

The physical, psychological, and social needs of caregivers should be a regular consideration for providers working with individuals with advanced illness, particularly as their needs begin to intensify. Since many caregivers cannot and do not anticipate the depth of responsibilities they may face, they need realistic information about what caregiving may entail and access to supportive services. As the likelihood of their loved one's death approaches, caregivers need more specialized support during and after this painful life event; this need is best addressed through quality hospice care.

40-70%
of caregivers suffer from depression.

Caregiver Assessment: Voices and Views from the Field, 2006⁹

Nearly 60%
of caregivers see their own health decline moderately or a lot as a result of caregiving.

Evercare Study of Caregivers in Decline, 2006¹¹

Snapshot

CHOOSING WISELY®

The ABIM Foundation's Choosing Wisely® campaign has created a national dialogue between healthcare practitioners and consumers about avoiding wasteful or unnecessary medical tests, treatments, and procedures, which may lead to increased costs and risks but do not add value to patients and their families. The campaign promotes conversations between providers and patients informed by evidence-based recommendations. Those caring for aging friends or relatives may be inclined to try every possible treatment, but some interventions may not help and may even be harmful. [Advice for Caregivers—Treatments and Tests for Seniors](#) outlines considerations for a variety of illnesses, including cancer, dementia, and chronic pain, such as the avoidance of certain drugs, procedures, or screening tests which may not be appropriate.

CAPITAL CARING'S TELECARING™ MODEL

Capital Caring, a provider of hospice services in the Washington, DC, metropolitan area, launched TeleCaring™ in 2011. In this model, hospice staff proactively reach out to patients and their families by telephone on a daily basis to identify patient or caregiver needs and provide support. In particular, the model frequently addresses issues such as uncontrolled symptoms or prescription problems. A [recent assessment of the TeleCaring™ program](#) found that it reduced nonscheduled medical visits and disruptive transitions and increased caregiver confidence and family satisfaction.

Financial Security

When thinking about advanced illness, Americans rank the cost of treatment as a major concern.⁸ Personal expenses related to advanced illness cost families and caregivers an estimated average of \$2,400 per year.⁹ With an average household income in the U.S. of \$52,000, this is a significant expense for many. A MetLife study found that a woman could lose up to \$325,000 in wages and retirement benefits as a result of caregiving.¹⁰

Financial security is an often neglected, but important aspect of decision making when coping with advanced illness. During a period when people and families should focus on maximizing their quality of life, out-of-pocket expenses or a looming financial crisis can cause significant stress. If people with advanced illness are no longer able to—or choose not to—work a full schedule, they may experience reduced income and unanticipated cash flow problems associated with co-pays, prescription drug expenses, or the need for personal care services at home or in a facility. Those who can no longer work may face loss of insurance and the need to draw on retirement or other financial assets. Some may have trouble securing basic needs like food and housing, and may even delay or avoid necessary healthcare. Individuals may need support applying for and navigating complex financial or legal assistance programs.

As individuals settle their financial matters, they may also want to consider how to allocate their resources and the ramifications for relatives, friends, and caregivers. Symptoms related to advanced illness, such as cognitive loss, may also impact a person's ability to make financial decisions.

Opportunities to improve financial security begin with improved transparency about the true costs of care. Individual healthcare providers are generally unprepared to discuss financial issues, but should offer suggestions for resources to help patients and their families understand financial risk, access financial planning support, or tap into legal assistance programs as necessary.¹¹

Individuals with cancer are twice as likely to file for bankruptcy.

Health Affairs, 2013ⁱ

25% of seniors spend all their assets during their last 5 years of life to pay for advanced illness care.

Journal of General Internal Medicine, 2012^j

Snapshot

ASSOCIATION OF COMMUNITY CANCER CENTERS' FINANCIAL ADVOCACY NETWORK

Launched in 2012, the Association of Community Cancer Centers' Financial Advocacy Network provides tools and resources to oncologists including financial advocacy case-based workshops, online courses, a toolkit, and a forum. The network provides job descriptions and recruitment tools for financial advocacy positions and tools to deliver and improve effective financial advocacy services, including those aimed at communicating with patients, understanding the insurance process, and handling denials and appeals. The [2015 Patient Assistance and Reimbursement Guide](#) offers information about how to use patient assistance programs.

AMERICAN INSTITUTE OF CERTIFIED PUBLIC ACCOUNTANTS (AICPA)

The Elder Planning Task Force of AICPA, the national professional organization for certified public accountants, identifies services, issues, and concerns for CPAs who provide personal financial planning services to older clients and their children. The group develops resources for both professionals and the public. AICPA has partnered with stakeholders to develop the report [A Guide to Financial Decisions: Implementing an End-of-Life Plan](#), which helps individuals and their families address issues related to dependent care, retirement accounts and pensions, insurance, estate planning, and survivor benefits.

NATIONAL CENTER FOR MEDICAL LEGAL PARTNERSHIPS

The [National Center for Medical Legal Partnerships](#) is an emerging national network of hundreds of partnerships between legal aid organizations and medical institutions working to ensure that legal issues related to medical situations are addressed. A medical-legal partnership (MLP) embeds lawyers and paralegals alongside healthcare teams to detect, address, and prevent health-harming social conditions for people and communities. Healthcare outcomes often improve when legal issues are addressed. Moreover, the healthcare institution is often the best place to identify such needs.

Peaceful Death and Dying

While death and dying can be an uncomfortable topic for patients, families, caregivers, and clinicians, it is an important element of advanced illness care. In order to experience death and dying on one's own terms, people need to 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 be provided information about personal rights and choices available to them.

Advanced illness care can support a person's experience of death and dying by eliciting preferences as early as possible, with the understanding that these preferences may change and evolve as an illness progresses. Information on how medical interventions, particularly life-sustaining treatments, affect quality of life is particularly important to help people make appropriate choices. As end of life approaches, people may worry about becoming a burden to their families. They may also feel the need for family members to come together and reconcile if they are estranged or if they disagree with each other or with the individual on care choices. Individuals may want to think about creating plans for death, which could include funeral arrangements or how they would like their life to be celebrated. Advanced illness care should elicit, honor, and support these preferences.

Although most Americans believe it is important to talk with their family about end-of-life wishes, it is currently estimated that fewer than one-third do so.¹² Most people prefer not to think about death and dying, but perhaps more concerning, physicians do not regularly engage in conversations about preferences for medical treatment toward the end of life.¹³ This gap may be due in part to a lack of formal training on end-of-life care with nearly 50 percent of physicians reporting feeling uncertain about what to say.¹⁴

Advanced illness care should capture a person's preferences for death and dying and tailor care to achieve those goals. Using open-ended questions to elicit what people and families think a peaceful death would look or feel like can be helpful in better understanding people's preferences. Retrospectively, care teams can evaluate the quality of discussions and identify communication challenges to address. They can review how well their patients' preferences were honored and how well the needs of families and caregivers were met. Perhaps most importantly, engaging in advance care planning and shared decision making on a regular basis can serve to keep everyone—patients, families, caregivers, and professionals—on the same page and comfortable and confident that a plan is in place.

50% of physicians frequently or sometimes feel unsure of what to say during end-of-life conversations.

Conversation Stopper: What's Preventing Physicians from Talking with Patients about End-of-Life and Advance Care Planning, 2016^k

More than 90% of people believe that having conversations with family about end-of-life wishes is important; fewer than 30% have had these conversations.

The Conversation Project, 2013^l

Snapshot

THE CONVERSATION PROJECT

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care. Working in collaboration with the Institute for Healthcare Improvement, the project provides people with resources and tools to figure out what matters the most. The project provides the **Conversation Starter Kit** to help people put their thoughts together and to talk to loved ones about wishes and expectations for end-of-life care. These tools emphasize individuals as experts on their own wishes. The group has also launched an **Alzheimer's disease and dementia Starter Kit** to assist families caring for loved ones to navigate end-of-life conversations and manage care for loved ones.

USE OF VIDEO DECISION AIDS AT HILO MEDICAL CENTER

Hilo Medical Center, a 276-bed hospital, was the first hospital in the state of Hawaii to make advance care planning part of its standard of care for patients. In early 2013, the hospital provided clinicians, hospice staff, and primary care physicians training and access to advance care planning video decision aids in English, Japanese, Cantonese, Vietnamese, Samoan, Korean, Ilocano, Tagalog, Spanish, and Marshallese. Produced by Advanced Care Planning Decisions (ACP), the videos aim to empower patients and families to consider their preferences, care options, and impact on treatment. ACP Decisions has designed the 10-minute videos to include broad questions and to be accessible to general audiences. A **study led by Massachusetts General Hospital** tracking this pilot program over 21 months found that conversations increased from nearly 0 to 40 percent. Admissions to hospice increased by almost a third in 2013 and by over 50 percent in 2014, compared with 2012.

A NATIONAL MOVEMENT TO TRANSFORM ADVANCED ILLNESS CARE

Aging and the prevalence of chronic disease are central to addressing many healthcare challenges in the United States. Healthcare providers, the federal government, and private insurers are particularly concerned about how to plan adequately for the millions of older Americans with advanced illness who will soon require a wide range of healthcare and social services. As a result, the healthcare community is engaged in conversations about how to embed principles of hospice and palliative care in basic medical care and how best to expand the availability of needed services. However, focusing on healthcare alone is not the solution. Society must better integrate healthcare, social services, and community organizations and efforts, drawing on the strengths that each provides. Faith communities, innovative community-based programs that support conversations about end of life, and national initiatives to help people who want to remain in their homes and out of institutions are playing a growing role. There is palpable momentum for a national advanced illness care movement with clearly defined priorities, goals, and measures to improve people's lives.

National Priorities and a Measurement Strategy for Advanced Illness Care

Setting national priorities has helped to galvanize efforts and drive stakeholders towards shared goals for social change. Examples of such movements in healthcare quality include campaigns such as [5 Million Lives](#), [Partnership for Patients](#), and [Million Hearts](#). The advanced illness care movement has an opportunity and a pressing need to define its value, and to articulate its goals and a measurement strategy that will resonate beyond the healthcare system. A shared measurement and improvement strategy would provide welcome guidance to a wide range of organizations working nationally to improve advanced illness care. NQF has endorsed several performance measures in this area, yet most focus on clinical care. The preferences outlined in this issue brief provide a foundation for advancing person-centered measurement

to ensure that care focuses on what is most important to individuals with advanced illness, their families, and caregivers. Two initiatives—one national and one international—are highlighted here as potential opportunities for aligning measurement in advanced illness care.

International Consortium of Health Outcomes Measurement

With increased attention worldwide on issues of aging and chronic disease, building on an existing international framework may be helpful. The [International Consortium of Health Outcomes Measurement](#) (ICHOM) is a nonprofit organization that seeks to transform healthcare systems globally by measuring and reporting patient outcomes using a standardized approach. In 2016, ICHOM released several measure sets including one focused on older persons and one focused on individuals with lung cancer. Both sets offer opportunities to align measurement in selected areas identified in this issue brief and

offer specifications to support data collection at an individual patient level. Collecting and aggregating this data could be highly valuable in monitoring person-centered outcomes in advanced illness care and benchmarking progress internationally.

Sample International Consortium of Health Outcomes Measurement Measure Concepts

- Autonomy and control
- Loneliness and isolation
- Participation and decision making
- Mood and emotional health
- Caregiver burden
- Activities of daily living
- Pain
- Frailty
- Place of death
- Fatigue and vitality
- Health-related quality of life
- Shortness of breath
- Duration of time spent in hospital at end of life
- Acute complications of treatment

AAPHM and HPNA Measuring What Matters

The **Measuring What Matters** initiative—led by the American Academy of Hospice and Palliative Medicine (AAPHM) and Hospice and Palliative Nurses Association (HPNA)—represents a major advancement in aligning performance measurement among healthcare professionals in the fields of hospice and palliative care. Through a consensus process, this effort proposed a set of 10 quality measures to use for program improvement,¹⁵ many of which address the preference areas outlined in this brief.

Measuring What Matters

- Comprehensive assessment of physical, psychological, social, spiritual, and functional needs
- Screening for pain, shortness of breath, nausea, constipation
- Pain treatment
- Shortness of breath treatment
- Discussion of emotional or psychological needs
- Discussion of spiritual/religious concerns*
- Documentation of surrogate decisionmaker and contact information
- Documentation of preferences for life-sustaining treatment*
- Care consistency with documented preferences
- Global measure of patient and family experiences of care

*NQF-endorsed

Filling Measure Gaps

Many initiatives have identified gaps in the availability of quality measures to drive improvement and incentivize high quality in advanced illness care. Challenges exist in clearly identifying the advanced illness population for measurement purposes. The measure gaps identified—particularly those emphasizing person-centeredness—generally align with the preferences outlined in this brief, and should be considered priorities for measure development. For example:

- **NQF's Palliative and End-of Life Care Project** evaluated 24 performance measures for endorsement and noted important gaps in measures of treatment burden, financial toxicity, caregiver support, and shared decision making.

- The Agency for Healthcare Research and Quality is reviewing [Assessment Tools for Palliative Care](#) based on the National Consensus Guidelines for Palliative Care domains for palliative care. To provide a comprehensive overview of palliative care assessment tools, the project is identifying key issues and research gaps in use of assessment tools for clinical care, quality measurement, and evaluation of interventions. This technical report may provide additional guidance on approaches to developing new measures based on existing assessment tools.

Efforts to fill gaps in these areas should be expedited when possible. The [National Hospice and Palliative Care Organization](#), the [Center](#)

[to Advance Palliative Care](#), and the National Home-Based Primary Care & Palliative Care Network all support data registries, which could provide foundational data sources to advance quality measurement. NQF's Measure Incubator™ now offers a platform for facilitating measure development in priority areas by bringing together measure stewards, data holders, measure developers, and funders to expand the availability of measures, with a priority on person-centered measures. Organizations such as the Pew Charitable Trusts and the Gordon and Betty Moore Foundation, which are working to advance priority quality measures for specific settings where palliative and end-of-life care is received, could further support work to advance measures that really matter to patients and their families.

THE PATH FORWARD

In order to fully integrate the personal preferences of individuals with advanced illness, the healthcare system and policymakers need to address elements such as workforce, payment, measurement, and care delivery models. Achieving more comprehensive care requires expanding the palliative and hospice care workforce and embedding the guiding principles of these disciplines across healthcare, community, and social services.

In January 2016, the Centers for Medicare & Medicaid Services (CMS) started to pay physicians, nurse practitioners, physician assistants, and other clinicians for having advance care planning conversations with patients and family members. Topics can include preferences and goals, advance directives, and end-of-life care choices. However, many questions persist about how to embed advance care planning and shared decision making into

workflows, ensure communication across all providers, align care with a person's preferences, and integrate palliative and end-of-life care. Programs such as [Respecting Choices](#) and [VitalTalk](#) offer helpful tools, but healthcare providers need additional practical guidance to overcome the time and resource barriers they face every day. In addition, if communities had the tools to play a greater role in facilitating conversations around advanced illness care, individuals and families might better understand personal preferences before they engage with the healthcare system.

Building on the movement towards person-centered advanced illness care, the time is now to bridge medical care, social services, and community assistance to form a stronger support network for individuals with advanced illness and their families and caregivers.

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