



CITIZEN VOICES

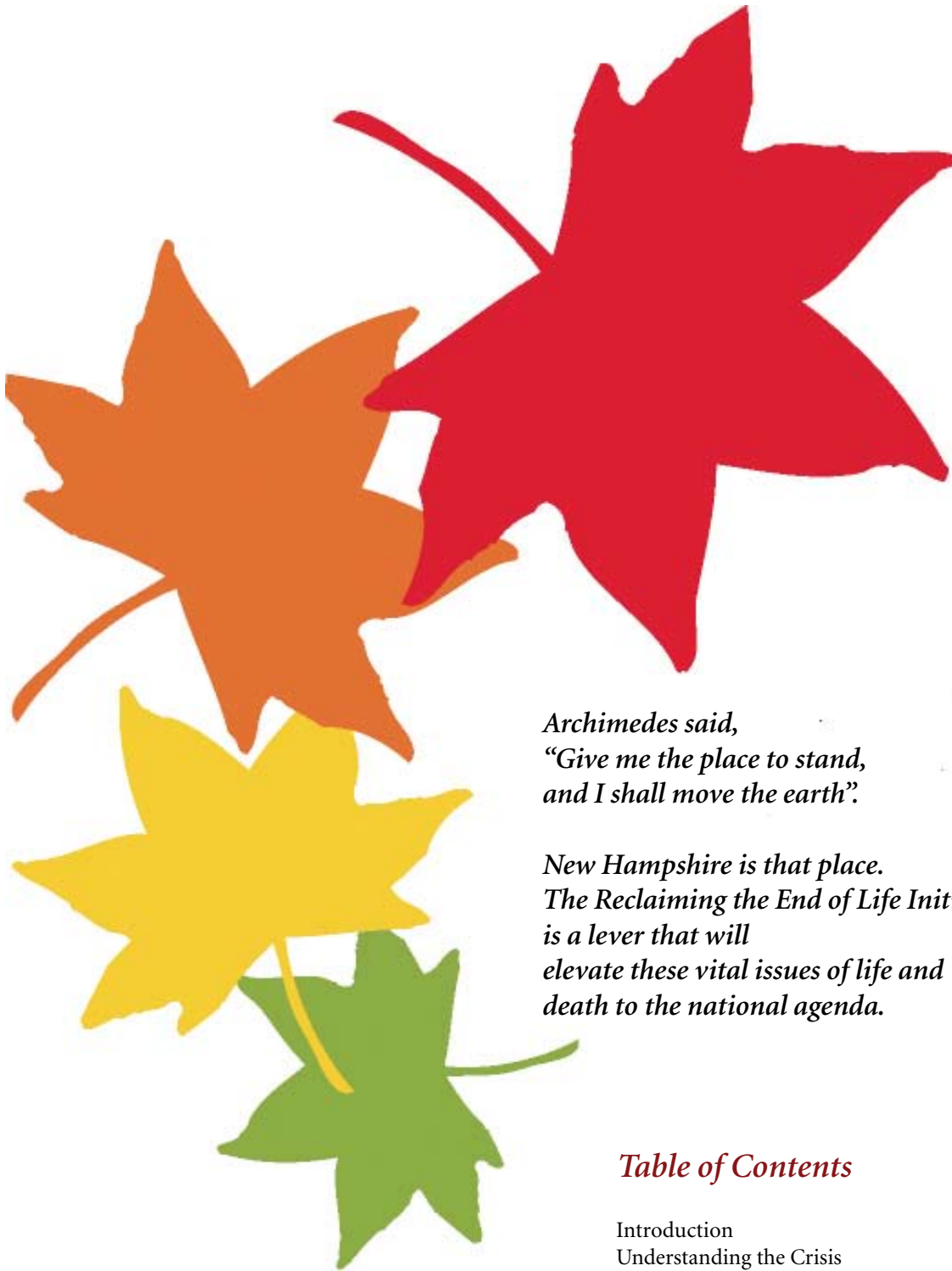
A Report on Aging, Living with Serious Illness and Family Caregiving

The Findings of Citizen Forums

March through July 2007

in

Littleton, Laconia, Manchester, Nashua, Keene,
Concord, Portsmouth and Lebanon



*Archimedes said,
“Give me the place to stand,
and I shall move the earth”.*

*New Hampshire is that place.
The Reclaiming the End of Life Initiative
is a lever that will
elevate these vital issues of life and
death to the national agenda.*

Table of Contents

Introduction	1
Understanding the Crisis	2
Model Programs and Approaches for Caring Well	4
Starting the Conversation	8
What it Means	14
Sponsors/Partners	16
Authors	16
References	17



Introduction

Reclaiming the End of Life is a non-partisan citizen initiative that is meant to compel presidential candidates to address the issues of vital importance to the swelling population of frail elders, chronically ill Americans and the families who care for them. The Initiative is made up of people in New Hampshire and focuses on our state's first-in-the-nation primaries to address problems of national importance.

We have a crisis

In the days that follow national tragedies such as hurricane Katrina's devastation of New Orleans or the collapse of the I-35W Twin Cities Bridge, we often learn that experts had been warning for years of untended problems and a looming catastrophe. The problems had been studied and sometimes, as the story unfolds, we learn that effective solutions exist, that various proven approaches and policies have been proposed but never implemented.

Americans rightly assume that if their elected officials, particularly their President, knew that a catastrophe was coming that would affect every American family, they would do everything in their power to prevent it.

In fact, a demographic tide of elderly and chronically ill Americans has already exposed serious fractures in our nation's health care and social systems. Soon the swelling populations of those in need and deepening shortages of direct care workers – particularly nurses, nursing home staff and home health aides – will overwhelm American families and communities. We still have time to avert disaster, but only if we start now.

The first step is to acknowledge the full extent of the problem and make caring for people through the end of life a national priority. The next President of the United States must be knowledgeable about the components of the current public health concerns and unprecedented coming social challenges. Recent advances in clinical models and the science of health services delivery offer tangible reasons to hope that this crisis can be solved. Many of the clinical and social programs, and residential community approaches that have been developed in recent decades would actually save money for our health care system. Most importantly, such approaches would preserve the dignity and quality of life for millions of frail elders and terminally ill Americans, as well as the families who care for them.

The *Reclaiming the End of Life Initiative* exists to bring attention to this gathering storm and present policymakers with the facts they need, including practical, constructive and affordable steps we can take to safeguard our ill and elderly now, and prevent a national tragedy in the next two decades. For far too long the struggles and suffering of literally millions of aged and ill Americans has gone unseen, their plaintive voices unheard by the body politic. This year in New Hampshire, the Reclaiming Initiative has held forums across the state to survey the needs of ordinary citizens as they face or contemplate the last chapters of life. Their voices will not be ignored.

The Findings contained in this report are striking. These New Hampshire citizens feel passionately about the problems of care and inadequate support for daily life, both for their loved ones and for themselves. They are frightened and frustrated by the gaping holes in the infrastructure of medical care and basic social services for our sick and elderly relatives, friends and neighbors. Even those with advanced degrees and those who work in health care expressed how hard it is to care for parents who are ill or simply living with the accumulated frailties of old age.

Although there is far from unanimity — indeed, significant divergence of opinion on a few issues — what stands out is the high degree to which these citizens concur on fundamental values, concerns and expectations. People most want their dignity respected, their preferences honored, their pain controlled. They want to be at home, if possible, and they want to safeguard their family's well-being.

They endorse strong action on health care reform, medical and nursing education, clinical practice, pain management, governmental oversight, Medicare and insurance coverage, long-term care, and provision of care in rural areas.

“

My mother was suffering from several health issues. She spent 6 days in the hospital. These were horrible. I had to fight for proper pain care and anti-anxiety care. The hospital was sorely understaffed and I often had to do things I was not qualified to do. My father spent the days and I spent the nights.

Our options regarding surgery were not explained and we had to stop a doctor from doing an unwanted procedure. I had no recourse to deal with a doctor in charge who was uncooperative. I need to say the nurses were kind and compassionate... My father and I took care of her at home. We used respite people from hospice, who were wonderful.

—**Patricia L. Patten**, hairdresser,
New Hampshire citizen

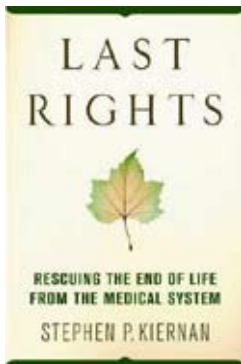
”

“

Pain is soul destroying. No patient should have to endure intense pain unnecessarily. The quality of mercy is essential to the practice of medicine; here, of all places, it should not be strained.²

—Dr. Marcia Angell

”



**INSTITUTE OF MEDICINE
APPROACHING DEATH, (1997)**
DOMAINS AND DIMENSIONS OF
DEFICIENCIES

- Too many people suffer needlessly at the end of life, both from errors of omission and from errors in commission.
- Legal, organizational, and economic obstacles conspire to obstruct reliably excellent care at the end of life.
- The education and training of physicians and other health care professionals fail to provide them the attitudes, knowledge, and skills required to care well for the dying patient.
- Current knowledge and understanding are insufficient to guide and support the consistent practice of evidence-based medicine at the end of life.

Understanding the Crisis

PAIN

The science of pain has advanced, and treatment of conditions such as pain caused by cancer has improved significantly. Despite these successes, studies continue to document inadequate pain control for people suffering from chronic degenerative diseases, including arthritis and osteoporosis.

At least 50 million Americans live with chronic pain that inhibits normal activities. Suffering and impaired function conspire to erode quality of life. Despite notable advances in understanding the physiology of pain and its treatment, the problem of under-treated pain is growing. Comprehensive, interdisciplinary approaches have been proven successful, but many pain clinics have closed because insurance favors high tech, short term interventions and effectively discourages long-term, behavioral and physical therapies for people in pain. Pain assessment and management is minimally included in medical school education. Although pain accounts for more than 20% of medical visits and 10% of prescription drug sales, the search to understand and advance solutions to chronic pain garners less than 1 percent of National Institutes of Health research funds.¹

END-OF-LIFE CARE

Most people want to live out their last days – at whatever age they occur – at home, surrounded by family. Instead, fully 20% of deaths in America occur in intensive care units³, part of the approximately 50% of people who die in hospitals. Nursing homes are the site of about 30% of deaths, while annually just over 20% occur at home.

A 2005 survey of the general public by the Massachusetts Commission on End-of-Life Care found that 84% of respondents agreed that “Dying is an important part of life”, 83% felt “There is special value in getting old” and 77% believed that “Caring for people who are dying is rewarding.”⁵

HEALTH CARE FINANCING

The number of Americans without health insurance rose to 47 million, 15.8 percent of the population, according to August 2007 census figures.⁶ A year of care at home involving three-times-a-week visit services of a home health aide costs approximately \$16,000.⁷

Out of pocket costs of medications are another source of financial stress experienced by patients with serious illness. As with so many other effects of illness, it is not only the individual with the diagnosis who is affected. Each year, 400,000 American families file for bankruptcy because of medical expenses.⁸

Cancer will claim the life of 560,000 Americans this year, second only to heart disease. One in 10 cancer patients has no health insurance. One of every four families with a person undergoing cancer treatment is effectively pauperized by medical expenses and the loss of income. This included 20% of those who have insurance.⁹

AGING AND CAREGIVING

An estimated 53.4 million caregivers in the United States — more than one in five adults — provide unpaid care to people with disabilities and chronic illness. The economic value of this caregiving is between \$257 to \$309 billion, dwarfing both paid home health and long-term care.^{10,11} Family caregivers typically devote 18 or more hours per week.¹⁰

Caregiving takes a toll on the health of those giving care. Family caregivers, who are often an elderly spouse, are at higher risk of serious health problems from the strain of caregiving.¹² Nearly a third of families caring for a person with a chronic, incurable illness reported the loss of most or all of the family’s income, and a third reported the loss of most or all of their life savings.¹³

About 15 million people, most of them seniors, rely on home-based caregiver services today — a number that is expected to double by 2050 when baby boomers start to require such care in record numbers. Many boomers will be scrambling to find the help they need, or be forced to go without care and risk a downward spiral that could put them in a nursing home.^{14,15}

Currently a high percentage of elders live alone – nearly 25% of men and 50% of women 75 years of age or older.¹⁶ This brings with it discernible dangers. Elders who live alone are at high risk for falls or other emergencies that leave them in peril without help.

A study by the National Association of Area Agencies on Aging published in 2006 found half of the nation's cities and communities have no plan in place to meet the needs of boomers as they age.¹⁷

NURSING SHORTAGE — WHO WILL CARE FOR THE ILL AND ELDERLY?

A wide-spread shortage of nurses already exists in hospitals, nursing homes, home health and assisted-living facilities.^{15, 18, 19} Nurses, who are the key professionals caring for America's parents and grandparents, have been aging along with the baby boomers. By 2010, nearly half of all nurses will be over age 50, further exacerbating an already serious national nursing shortage. We don't even have enough faculty nurses to train the nurses we need. U.S. nursing schools turned away 42,866 qualified applicants in 2006 due to insufficient number of faculty, clinical sites, classroom space, clinical preceptors, and budget constraints. In a survey conducted last year, 71.0% of nursing schools pointed to faculty shortages as a reason for not accepting all qualified applicants into their programs.

The shortfall of RNs needed in the United States is estimated between 340,000 to as many as 800,000 by 2020.²⁰

The shortage of paid, paraprofessional direct care workers is even more severe. Low wages and lack of health benefits is a frequently cited cause.¹⁵

LONG-TERM CARE

A Congressional study found that more than 90 percent of nursing homes have too few workers to care for patients.²¹ A Commonwealth Fund study from 2001 estimated that 30 percent of nursing home residents are malnourished because they do not receive enough help in eating from aides who must assist as many as 15 patients at mealtime.²²

Another Congressional study in 2001 uncovered an epidemic of physical abuse in our nation's nursing homes – and not predominantly because workers were mean-spirited, but rather because they became overwhelmed by demands of multiple residents at once and often struck back at confused, aggressive residents. More than 30%, or 5,283, of the nursing homes investigated were cited for abuse.^{23, 24} In most instances described both the employee and resident were victims of short staffing and unrealistic demands on well-intentioned workers. Tragically, nearly 10% of the abuses resulted in serious injury or death.

The reasons it is so difficult to recruit and retain sufficient staff in long-term care facilities are not mysterious. The nursing aides and home health aides that care for America's grandparents, parents and sick children are among our nation's lowest paid workers. Nursing aides typically earn less than \$10 per hour, less than \$21,000 per year, and home care aides less than \$8 per hour or about \$17,000 per year.^{15, 25} And yet, projections suggest as many as half of Americans who live to 65 will enter a nursing home before they die.²⁶

Called to Action

The Institute made broad recommendations for action on the part of clinicians, health systems, medical educators, payers, and the government as a payer, as a funder of research and in oversight.

In 2002, the National Association of Attorneys General (NAAG) chose to address inadequacies in end-of-life care as its priority initiative. Uniquely, they took the position that these issues were a matter of rights, vital for consumer protection. They argued that elderly and ill persons had rights, and patients held reasonable expectations that must be met.

Drew Edmondson, Attorney General (OK), NAAG 2002-03 President



THE CITIZENS' HEALTH CARE WORKING GROUP

The Citizens' Health Care Working Group was established by Congress to "engage in an informed national public debate to make choices about the services they want covered, what health care coverage they want, and how they are willing to pay for coverage." Following six regional hearings held in 2005 with experts, stakeholders, scholars, and public officials, the Working Group issued The Health Report to the American People, a report intended

APPROACHING DEATH



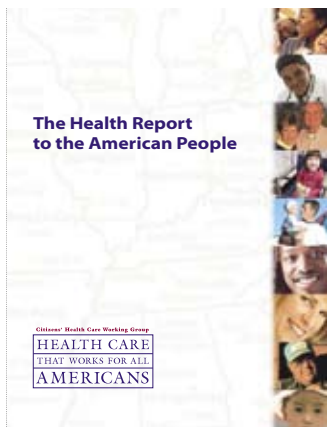
It has been 10 years since the Institute of Medicine released its landmark report, *Approaching Death*. This was a comprehensive survey and analysis of how our nation and

society cares for people facing the end of life. The report was a sobering description of broad deficiencies in care and dysfunctional health care and social systems.

The report described common practices of doctors and hospitals reflecting a fixation on disease, often to the exclusion of caring for patients as persons living with complex needs, and ignoring the families who are often struggling to meet those needs. It described the structures and processes of the health care system that reinforce this narrow focus, and reimburse for disease-based treatments while inadvertently discouraging communication, coordination and comfort-oriented interventions.

Consistent with its charge to advise Congress on matters related to the public health, *Approaching Death* focused mostly on clinical practices and outcomes, and health services delivery. But being frail or facing the end of life is only partly medical. Multiple studies have shown that people identify transportation, being safe at home, feeling connected to a community and concern for their family among their most important needs.²⁷

In *Approaching Death*, the Institute of Medicine attempted to call attention to innovative developments in clinical approaches, residential models, and community-based programs and services.

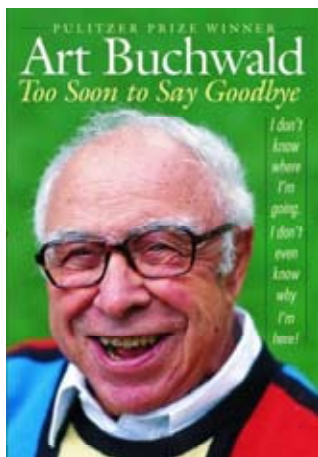


“

How one dies remains in the memories of those who live on.

—Dame Cicely Saunders, MD,
Founder of Modern Hospice

”



Hospice in the 20th century began with the vision of Dame Cicely Saunders, a nurse, who became a social worker and then physician. Dame Saunders founded St. Christopher's Hospice in the south of London, the first residential hospice. Hospice in America began in the 1970s as a counter-cultural response to medicalized dying. It was led primarily by nurses and social workers, but involved a variety of professionals in medicine, ministry and the community at large.

to facilitate a national dialogue on health care reform. In addition, the Working Group made the presentations from its hearings available to the public via the Internet, at www.CitizensHealthCare.gov.

The Working Group heard from thousands of people who believe that all Americans deserve to receive the health care they need, when they need it. In September 2006, the Citizens' Health Care Working Group sent recommendations to the Congress and the President. Its final recommendation stated that, “End-of-life care should be fundamentally restructured so that people of all ages have increased access to these services in the environment they choose.”²⁸

RECOMMENDATION 6

FUNDAMENTALLY RESTRUCTURE THE WAY END-OF-LIFE SERVICES ARE FINANCED AND PROVIDED

- End-of-life care should be fundamentally restructured so that people of all ages have increased access to these services in the environment they choose.
- Public and private payers should integrate evidence-based science, expert consensus, linguistically appropriate and culturally sensitive end-of-life care models so that health services and community-based care can better handle the clinical realities and actual needs of patients of any age and their families.
- Public and private programs should develop and support training for health care professionals that emphasizes proactive, individualized care planning and clear communication between providers, patients and their families.
- At the community level, funding should be made available for support services, including nonmedical services, to assist individuals and families in accessing the kind of care they want for the last days of their lives.

Model Programs and Approaches for Caring Well

There are many reasons to feel hopeful. This truly is one national crisis we can fix. Once we turn our national attention to these problems, we'll find that solutions are within reach.

Beginning with the emergence of hospice care in Britain, over the past 40 years a variety of pro-active, person-centered approaches to care and assistance in living with the frailty of age or illness have developed. In the past 15 years, accelerated development and testing of models of care for people facing the end of life was made possible by carefully planned initiatives of leading health care foundations with philanthropic support of over 220 million dollars.²⁹ Several innovative approaches to care have demonstrated measurably higher quality outcomes without increased costs.³⁰⁻³⁹ Some of those clinical and residential models have now become mainstream, others seem poised to be adopted widely, while still others are promising and deserve attention, but have yet to catch on.

HOSPICE PROGRAMS

Hospice is the gold standard for end-of-life care. Having begun in the 1970s as a social movement and response to medicalized dying, Hospice has matured to become a sophisticated program of medical, nursing, rehabilitation, spiritual, psychological and social support services delivered where the patient lives — usually in their own homes. There are now over 4,000 hospice programs across the country. Over 1.2 million people will be served by hospice programs in 2007, although many of them for just a few days. Medicare pays for hospice care and 46 states have a Medicaid hospice benefit. The Veterans Administration provides hospice coverage for eligible veterans. Military personnel and their dependents are covered for hospice care under Champus/TriCareit.⁴⁰ These are broad insurance benefits covering all medical and support services, including medications needed for care of symptoms related to the terminal diagnosis.

The 1982 law enacting the Medicare benefit requires people to choose between hospice care for their comfort and quality of life, and treatments directed at the disease and the goal of living longer. In the 1980s that made sense, but since then treatments have been developed, including a number of targeted chemotherapy and cardiac drugs, that both improve quality of life *and* enable people to live longer. In focusing on comfort, we now know that hospice often prolongs life. The best known example is Art Buchwald who was expected to die, but instead

thrived under hospice care — as he described in his best selling book, *Too Soon to Say Goodbye*.⁴¹ Research analyzing Medicare data published this year found that hospice patients with congestive heart failure, lung cancer and pancreatic cancer survived an average of 29 days longer than patients with the same conditions not receiving hospice services.⁴²

Hospice care has also been shown to diminish pain in nursing home residents, and the frequency of residents being transferred to hospitals at the very end of life.⁴³⁻⁴⁵ At least three-fourths of people receiving hospice care are able to remain at home through the end of life.

Congress intended hospice to be available under Medicare for the last 6 months of people's lives. Despite this and the documented benefits of hospice, the large majority of hospice patients are served for just a few weeks. The median length of hospice services is only 21 days, and a third of people receive care for a week or less.⁴⁶

PALLIATIVE CARE

Palliative care refers to the discipline of care that hospice represents. The definition of palliative care is interdisciplinary team-based care for patients with life-threatening illness or injury that seeks to address physical, emotional, social and spiritual needs, and to improve quality of life for the affected person and his or her family.

Palliative care programs have grown from the successful approach that hospice represents to serve patients in settings and circumstances that hospice programs have had difficulty reaching. Efforts funded by the Robert Wood Johnson Foundation and other major American foundations have supported development of programs to deliver palliative care in challenging settings, serving people with a variety of ages, diagnoses and living situations.^{31, 47-50}

In the last decade, innovative programs have developed to serve patients with cancer who are undergoing active treatment, end-stage renal failure undergoing dialysis, HIV disease and concomitant psychiatric illness, veterans, residents of isolated rural and frontier communities, and children in specialized pediatric hospitals. 50,000 children die each year – mostly from birth defects, neurological disorders and cancer. Palliative care for children is rapidly expanding.^{51, 52}

Medicare does not provide coverage for palliative care in a manner comparable to hospice care. Despite the lack of a designated payment for services, in the past decade nearly a fifth of American hospitals have developed hospital-based clinical palliative care services. These teams offer core medical and nurse-consultant services often complemented by social services and spiritual care for patients with serious illness and their families. Palliative care assists patients in clarifying goals of care, making difficult decisions, controlling physical symptoms, alleviating emotional distress, and completing personal affairs and relationships. Palliative care programs also support families in adjusting to the impact of the person's illness, the challenges of caregiving and the pain of grief.

In September 2006, Hospice and Palliative Medicine earned full subspecialty status from the American Board of Medical Specialties

ALTERNATIVE APPROACHES TO LONG-TERM CARE: EDEN, GREEN HOUSE, WELLSPRING, PIONEER NETWORK

The Eden Alternative is the most well known and widely respected “alternative” model of long-term care. Dr. Bill Thomas, founder of the Eden Alternative, refers to himself as “abolitionist” of nursing home. In Eden Alternative nursing homes and in the small, 8 to 10 person Green House residences that Dr. Thomas has developed, there are plenty of staff to spend time with each resident. Plants, pets and children are a natural part of life in these small communities. And everyone in the community – from the residents to nursing aides to the directors and administrators – has a voice in decisions that affect community life.

Similar initiatives include Wellspring long-term care facilities and the Pioneer Network that strive for quality of resident-centered care, but also on improvements in the workplace for nurses, aides and support personnel. Despite higher levels of staffing, offsetting savings make these approaches cost effective. So far, these approaches are still seen as “alternative” to the large majority of nursing homes, but they are gradually taking root and blossoming here and there across the country. Experience shows that they are universally well-accepted and effectively control costs through continuity of care, fewer emergency hospitalizations and dramatically lower staff turnover.

“

With our nation's aging demographic mix and the complexity of serious health issues facing many people, palliative care is becoming an increasingly important component of the continuum of care all people are entitled to.”

—Donald Schumacher, Psy.D.
President and CEO, National Hospice and Palliative Care Organization

”

“



We must teach ourselves to see Long Term Care facilities as habitats for human beings rather than institutions for frail and elderly. We must learn what Mother Nature has to teach us about the creation of vibrant, vigorous habitats.

—William H. Thomas, MD,
Founder, The Eden Alternative

”

“

Underlying ageism can explain, in part, why this crisis receives less attention than it warrants. Older people receiving care are deemed disposable and without value.

—Dr. Robert Butler,

Co-Director of The Caregiving Project
for Older Americans and President and
CEO of the ILC-USA

”

“



PACE did the impossible for my mother. I never thought she would be able to live with us again.

”

GERIATRIC CASE MANAGEMENT

Professional Geriatric Care Managers (PGCMs) are health and human services specialists who help families care for older relatives, while encouraging as much independence as possible. The PGCM may be trained in any of a number of fields related to long-term care, including, but not limited to, nursing, gerontology, social work, or psychology, with a specialized focus on issues related to aging and elder care. The PGCM acts as a guide and advocate – identifying problems and offering solutions.

A geriatric care manager helps coordinate the care of an elder. This often includes conducting assessments to identify problems, eligibility for assistance, and need for services; coordinating medical services, including physician contacts, home health services and other necessary medical services; screening, arranging and monitoring in-home help or other services; reviewing financial, legal, or medical issues and offering appropriate referrals to community resources; providing crisis intervention; ensuring everything is going well with an elder and alerting families to problems; and assisting with moving an older person to or from a retirement complex, care home, or nursing home.

PACE – PROGRAMS FOR ALL-INCLUSIVE CARE OF THE ELDERLY

PACE programs are modeled on the system of acute and long-term care services developed by On Lok Senior Health Services in San Francisco, California. The PACE model addresses the needs of long-term care clients and the interests of providers, and payers. It was tested in the 1980s by Medicare and adopted as a benefit in conjunction with state Medicaid. For most participants, the comprehensive service package permits them to continue living at home while receiving services rather than be institutionalized. <http://www.cms.hhs.gov/pace/>

An interdisciplinary team, consisting of professional and paraprofessional staff, assesses participants' needs, develops care plans, and delivers all services (including acute medical care and skilled nursing facility services when necessary) which are integrated for a seamless provision of total care. PACE programs provide social and medical services primarily in an adult day health center, supplemented by in-home and referral services in accordance with the participant's needs.

ACCESS TO SERVICES

New Hampshire's ServiceLink is a great example of a collaborative effort among state agencies and community-based organizations, some with federal funding, to serve elders. ServiceLink is a statewide network of community-based agencies and offices providing information and referrals to support services and resources for older adults, adults living with disabilities, chronic illness, and their families and caregivers. It is one-stop shopping for people who need help.

ServiceLink Resource Centers emphasize the “front end” of the consumer process with the objective of improving access for consumers, reducing duplication of effort, and enhancing coordination. Each SLRC is staffed with a manager, a Long Term Support counselor, and a referral specialist. The ServiceLink Resource Center team works in partnership with community leaders and providers to develop solutions to service gaps. ServiceLink is assisted by web-based tools and supported by the community, New Hampshire's Division of Family Assistance Family Services Specialists, Bureau of Elderly and Adult Services Long Term Care nurses, Adult Protective Services social workers, and Home and Community Based Care case managers. www.servicelink.org or 1-866-634-9412

ACS NAVIGATORS

The American Cancer Society's Navigator program is an example of serving patients recently diagnosed with a serious illness, like cancer, ensuring that they gain access to the diagnostic tests and recommended treatments for their disease, as well as their well-being.

Navigators assist people diagnosed with cancer in gaining access to the resources and services they need for treatment, and for their and their family's well-being. Navigators are trained to listen, learn about the individual needs of a person living with cancer and put together a tailor-made plan of action. ACS Navigators can provide people with referrals to an array of community services, including supportive care, such as Reach To Recovery, Look Good...Feel Better and I Can Cope.

ACS Navigators can:

- Provide extensive cancer information
- Assist in locating local and national resources
- Arrange for durable medical equipment such as wheelchairs, walkers and beds
- Coordinate transportation and lodging
- Help people obtain wigs, hats and prostheses resources

People living with cancer can call 1.800.ACS.2345 to find a Navigator in their own community. Navigators reduce barriers to treatment, particularly by people living in poverty, in inner cities, as well as in isolated rural areas – by helping to arrange transportation, providing education in pain management and securing needed durable medical equipment.

VILLAGE MUTUAL-ASSISTANCE COMMUNITIES

A hopeful trend to watch is the emergence of naturally occurring retirement communities, or NORCs, which are often called villages. These are a community of neighbors who come together to share resources and help one another with basic things. Building from the early example of Boston's Beacon Hill Village, members pay annual dues, typically \$350 to \$1,000 for an array of household needs like grocery shopping, shoveling snow, transportation and fixing things around the house. Some services are bartered or banked – one member helps preparing a holiday meal for out-of-town guests, while another helps filling out Medicare forms, and another does minor plumbing.

There are over 100 such communities which currently exist, or are in the process of forming. Although these NORCs, or villages, are not government programs, local and state governments, most notably New York State, have supported early development of several self-help communities. Congress included these communities in the 2006 Older Americans Act.⁵³

We now know that this is one crisis that can be fixed – it will not be easy, but dramatically better outcomes are clearly feasible and affordable.



“

The call came from the assisted living facility on Mother's Day Night. 'We found your mother unresponsive in her chair.' Knowing my mother was physically worn, emotionally beleaguered and spiritually frustrated after living seven years with her advancing dementia, I received this news with both apprehension and relief. Perhaps my mother's long-awaited time of release from what she called "not living" had come. But, no! When I asked the nurse if they could simply put my mother to bed and make her comfortable, she informed me, 'The paramedics are already here, preparing her for transport.' 'This', I thought, 'even though they knew my mother's wishes...

—Ed Koonz,
Pastor, New Hampshire citizen

”



photo: WestRidge Creative

Starting the Conversation in New Hampshire

The findings of scientific research and recommendations of institutes and panels, even when mandated by Congress, can be gradually lost in the endless river of information and 24 hour news cycles that mark contemporary life.

Democracy offers a way of calling attention to the things that matter most to people. The presidential primaries in New Hampshire and Iowa are the closest thing to pure representative democracy that can be found in America today.

At the Citizen Forums participants from across New Hampshire were asked to consider and rate a number of ideas and proposed approaches to health care and social support that have been developed over the past two decades. The facts, approaches to care and specific ideas that were presented had been distilled from recommendations of formal bodies – of Institute of Medicine reports, as well as governmental and professional associations and patient advocacy groups – and published reports of innovative models of care that have demonstrated great promise and are worthy of consideration for adoption nationally.

LISTENING TO THE VOICES OF NEW HAMPSHIRE

These Forums enabled citizens to consider and decide what policy makers should do to improve care and support for frail elders, people who may be dying, and family caregivers. Over the course of 2 1/2 hours, citizens were presented with recommendations distilled from the Institute of Medicine, the Citizen Health Care Working Group, as well as from over two decades of expert panels and advocacy groups addressing the end of life.

Using the participant-response technology, these citizens generated data as they expressed their values and rated proposed steps that can be taken by policy makers and leaders of health care and social services.

The dissatisfied dead cannot noise abroad the negligence they have experienced.⁴

—Dr. John Hinton

The Reclaiming the End of Life Initiative utilized a naturally occurring affinity network of community-based Senior Centers, Aging Services, hospital-based home health, hospice and long-term care providers, as well as faith communities and public libraries to reach out to New Hampshire citizens. Over 460 people participated in the 8 Citizen Forums held across the state.

During the first Citizen Forums, participants were asked to identify any items that were unclear and to suggest important questions that seemed to be missing. The item list was refined for the fourth and subsequent Citizen Forums. (A complete set of items is available by request at www.ReclaimTheEnd.org)

This report is timed to enable candidates for President of the United States to hear the voices of these New Hampshire citizens in time to respond to their concerns and priorities in crafting proposed policies and social programs.

PROFILE OF PARTICIPANTS

A total of 463 participants attended the Citizen Forums. The majority of participants were white (96.8%), middle-aged or older, and female. Three-fourths (76%) were women and 24% men. Fifty-five percent were 45-64 years old and 32% were older than 64. A minority (9.4%) were 25-44 years old or younger than 25 (3.5%).

Fifty-nine percent had employer-based insurance, 26.5% Medicare and 7.1% reported self-purchasing insurance, and 1.8% had VA benefits.

The Citizen Forum participants were generally well-educated; 39% had a graduate degree, 30.6% a bachelor's degree, 12% had attended college without receiving a degree, 11% had attended vocational school. Only 6.2% had completed formal education with high school diploma.

Participants were asked a series of questions designed to identify what is most important to them when they think about the waning phase of life for themselves or someone they love. The individual items were adapted from surveys, public polls and interview studies conducted over the past 25 years. It



photo: WestRidge Creative

is not surprising that a majority of people would find the listed values and concerns to be relevant and important. Therefore, this report highlights those items that were felt by the large majority – 70% or above – to be very or extremely important.



photo: WestRidge Creative

WHEN THEY THINK ABOUT THE “WANING PHASE OF LIFE”, THE OVERWHELMING MAJORITY OF THESE NEW HAMPSHIRE CITIZENS SAID THESE ITEMS WERE VERY OR EXTREMELY IMPORTANT TO THEM:

- Honest, clear communications with doctors and health care providers – 96%
- Having my choices honored – 95%
- Having my dignity respected – 94%
- Having pain controlled – 91%
- Timely referrals to palliative care and hospice – 92%
- Adequate insurance coverage – 93%
- Not leaving my family with debt – 91%
- Being able to communicate – 90%

ATTRIBUTES OF CARE AND PERSONAL EXPERIENCE THAT WERE RATED AS IMPORTANT OR VERY IMPORTANT BY 80% OR MORE PARTICIPANTS INCLUDED:

- Making sure I do not suffer – 87%
- Clear and simple health care billing – 84%
- Having services at home paid for – 86%
- Being physically safe at home – 86%
- Protection from fraudulent and predatory business practices – 81%
- Attention to my emotional well-being – 86%
- Help making medical decisions that are true to my values – 88%
- Smooth transitions from curative treatments to care directed at quality of life – 89%
- Having a residential hospice available if I need it – 82%
- Continuity of care between appointments and among health care professionals – 84%
- Not being abandoned by health care professionals – 87%
- Not losing all our savings – 81%

OTHER ASPECTS OF CARE DURING THE WANING PHASE OF LIFE THAT WERE STRONGLY FAVORED BY 70% OR MORE PARTICIPANTS WERE:

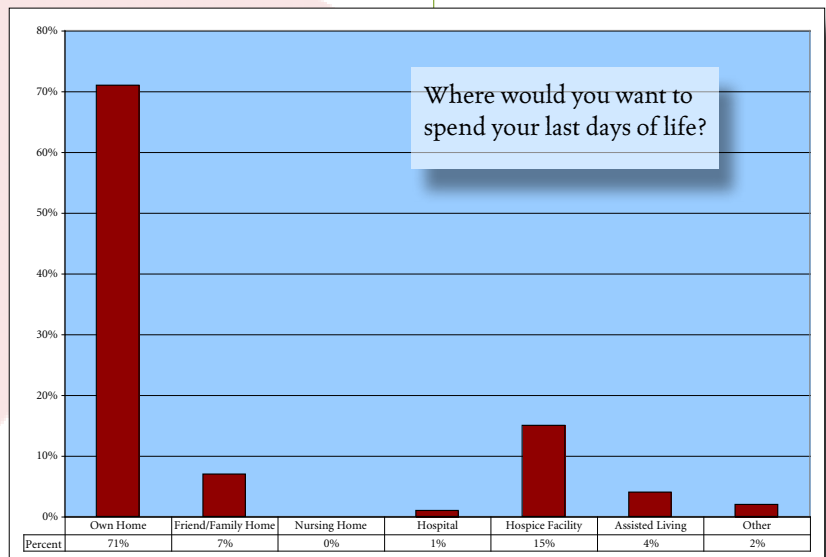
- Not being a burden to my family – 77%
- Help with bowel and bladder control – 75%
- very important by 30% and extremely important by 45%.
- Being at home – 72%
- Personal care – dressing, grooming, toileting – 78%
- Transportation for my needs and activities – 71%
- Help taking care of loose ends in my affairs – 71%
- Help achieving a meaningful closure to life – 73%

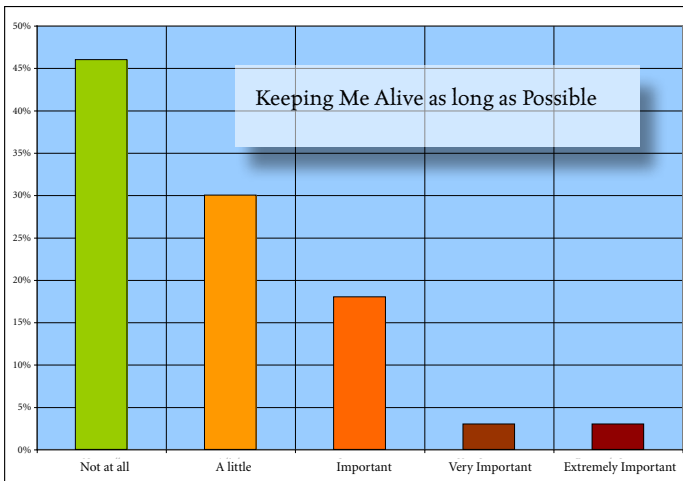
WHERE WOULD YOU WANT TO SPEND YOUR LAST DAYS OF LIFE?

- **The large majority (71%) want to spend their last days at home.** Less than 1% of participants indicated they would want to be in a hospital and not a single participant said that they would want to be in a nursing home during the last days of life.

HOW IMPORTANT IS IT TO YOU TO SPEND THE LAST DAYS OF YOUR LIFE IN THE PLACE YOU CHOSE?

- **71% said it was very to extremely important.**



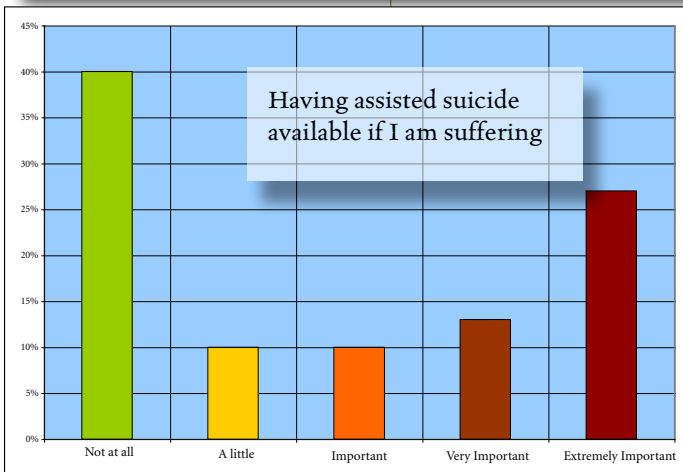


In contrast to the strong endorsement of the values and characteristics listed above, **less than 50%** of participants felt that the following items were very or extremely important:

- Having state-of-art life-saving treatments – 37%
- Keeping me alive as long as possible – 7%
- Not having too many health professionals involved in my care – 48%
- Attention to my personal appearance – 48%
- Estate planning services that can come to me if I am living alone – 41%
- Leaving a legacy to my family – 46%
- Having people pray with me – 43%
- Having people to pray for me – 42%
- Help planning my funeral – 26%

THE CONTROVERSIAL, CULTURALLY POLARIZING TOPICS OF ASSISTED SUICIDE AND EUTHANASIA DREW PREDICTABLY MIXED RESPONSES FROM PARTICIPANTS:

- **Having assisted suicide available if I am suffering** – 40% felt that it was very or extremely important — while 39% rated it “not at all” important.
- **Having an injection to cause death (euthanasia) available if I am suffering** – 34% felt that it was very or extremely important — while 40% felt that it was “not at all” important.



WHAT DO YOU WANT POLICY MAKERS TO KNOW...

Then we asked Citizen Forum participants what they want policy makers to know as they craft public policy to improve care for frail elders and incurably ill people, and support for family caregivers.

The ideas on which this survey was based were distilled from a variety of formal recommendations for improving care and family support by professional organizations, official expert panels, such as the Institute of Medicine or Citizens Health Care Working Group, and patient and citizen advocacy groups. It is not surprising, therefore, that most items were endorsed by the majority of participants. A full set of items and rating scores is available at www.ReclaimTheEnd.org under the Citizen Voices tab. **This report highlights items that were rated agree or strongly agree by 80%, or more of participants.**

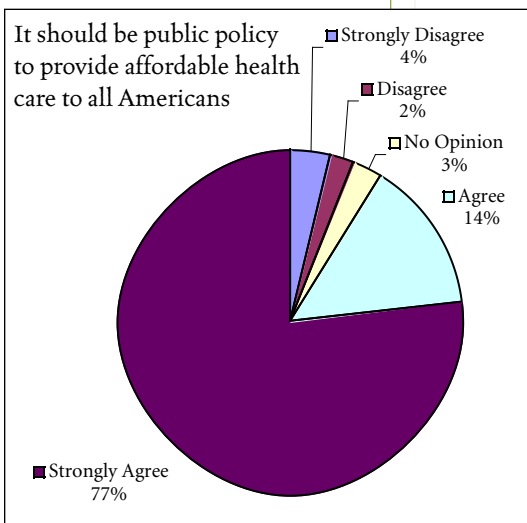
ON HEALTH CARE

Over 97% of New Hampshire citizens surveyed feel the US health care system has major problems (47%) or is in a state of crisis (49.8%).

They are looking for strong action!

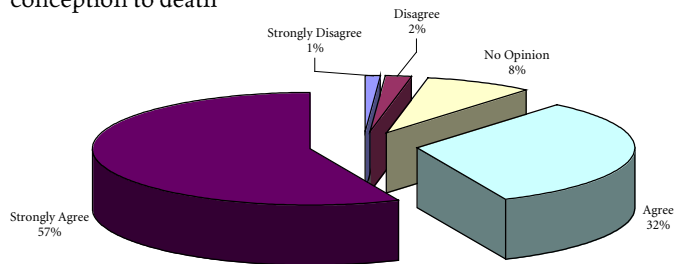
These citizens expressed strong opinions that are pertinent to **health care, especially pain management, elder services, hospice and palliative care.**

- **91%** believe it should be public policy to provide affordable health care to all Americans
- **85%** would require the National Institutes of Health to spend at least 1% of annual appropriations on research into pain management and palliative care
- **91%** would require palliative care to be available in all residential long-term care and acute clinical settings as a condition for licensure and accreditation
- **96%** would require the Centers for Disease Control to study and monitor health aspects of pain management as a public health concern



- **84%** would require government agencies and professionals to promote effective pain prescribing while preventing diversion and falsification of prescriptions
- **94%** want to revise or revoke federal and state regulations that are barriers to effective pain prescribing
- **90%** would require government-subsidized Community Health Centers to include hospice and palliative care as core services
- **89%** feel strongly that insurance companies with unscrupulous business practices should be prosecuted and fined

Willing to pay a modest percentage of income across their working life for appropriate, timely comprehensive care from conception to death



- **88%** say they are willing to pay a modest percentage of income across their working life for appropriate, timely comprehensive care from conception to death.

- **96%** want paperwork of billing and documentation streamlined to allow clinicians to spend more time with patients
- **Over 91%** believe electronic medical record formats must be standardized enabling transfer of patients' health records between doctors and health care facilities
- **94%** want quality improvement efforts to include a focus on continuity of care between health care providers and facilities
- **97%** want improved collaboration between mental health and public health programs to meet the needs of frail elders
- **81%** feel Medicare should reimburse physicians for counseling, care planning and shared decision-making at a level consistent with the time and complexity of those services
- **88%** Medicare and Medicaid should cover basic dental care, including dentures.
- **90%** would require health services to respect diversity of religious beliefs and customs
- **83%** want to establish standards for licensing and accreditation and require health care institutions and professionals to demonstrate culturally competent practices
- **83%** want to ensure that medical translators are available when needed

ON MEDICAL AND NURSING EDUCATION FOR PAIN TREATMENT, AGING AND PALLIATIVE CARE

THEY WANT THEIR DOCTORS AND NURSES TO BE WELL-TRAINED AND SKILLED IN CARE OF ELDERLY AND DYING PEOPLE.

- **97%** believe medical and nursing students must be taught basic knowledge and skills of:
 - ✓ Medical decision-making
 - ✓ Pain & symptom management
 - ✓ Communication
 - ✓ Care for frail elders
 - ✓ Nursing home management
 - ✓ Home visiting
 - ✓ Estimating life-expectancy
 - ✓ Patient and family-centered care
- **97%** agree – including **82.7%** who strongly agree – that **faculty** of medicine and nursing schools should be required to have knowledge and skill in geriatrics, palliative and end-of-life care

A MATTER OF RIGHTS

In 2002, the National Association of Attorneys General chose to address inadequacies in end of life care as its priority initiative. They took the position that these issues were a matter of rights that are vital for consumer protection. They argued that elderly and ill persons had rights and patients held reasonable expectations that must be met.

In the course of their 3-year effort, the Attorneys General association defined three questions that any health care consumer had a right to ask – and have answered Yes.

The *Reclaiming the End of Life Initiative* has built upon these questions, adding definition and a fourth focus on family caregivers.

- Will my pain be managed?
- Will my wishes be known and honored?
- Will I receive competent care?
- Will my family be supported?

These four questions — and the more specific questions they suggest — resonated with the New Hampshire citizens who participated in the 8 Citizen Forums held throughout the state.

Will my pain be managed?

- Will my doctors and nurses be adequately trained in pain assessment and treatment?
- Will my doctors have passed an examination of minimum knowledge in pain management?
- Will my doctors feel able to prescribe the type and amounts of medicine I need to control my pain?
- Will my pharmacy carry the pain medications my doctors prescribe for me?

continued on page 13

Of the 2.4 million Americans who are expected to die this year, 730,000 will be military veterans. The typical veteran who will die in 2007 and 2008 will be 81 with service to our country during World War II. The Veterans Administration provides hospice coverage for eligible veterans.

Chronic conditions, including pain from combat injuries, are increasingly common among younger veterans. Thankfully, many young men and women who sustain life-threatening injuries in theaters of war in the Middle East are being saved. However, they are returning to life with special needs and ongoing medical problems that require higher levels of medical care and support to live productive and satisfying lives. We have a commitment to them.



- **Over 90%** would require medical and nursing schools to teach addiction prevention and treatment
- **91%** would require medical and nursing schools to teach pain management as a requirement for school accreditation and governmental subsidies.
- **94%** would require medicine and nursing schools to teach the health effects of caregiving and support for family caregivers
- **91%** would require physicians to pass tests of basic knowledge and skills in pain management as a condition for being licensed to practice medicine
- **89%** would require physicians to pass tests of basic knowledge and skills in pain management as a condition for being licensed by the DEA to prescribe pain medications
- **86%** want medical and nursing schools to educate students regarding the indications for and use of complementary therapies
- **86%** want medical and nursing schools to include core content in ethnic and cultural norms and preferences for health care decision-making.

POST GRADUATE MEDICAL TRAINING

- **95%** believe Medicare should require primary care residency and fellowship training to include palliative care and geriatrics
- **93%** believe primary care specialty certification exams should test for basic attitudes, knowledge and skills in geriatrics and palliative care

ON ELDER SERVICES AND LONG-TERM CARE

NEW HAMPSHIRE CITIZENS SURVEYED WANT MAJOR CHANGES IN LONG TERM CARE.

- **96%** of Citizen Forum participants want to see expanded assisted housing alternatives where elders not needing skilled nursing care can live independently
- **94%** would set and enforce recommended minimum staffing requirements for nurses and aides in nursing homes and assisted-living facilities
- **96%** would require that nursing aides in long-term care receive a “living wage,” including health care coverage
- **96%** want improved transportation for frail elders and physically challenged people
 - **87%** want to expand and implement Eden and Greenhouse models of long-term care facilities with higher staffing levels, support for paid caregivers and regular involvement of children, pets and plants
 - **93%** want to expand and enhance use of music therapy, art therapy and pet therapy
 - **82%** want Medicare to reimburse for personal geriatric case management services
 - **81%** would provide tax deductions for long-term care insurance premiums

ON HOSPICE AND PALLIATIVE CARE

THEY WANT TO SEE HOSPICE AND PALLIATIVE CARE BECOME ROUTINE.

- **94%** would mandate coverage for adult and pediatric hospice and palliative care through all private insurers, state Medicaid, and state employee-based coverage
- **93%** would want a residential hospice available if they needed it, including 22% who felt it was very important and 60% extremely important
- **80%** would expand access to hospice under Medicare for life-threatening conditions, by removing current requirements of a 6 month life-expectancy and the need to give up treatments directed at the disease and intended to prolong life
- **87%** would make financial support available for practicing health care professionals to further education and training in palliative care

ON SUPPORT FOR FAMILY CAREGIVERS

- **87%** would expand family leave for caregiving
- **Over 80%** would extend Medicare coverage to individuals who lost employer-based health insurance due to family caregiving responsibilities for a Medicare-eligible person.
- **81%** would provide Medicare and insurance coverage to support hired aides to enable respite care in a family's home
- **87%** would expand family leave for caregiving
- **81%** would extend Medicare coverage to individuals who lost employer-based health insurance due to caregiving responsibilities
- **87%** would expand respite care for frail elders or physically ill people for up to two weeks in an assisted living or nursing home
- **80%** favor providing bereavement support to spouses and grieving family members through the health care system and aging services

ON RURAL CARE FOR SERIOUSLY ILL PEOPLE AND THEIR FAMILIES

THEY WANT ATTENTION TO AGING, CAREGIVING AND DYING IN RURAL COMMUNITIES.

- **88%** want the government to relax restrictions on rural "Critical Access Hospitals" to allow them to care for hospice and palliative care patients
- **96%** would require pharmacies serving rural communities to carry basic medications needed for pain management and palliative care
- **86%** feel Medicare payments should be adjusted to cover true costs of services in rural areas
- **87%** want Medicare and Institutes on Health to fund and test regional models of hospice care for rural residents

A complete set of questions and results is available at www.ReclaimTheEnd.org under the *Citizen Voices* tab



A MATTER OF RIGHTS...continued

Will my wishes be known and honored?

- Will I be helped to complete an advance directive?
- Will my advance directive be kept on file so that it is available when and where I need it?
- Will the doctors read it?
- Will doctors and others make a good faith effort to follow my wishes?
- Will my family be allowed to make decisions for me if I can't speak for myself and an advance directive can't be found?
- Will I be forced to have treatment I don't want?
- Will I be forced to give up treatments that I do want?
- Can I have a DNR order and still have treatment to keep me alive? (i.e. be admitted to the hospital? Have antibiotics for infection? Have surgery?)

Will I receive competent care?

- Will the treatments for my illness be consistent with current standards of care?
- Will my care be coordinated between visits and the different doctors involved in my treatments?
- Will I know whom to call if I have a problem at night or on a weekend?
- Will my doctors know what medicine I have been prescribed by other doctors?
- Will there be enough nurses in the hospital to care for me?
- If I don't speak English, will there be interpreters available so that I can talk with my doctors?
- If I am seriously ill, will I have the medicines at home to treat frightening symptoms, such as pain or shortness of breath?

continued on page 15

“

Fundamental reforms are required to ensure that poor, sick, disabled and frail elderly – as well as children and others in need – have access to adequate health and long-term care.

Reforms must be based on sound policy; there are ways that have proven effective in many states. These include buying prescription drugs more cheaply, properly managing the care of those with chronic conditions, and redirecting spending more toward home and community-based care and less on nursing homes.

—Bill Novelli, CEO AARP

”

What it means

The issues that surround aging, dying and caregiving understandably evoke strong feelings.

Once they move beyond the cultural tendency to avoid these subjects, people express concerns about the kinds of care their family members will receive. They are concerned about how they will be cared for when they eventually face the end of life, and the impact of their illness will have on their children, and others.

It is no surprise that over 75% of participants were women. These issues carry particular interest for women. The majority of family caregivers are women. By and large, women outlive men and are therefore more likely to live alone, without a spouse to care for them, and are more reliant on social services.

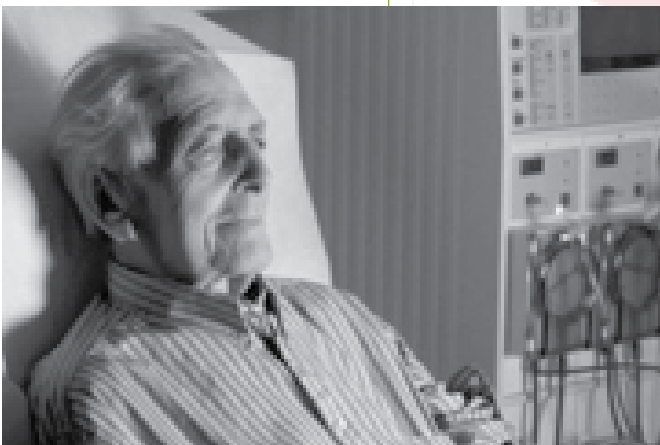
The concerns and preferences of these citizens carry important policy implications.

Elected officials and public policies cannot accomplish all that needs to be done – this is truly a social and cultural challenge. However, elected officials and public policies can influence the political and social climate in which services to frail elders and chronically ill people are provided, paid for and overseen by public and private sectors. Both the executive and legislative branches of government have the authority to commission studies, hold hearings and propose new or updated laws. The President on the federal level and governors of each state appoint department heads who set the tenor of administrative oversight, the manner in which regulations are interpreted and the intensity in which they are applied.

Participants in the Reclaiming the End of Life Citizen Forums want policy makers to know they support:

- Requiring adequate staffing and living wages for aide-level workers in long term care
- Setting standards for training of physicians, nurses & allied clinicians – as a condition for licensure, certification and public financial support
- Removing regulatory impediments to effective pain management
- Eliminating the arbitrary distinction between “curative” treatments and palliative care, including hospice
- Requiring health insurance companies to include hospice and palliative care as a basic benefit
- Establishing clinical standards that reflect reasonable expectations of patients and families
- Publishing ‘report cards’ that grade hospitals, nursing homes, home health and hospice organizations on pain management, honoring of patient preferences, and levels of staffing
- Providing funding for Senior Centers & Aging Services to enhance community-based services people’s needs
- Funding research into health service delivery to promote a continuum of care with efforts to cure and treat diseases proportionate with efforts to alleviate symptoms and improve quality of life

BARRIERS AND OPPORTUNITY FOR LEADERSHIP



There is good news in this report that gives us hope to meet the unprecedented challenges we face at this time in our nation’s history. Many of the basic elements and tools required for clinical and social change of this magnitude have already been developed. Alternative models of health care and residential assistance that have been developed over the past 15 years hold promise for achieving higher quality of life, with no greater costs. When caregivers are overwhelmed or become ill themselves from the strain of caregiving, the frail person becomes a “patient” and costs soar. When families are supported in caregiving, caregiving tends to remain a family matter and costs are controlled.

The steepest barrier to resolving the problems experienced by elders, chronically ill people and family caregivers is that few people are

talking about them. It is ironic that during a period when virtually every family of baby boomers has been caring for a parent or in-law during the waning phase of life, as a generation and culture, we just don't want to think about it.

Fear of death and of physical frailty and dependence influences the way we approach the end of life – or rather avoid approaching it – and not just in health care, but also in our workplaces, our schools, even our faith communities. Cultural aversion underlies the reluctance of elected officials to engage this crisis. The problems of frail elders and dying people seem depressing and the challenges of delivering reliable, high quality services seem too complex and daunting to yield any success. It is often easier to divert discussion to other issues when these topics are raised.

Our nation can no longer afford to be distracted. As hard as these challenges of caring well for people through the end of life are, they will get harder and more expensive to meet the longer we delay.

Real leadership is needed. Over months of planning and conducting the Citizen Forums, New Hampshire citizens made it clear that they are worried about the last chapter of their and their family members' lives, and that they are hungry for leadership.

Their values could hardly be stronger. The New Hampshire citizens who participated care deeply about their families and the effects that illness and caregiving have on one another.

The things they hope for are achievable. Goals of comfort, dignity, communication and support for their families come to the fore when people contemplate the waning phase of life.

Health care must change, but that won't be sufficient.

Often, care for people in the last chapters of life is seen only through the lens of health care. It is true that many of the problems confronting aged and ill people – though not all – would be alleviated by comprehensive health care reform.

But aging, dying and caregiving are fundamentally personal for individuals and for their families. These are commonly difficult, frequently poignant, experiences, but also often rich times of life for individuals and those who love them. Beyond health care reform, Citizen Forum participants want to live fully through the “waning phase of life.” Cultural leadership is needed to ensure frail elders and chronically ill people are not seen as expenses to be managed, but as people who are valued.

The New Hampshire citizens represented here support putting policies in place to improve access and quality of health care. However, they do not want the government or professionals to take over control. They prefer to live and be cared for at home, whenever possible by family.

Commensurate with the magnitude of the challenge before us are historic opportunities for political, social and cultural leadership. The next president will be sorely tested to preserve basic human values during unprecedented circumstances.

It is often said that the moral worth of a civilization can be gauged by the manner in which it treats its most vulnerable members. Our nation will grapple with difficult decisions involving competing priorities and limited resources. By his or her words and actions, the next president can influence the evolution of western civilization and culture.

A MATTER OF RIGHTS...continued

- If I have an incurable illness, will I be forced to choose between treatments for my disease and comprehensive care for my comfort and quality of life?
- Will my records be available to the different caregivers who help care for me?
- If I have to live in a nursing home, will there be enough nurses and nurses aides in the facility to care for me?
- If I have to live in a nursing home, will I be free from abuse and neglect?

Will my family be supported?

- If I cannot speak for myself, will my family be supported in making difficult decisions about my care?
- Will my family have help in arranging for the care and services I need – whether at home, in the hospital, or in an assisted living or nursing facility?
- Will my spouse have to sacrifice his or her own health in taking care of me?
- Will my spouse or adult children lose their employer-based health insurance in the process of taking care of me?
- Will my family lose our savings and become poor because of my illness?
- Will I leave my family with debts to pay?



Sponsors and Partners

THE RECLAIMING THE END OF LIFE INITIATIVE IS HONORED BY THE SUPPORT OF THE FOLLOWING SPONSORS AND PARTNERS

SPONSORS

Alive Hospice, TN
American Cancer Society, New
England Division
Americans for Better Care of the
Dying
Beacon Hospice
Capital Hospice, VA
Charles W. Engelhard Foundation

New Hampshire Endowment
for Health
The Hoffman Family
Foundation
Deming P. Holleran
Hospice of the Florida Suncoast
Hospice of Michigan

Hospice & Palliative Care of
Western Colorado
Hospice of the Western Reserve
Kathy's Trust
Joanne Lamprey
New Hampshire Charitable
Foundation

Samira K. Beckwith, Hope
Hospice, FL
The Lighthouse Foundation
True R. Ryndes
VistaCare Foundation, AZ
James Tracy

PARTNERS

AARP
Alabama Hospice Organization
Anthem Blue Cross and Blue
Shield Foundation
Colorado Hospice Organization
Dartmouth-Hitchcock Medical
Center
Dartmouth Community
Medical School

Hospice and Palliative Care
Association of New York State
The Elder Rights Coalition of
New Hampshire
The HOPE of Wisconsin
Hospice Minnesota
National Coalition for Cancer
Survivorship
National Citizens Coalition for

Nursing Home Reform
National Family Caregivers
Association
National Hospice and Palliative
Care Organization
Nebraska Hospice and Palliative
Care Partnership
New Hampshire Hospice and
Palliative Care Organization

New Hampshire
Comprehensive Cancer
Collaboration
New Hampshire Council of
Churches
New Hampshire Pain Initiative
New Hampshire Partnership
for End of Life Care

This report is authored by:

Co-founder and Director

Ira Byock, MD
IByock@ReclaimTheEnd.org

Ira R. Byock, MD, is Director of Palliative Medicine at Dartmouth-Hitchcock Medical Center in Lebanon, New Hampshire. He is also an Associate Director of the Norris Cotton Cancer Center at Dartmouth, in charge of Cancer Survivorship and Palliative Care. Additionally, Dr. Byock holds the title of Jack and Dorothy Byrne Distinguished Chair in Palliative Medicine and is a professor of Dartmouth Medical School in the departments of Anesthesiology and Community and Family Medicine.

Dr. Byock has been involved in hospice and palliative care since his family practice residency in 1978, when he helped found a hospice home care program for the indigent population served by the university hospital and county clinics of Fresno, California. He is a past president (1997) of the American Academy of Hospice and Palliative Medicine. From 1997 through July of 2006, Byock served as director of Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation.

Co-founder and Project Manager

Yvonne Corbeil
YCorbeil@ReclaimTheEnd.org

Yvonne Corbeil is cofounder of the Reclaiming the End of Life Initiative. Yvonne is a nurse administrator with extensive experience in hospice and palliative care programs. She served for 15 years as Assistant Director for Palliative Care at McGill University. She is currently Director for Network Development for the Palliative Care at Dartmouth-Hitchcock Medical Center in Lebanon, NH, where she oversees development of new programs and outreach to regional hospitals, home health, and hospice programs. From 2004 until May of 2007 Yvonne served as Executive Director for the New Hampshire Hospice and Palliative Care Organization and currently serves on the organization's board of directors.



References

1. Max MB. How to move pain and symptom research from the margin to the mainstream. *J Pain*. Sep 2003;4(7):355-360.
2. Angell M. The quality of mercy. *N Engl J Med*. Jan 14 1982;306(2):98-99.
3. Angus DC, Barnato AE, Linde-Zwirble WT, et al. Use of intensive care at the end of life in the United States: an epidemiologic study. *Crit Care Med*. Mar 2004;32(3):638-643.
4. Hinton J. *Dying*. London: Viking Press; 1967.
5. Charles Asp P, Barbara K. Spring, PhD, and Magdalena P. Sokolowski, BA, . *The Massachusetts Commission on End of Life Care Survey* September 2005.
6. Bureau UC. *US Census Bureau*
7. A NCFI-TC. 2007.
8. Leland J. When Health Insurance Is Not a Safeguard. *New York Times*, 2005.
9. Cancer Society Focuses Its Ads on the Uninsured. *New York Times*, Aug. 31, 2007.
10. Arno PS, Levine C, Memmott MM. The economic value of informal caregiving. *Health Aff (Millwood)*. Mar-Apr 1999;18(2):182-188.
11. www.caregiving.org/data/04finalreport.pdf NAFCaAAA. *Caregiving in the US*. Washington, DC: National Alliance for Caregiving and AARP; 2004.
12. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *Jama*. Dec 15 1999;282(23):2215-2219.
13. Covinsky KE, Landefeld CS, Teno J, et al. Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? SUPPORT Investigators. *Arch Intern Med*. Aug 12-26 1996;156(15):1737-1741.
14. Fackelmann K. Rough time' ahead for boomers as they age. *USA TODAY*. September 26, 2006.
15. Butler R, Wright L. *Caregiving in America*: International Longevity Center and Schmieding Center for Senior Health & Education www.ilcusa.org; 2006.
16. CDC. Aging in America. *CDC*. June.
17. The Maturing of America. 2006.
18. MetLife. *The Maturing of America: Getting Communities on Track for an Aging Population* September 2006.
19. AACN.
20. AACN. Nursing Shortage Fact Sheet.
21. Pear R. 9 of 10 Nursing Homes Lack Adequate Staff. *New York Times*. February 18, 2002, 2002.
22. Cooper K. *Washington Post* September 16, 2001, 2001.
23. Division SI, Waxman PIRHA. *Abuse of Residents Is a Major Problem in U.S. Nursing Homes*: Committee on Government Reform U.S. House of Representatives, ; July 30, 2001 2001.
24. Trapps TE. Violations Mount As Long-term Care Facilities Have a Hard Time Finding and Keeping Good Help *Los Angeles Times*. July 31, 2001, 2001.
25. *National Occupational Employment and Wage Estimates*: Bureau of Labor Statistics U.S. Department of Labor 2003.
26. Zerzan J SS, Hanson L, JAMA Nov 15. Access to Palliative Care and Hospice in Nursing Homes. 2000:2489-2494.
27. Emanuel EJ, Fairclough DL, Slutsman J, Alpert H, Baldwin D, Emanuel LL. Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *N Engl J Med*. Sep 23 1999;341(13):956-963.
28. Final Recommendations HCTWfAA. Citizens Health Care Working Group; 2006.
29. Perry S. An Untimely Death? Charities working to improve care for dying patients mourn the loss of two major foundations *Chronicle of Philanthropy*. 2005.
30. *Financial Implications of Promoting Excellence in End-of-Life Care*: Promoting Excellence in End-of-Life Care, a national program of The Robert Wood Johnson Foundation; 2002.
31. Morrison RS, Maroney-Galin C, Kralovec PD, Meier DE. The growth of palliative care programs in United States hospitals. *J Palliat Med*. Dec 2005;8(6):1127-1134.
32. Thomas WH. *Life Worth Living: How Someone You Love Can Still Enjoy Life in a Nursing Home*. Acton, MA: VanderWyk & Burnham; 1996.
33. Thomas W, Stermer M. Eden Alternative Principles hold promise for the future of long-term care. *Balance*. Jul-Aug 1999;3(4):14-17.
34. Hansen JC, Van Steenberg C. Keeping PACE with older adults: the program of all-inclusive care to the elderly. *Am J Nurs*. Jan 2005;105(1):92.
35. Eng C. Future consideration for improving end-of-life care for older persons: Program of All-inclusive Care for the Elderly (PACE). *J Palliat Med*. Apr 2002;5(2):305-310.
36. Rich ML. The PACE model: description and impressions of a capitated model of long-term care for the elderly. *Care Manag J*. Winter 1999;1(1):62-70.
37. Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Am J Manag Care*. Feb 2006;12(2):93-100.
38. Sweeney L, Halpert A, Waranoff J. Patient-centered management of complex patients can reduce costs without shortening life. *Am J Manag Care*. Feb 2007;13(2):84-92.
39. Pyenson B, Connor S, Fitch K, Kinzbrunner B. Medicare cost in matched hospice and non-hospice cohorts. *J Pain Symptom Manage*. Sep 2004;28(3):200-210.
40. Campus/Tricare. Accessed September 14, 2007.
41. Buchwald A. *Too Soon To Say Goodbye*. New York: Random House; 2006.
42. Connor SR, Pyenson B, Fitch K, Spence C, Iwasaki K. Comparing hospice and nonhospice patient survival among patients who die within a three-year window. *J Pain Symptom Manage*. Mar 2007;33(3):238-246.
43. Miller SC, Mor V, Wu N, Gozalo P, Lapane K. Does receipt of hospice care in nursing homes improve the management of pain at the end of life? *J Am Geriatr Soc*. Mar 2002;50(3):507-515.
44. Miller SC, Gozalo P, Mor V. Hospice enrollment and hospitalization of dying nursing home patients. *Am J Med*. Jul 2001;111(1):38-44.
45. Bernabei R, Gambassi G, Lapane K, et al. Management of pain in elderly patients with cancer. SAGE Study Group. Systematic Assessment of Geriatric Drug Use via Epidemiology. *Jama*. Jun 17 1998;279(23):1877-1882.
46. Organization NHaPC. *2005 National Summary of Hospice Care*. Alexandria, VA 2006 2006.
47. Twohig JS, Byock I. Aligning values with practice. The "Promoting Excellence" program demonstrates the practicality of palliative care for patients, families, and caregivers. *Health Prog*. Jul-Aug 2004;85(4):27-33.
48. Byock I, Twohig JS, Merriman M, Collins K. Promoting excellence in end-of-life care: a report on innovative models of palliative care. *J Palliat Med*. Feb 2006;9(1):137-151.
49. Morrison RS, Meier DE, Fischberg D, et al. Improving the management of pain in hospitalized adults. *Arch Intern Med*. May 8 2006;166(9):1033-1039.
50. Meier DE, Thar W, Jordan A, Goldhirsch SL, Siu A, Morrison RS. Integrating case management and palliative care. *J Palliat Med*. Feb 2004;7(1):119-134.
51. Feudtner C, Silveira MJ, Shabbout M, Hoskins RE. Distance from home when death occurs: a population-based study of Washington State, 1989-2002. *Pediatrics*. May 2006;117(5):e932-939.
52. Feudtner C, Feinstein JA, Satchell M, Zhao H, Kang TI. Shifting place of death among children with complex chronic conditions in the United States, 1989-2003. *Jama*. Jun 27 2007;297(24):2725-2732.
53. Gross J. A Grass-Roots Effort to Grow Old at Home *New York Times*. August 14, 2007, 2007.

AT THE HEART OF THE MATTER

Will my pain be managed?

Will my wishes be
known and honored?

Will I receive
competent care?

Will my family be supported?



The Reclaiming the End of Life Initiative has captured the attention and participation of many New Hampshire citizens. The Reclaiming Initiative is committed to sparking discussion and debate among presidential candidates on the things that matter most to elders, seriously ill people of any age, and the families who care for them.

Please visit the www.ReclaimTheEnd.org website for updates.

The Reclaiming Initiative will be posing a set of Questions for Candidates and posting their responses at www.ReclaimtheEnd.org.

A full set of data from the Citizen Forums is available at www.ReclaimTheEnd.org under the tab: *Citizen Voices*