

The 17th Princeton Conference

Examining End of Life Care: Creating Sensible Public Policies for Patients,
Providers, Providers, and Payers

Session VII - Next Steps in Creating End of Life Policies May 20, 2010

We Can't Fix the End of Life by Merely Fixing Health Care



Ira R. Byock, MD

Director of Palliative Medicine

Dartmouth-Hitchcock Medical Center

Dennis 83 yo man

- Stable: CHF & ESRD on dialysis (3x/wk)
 - Admitted: Fall with facial laceration
 - Hypotension, severe dyspnea on exertion
 - New Dx: critical aortic stenosis
 - Lives alone
 - Church when has transportation, senior center, barber
 - Has Life Alert pendant
 - Needs med mgmt, Meals on Wheels, housekeeping
-



If all we do is improve medical treatment for dying people...



Sonya Hebert / The Dallas Morning News / 12/13/08

...the best we will achieve is a better medical experience of dying.



Sonya Hebert / The Dallas Morning News / 12/13/08

Patient-centered or Person-centered?



Dr. Mahlon Hoagland
Trina Scharf Hyman, circa 1989-90

Etymology of Patient *(from Latin)* One who suffers



Deidre Scherer
collection

When does a person become a patient?



Improving the End of Life

Dying is personal



Deidre Scherer
collection

Improving the End of Life

It Takes a Family



Nancy Medwell, Eternal Moments ©2010

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An individual receives a diagnosis...



Improving the End of Life

...a family gets the illness.



Definition of Family



“For whom it matters...”

Bastienne Schmidt & Philippe Cheng

Caregiving in U.S. – NAC & AARP

53.4 million caregivers in the United States – more than one in five adults – provide unpaid care to people with disabilities and chronic illness.

National Alliance for Caregiving and AARP 2004
www.caregiving.org

SUPPORT – *The Family Impact Study*

- 29% loss of most – or all – of their major source of income
- 31% reported loss of most – or all – family savings
- 20% a family member made a major life change



Covinsky KE, Goldman L, Cook EF, et al.
The Impact of Serious Illness on Patients' Families
JAMA December 21, 1994 - Vol 272, No 23. pp 1839-1844

Caregiver Health

Family caregivers who report mental or emotional strain associated with the chronic stress of caregiving had mortality risk 63% higher than non-caregiving controls.

Schulz and Beach
The Caregiver Health Effects Study
JAMA. 1999; 282:2215-2219

What Families Value

- Ensuring the “best care possible”



Bastienne Schmidt & Philippe Cheng

What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed



Robert Pope collection

What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed
- Knowing the person was treated in a dignified manner



Mal Warshaw collection

What Families Value

- Ensuring the “best care possible”
- Feeling that preferences were followed
- Knowing the person was treated in a dignified manner
- A chance to say and do the things “that matter most”



St. Paul Pioneer Press Dying Well: The miracle of death, Spring 2000

What Families Value

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- A chance to say and do the things “that matter most”
- Honoring and celebrating the person in his/her passing



St. Paul Pioneer Press Dying Well: The miracle of death, Spring 2000

What Families Value

- Ensuring the “best care possible”
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- Knowing the person was treated in a dignified manner
- A chance to say and do the things “that matter most”
- Honoring and celebrating the person in his/her passing
- A chance to grieve together

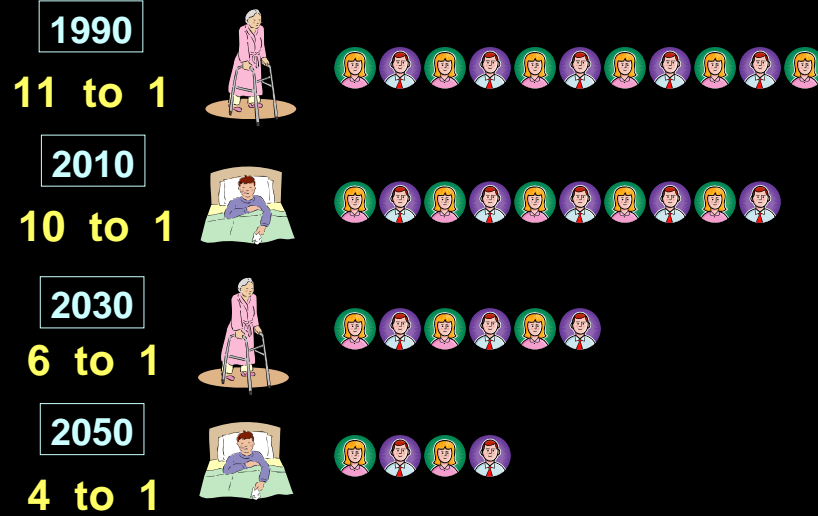


St. Paul Pioneer Press Dying Well: The miracle of death, Spring 2000

Improving the End of Life

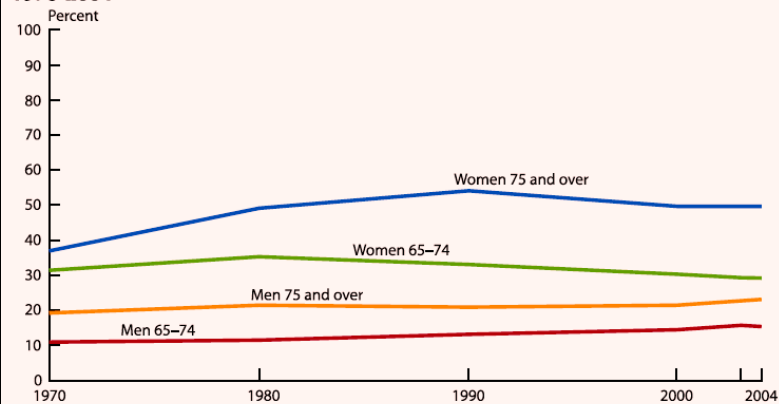
It Takes Community

The Shrinking Pool of Caregivers



Old Alone

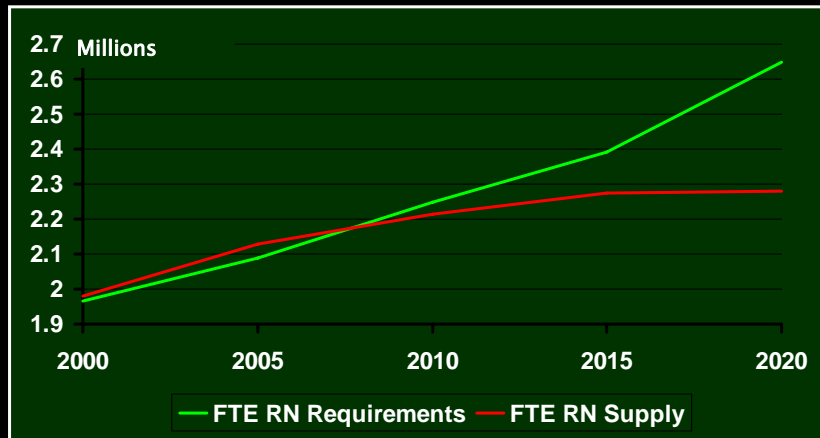
Population age 65 and over living alone, by age group and sex, selected years 1970-2004



Reference population: These data refer to the civilian noninstitutionalized population.
Source: U.S. Census Bureau, Current Population Survey, Annual Social and Economic Supplement.

www.AgingStats.Gov

The Current & Coming Crises in Nursing



Source: Projections by Division of Nursing BHP, HRSA, USDHHS, 1996

Why Community?



- Volunteerism
- Engaged local leaders
- Innovative approaches
- Local solutions
- Community-based surveillance
- Quality improvement initiatives

Community



- **Congregations / Faith communities**
- **Neighborhoods or apartment buildings**
- **Workplaces**
- **Schools**
- **Non-profit agencies** (food banks, shelters)
- **Service groups** (Lions, Kiwanis, Elks, Junior League)
- **Youth groups** (Scouts, 4H, FFA)
- **Social clubs**
- **Fire and Police**

Caring for One Another

HOME PASTOR'S RESOURCES PARISH NURSING HEALTH MINISTRY CONTACT US

Parish Nursing 

A specialty practice in nursing, functioning within health ministry to integrate faith and health across the age span of the congregation.

We'd love to hear from you. Please call us at **407-303-7153**

 **Center for Community Health Ministry**
The Center for Community Health Ministry and the Parish Nurse Institute brings the elements of physical, mental

 **Video Library**
Beyond Four Walls is an introduction to Parish Nursing from the Center for Community Health Ministry at Florida Hospital

 **Congregational Spotlight**
There are many congregations throughout Florida that have vibrant health ministries. Some of these congregations

 **Parish Nursing @ Florida Hospital**
Since 1994, Florida Hospital's Parish Nurse training programs have prepared over 500 nurses for their role as Parish Nurses

The Doula Program

The New York Times

New York, Sunday, January 25, 2004

In Death Watch for Stranger, Becoming a Friend to the End

By N. R. KLEINFELD

The first day, Bill Keating hoped that Lew Grossman was not a suspect. Anything else he thought he could handle, but please, not someone who cried.

In a nursing home bed, still as stone, Mr. Grossman looked awful. A bedraggled, brittle-looking man, 77, he was able to move only his left arm. He had a large nose and protruding ears. He had sunken cheeks, and all but five teeth were gone, victims of too much affection for sweets. Wispy white hair erupted from his head.

The doctors didn't imagine he had much longer. Too many things wrong. An odd time to meet someone, when that person's life is about gone. That was the point. It was supposed to be handshakes on death's doorstep.

Lew Grossman lived at the Inhabilla Geriatric Center, a sprawling, well-tended nursing home on Audubon Avenue in Washington Heights. For the most part, his days were spent chained to his room. No friends or visitors. His companions were the TV and his memories. The TV was always tuned to Channel 7. He was a stickler about that. "They've got good stuff on



Bill Keating, a volunteer, paid regular visits to Lew Grossman, who otherwise would have died alone.

Channel 7," was his explanation. In the next bed was a roommate who snored and smiled but never spoke, not one word.

In May 2002, when they met, Bill Keating didn't know a thing about Lew Grossman. Mr. Keating was no social worker or minister or anything like

that. He was a retired corporate lawyer in his mid-60's, recruited into a new program that paired volunteers somewhat enlightened in the particulars of death (they were called "doulas") with terminally ill people alone with their mortality. After all, there's no rental agency for friends, for when you're

The Doula Program

The New York Times

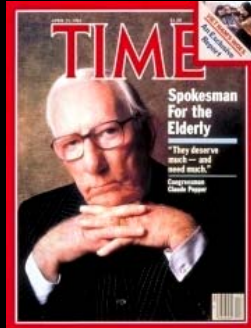
New York, Sunday, January 25, 2004



Bill Keating, a retired corporate lawyer, had doubts when he joined the Doula volunteer program, which provides companionship for the terminally ill. But he got into the spirit of it, considering it a way to express his gratitude for being prosperous, happy and healthy. He broke the ice with Lew Grossman by taking lox and cream cheese, big-band recordings and other treats to him at the geriatric center. Mr. Grossman died quietly on Jan. 2.

Improving the End of Life

Policy Matters Thinking Beyond Health Care



Improving the End of Life

The screenshot shows a website interface with a blue header. Navigation tabs include 'Health', 'Family', 'Lifestyle', 'Money', 'Legal', 'Senior News', 'Caregivers', and 'Contact Us'. A search bar is present with the text 'Find Local Senior Services'. Below the search bar, there are several filters: 'Home Care Agencies', 'Assisted Living Facilities', 'Retirement Communities', 'Adult Day Care', 'Elder Law Attorneys', 'Area Agencies on Aging', 'Hospice', 'Pharmacies', 'Senior Stores', and 'Senior Centers'. There is also a 'Zip Code' field and a 'Distance' dropdown menu. The main content area features several article teasers: 'Make Grandma's Day' with a photo of a woman and a child, 'Financial Planning for the Elderly' with a photo of a person holding money, and 'Help with Senior Care' with a photo of a woman. A sidebar on the right contains a 'Subscribe to Our Newsletter' form and a 'How do you stay young' section with radio button options.

Improving the End of Life

The screenshot shows the website for the PAS Center for Personal Assistance Services at UCSF. The page is titled "New Hampshire Agencies Related to PAS". It includes a search bar on the left, a navigation menu at the top, and a list of links to various state agencies. A map of New Hampshire is also visible.

PAS Center for Personal Assistance Services UCSF University of California, San Francisco

Home Need for PAS Home & Community-Based PAS Workers & Caregivers Economics & Workplace PAS PAS Users

Search This Site
[Search Box]
Search

Introduction
Index of New Hampshire Pages
New Hampshire Statistics
New Hampshire Disability Statistics
Number of Home and Personal Care Workers in New Hampshire
Wages for Personal & Home Care Aides in New Hampshire
State Program Data
Medicaid Waiver Data in New Hampshire

[State Information > Agencies related to PAS > New Hampshire](#) [Printer-friendly page](#)

New Hampshire Agencies Related to PAS

The following is background and contact information about state agencies involved with Personal Assistance Services.

- > [Medicaid Agency](#)
- > [Mental Health Services](#)
- > [State Unit on Aging](#)
- > [Protection and Advocacy Agency](#)
- > [Home Health Agencies](#)
- > [State Personal Care Agencies](#)
- > [State Independent Living Council and Centers for Independent Living](#)

Medicaid Agency

Medicaid is health insurance that helps many people who can't afford medical care pay for some or all of their medical bills. Medicaid is paid for by Federal and State funds. There is an organization in each state government that is responsible for administering Medicaid in that state. Each state sets its own guidelines regarding who can receive services (eligibility) and what services are covered under Medicaid.

Improving the End of Life

It Will Take

Advocacy and Activism

Advocacy and Activism

National Association of Attorneys General



Drew Edmondson
Attorney General
Oklahoma

“Attorneys General in each state are charged with protecting constituents in matters affecting the public interest, including consumer protection of those who are dying.”

Advocacy and Activism



National Association of Attorneys General

Will my pain be managed?

Will my wishes be known and honored?

Will I receive competent care?



Will my family be supported?

www.ReclaimTheEnd.org

Key Findings



> 80% said it was very or extremely important to have:

- Dignity respected
- Preferences honored
- Pain controlled
- Not leave family with debt.

Byock IR, Corbeil YJ, Goodrich ME.
Beyond Polarization: Public Preferences Suggest Policy Opportunities
to Address Aging, Dying, and Family Caregiving.
Am J Hospice & Palliative Care 2009

Key Findings



> 80% strongly endorsed

- Palliative care requirements for clinical licensure & reimbursement
- Expansion of family caregiver leave
- Respite care
- Bereavement support

< 50% strongly endorsed

- Being kept alive as long as possible
- Being prayed with
- Being prayed for

Byock IR, Corbeil YJ, Goodrich ME.
Beyond Polarization: Public Preferences Suggest Policy Opportunities
to Address Aging, Dying, and Family Caregiving.
Am J Hospice & Palliative Care 2009

Key Findings



Conclusion

By avoiding actions which elicit strong divergence of opinion and focusing on actions on which consensus exists, public officials and candidates can respond to problems and improve care and experience for frail elders, dying Americans, and their families.

Byock IR, Corbeil YJ, Goodrich ME.
Beyond Polarization: Public Preferences Suggest Policy Opportunities
to Address Aging, Dying, and Family Caregiving.
Am J Hospice & Palliative Care 2009

Policy Levers

- **Eliminate statutory-regulatory distinction between curative and palliative care**
 - **Require insurers to include hospice & palliative care as benefit similar to Medicare**
 - **Publish clinical standards for professionals and institutions**
 - **Publish “reasonable expectations” for consumers and citizens**
 - **Make data public in “report card” fashion**
 - **Expand funding Senior Centers & Aging Services**
-

Policy Levers

- **Require adequate (evidence-based) staffing of aides in SNF, LTC, ALF**
 - **Require living wages for aides in SNF, LTC, ALF**
 - **Est. standards for training of physicians, nurses & allied clinicians – as a condition for certification and public financial support**
 - **Fund health service research into delivery of continuum of care**
 - **Resolve political barriers to effective pain management**
 - **Public “report cards” and bulletin boards of all health services** (a public “Angie’s List”)
-

Policy Levers

Older Americans Act

- **Coordination and Planning to charge of Senior Services**
- **Case management, housing services, advance care planning**
- **Direct Care workforce initiatives**
- **Family caregiver support initiatives**

State government:

- **Licensure requirements for physicians, nurses**
 - **Insurance coverage for hospice and home care**
 - **Evidence based staffing levels in SNF, LTC, ALF**
-

Policy Levers

Grants to civic and faith-based organizations for home care to frail elders and ill people

Expanded family leave and caregiving support

Health insurance coverage for family caregiving

Tax deductions for family caregiving expenses

Expanded NIH / AHRQ supported research in

- Family caregiving
 - Secondary prevention
 - Community-based services
-



Satya Byock 02/15/10
