

WOMEN & WEALTH

Critical Conversations: Smart Medical, Legal and Financial Decision-Making for Life's Later Years



At Jeff Shields' memorial service, Genie Shields proclaimed that her husband's death has been a "gift," one that enriches all who receive it. When it became clear that lymphoma would take his life, Jeff decided to spend his remaining time with family and friends at their rustic Flying Bear farm in southern Vermont.

It was summertime. Jeff "let go of the medical stuff," lived in the moment, took walks, wrote letters, played with his grandchildren, conversed with friends, penned a memoir and reveled in the farm's natural beauty and cycles of life.

Looking back, Genie reflects, "Jeff soared those last few weeks. As his world shrunk to just a hospital bed in the living room, the space around him just grew bigger and bigger." The concentration of Jeff's generous spirit into that single spot radiated outward and infected all who came near with warmth, peace and equanimity.

Acclaimed author and surgeon Atul Gawande featured Jeff in a nationally-broadcast Frontline documentary, *Being Mortal*. Camera crews trailed Jeff and Genie during his final months. After his death, Gawande confided to Genie that Jeff was the program's "anchor." In a last noble act, Jeff Shields provides a compelling and very public example of dying well.

America's Death Spiral

Dean Nancy Kane of the Harvard School of Public Health often quips, "Americans believe death is optional." American culture keeps death at arms-length. Americans avoid difficult conversations about death. Too often, individuals and their families confront a death spiral under

duress with no preparation. They make bad decisions that cause catastrophic emotional, medical and financial consequences.

Consider these realities:

- Medicare spends 26% of its funding on beneficiaries in the last year of their life.¹
- More than 90 million Americans have at least one chronic disease and 70% of Americans die from chronic disease.³
- Out-of-pocket expenses during the last five years of life averaged \$39,000 for individuals, \$51,000 for couples and up to \$66,000 for people with long-term illnesses.⁴
- The percentage of Medicare patients seeing 10 or more doctors in the last 6 months of their lives increased from 30.8% in 2003 to 36.1% in 2007.⁵
- Medical expenses account for 62% of personal bankruptcies in the U.S. In 72% of these bankruptcies, individuals had health insurance.⁶
- 70% of Americans would prefer to die at home.⁷ Instead 70% die in hospitals, nursing homes or long-term care facilities.⁸
- More than 80% of patients wish to avoid hospitalization and intensive care during the terminal phase of illness, but those wishes are often overridden by other factors.⁹

In 2011, the average American consumed \$54,017 in healthcare services during their last year of life, a 58% increase from \$34,257 in 2002.²

89% of Americans think doctors should discuss end-of-life care with patients. Only 17% of Americans have discussed end-of-life care preferences with physicians.¹⁰

The majority of Americans do not receive end-of-life care consistent with their values and goals. Absent clear direction, the American medical system adopts an “all necessary measures” approach that generates excessive treatment, high costs and reduced life quality. Rather than end life on their own terms, patients die overburdened in institutional settings. Life’s final passage becomes a nightmare journey into oblivion. Everyone suffers.

It doesn’t have to be this way. Gunderson Health System in Lacrosse, Wisconsin is a national leader in advance care planning. Major healthcare organizations, including Kaiser Permanente and Dartmouth Hitchcock, integrate Gunderson’s *Respecting Choices* program into their care protocols. Applying advance care management leads to better treatment decision-making, higher patient satisfaction and lower costs. Gunderson’s cost during the last two years of life is 28% lower than Wisconsin statewide averages.¹¹ When hospitals, doctors and patients work together, everybody wins.

Disproportionate Impact: Women and Caregiving¹²

On average, women live five years longer than men and provide substantially more caregiving for spouses and aging parents. Approximately two-thirds of caregivers are women, who spend 50% more time providing care than male caregivers. It’s a heavy burden. Relative to non-caregiving women, female caregivers are six times more likely to experience depression when caring for a spouse and twice as likely when caring for a parent. Not surprisingly, higher stress levels, more chronic disease and greater financial insecurity plague women caregivers.

Demographics increase the probability that women will confront life’s later years alone. Almost half of women older than 75 are single. Moreover, 90% of women will be single at some time during their retirement.¹³ Being single increases the difficulties associated with addressing individual long-term care needs.

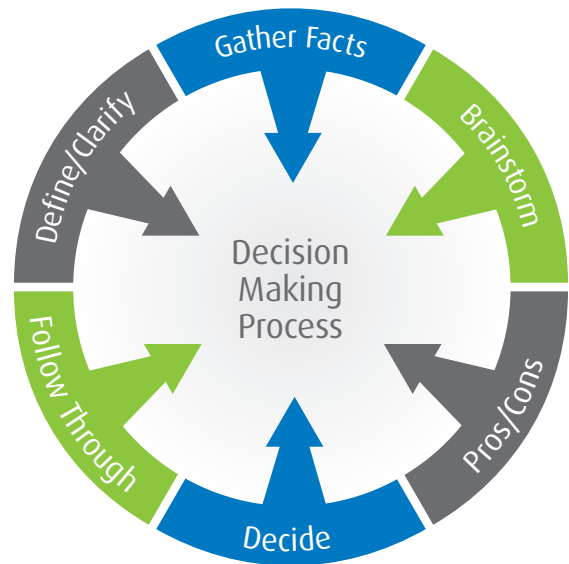
More caregiving responsibility, less personalized support and greater financial uncertainty make advance care planning even more important for women than men.

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Advance Care Planning: Effective Medical, Legal and Financial Decision-Making

The best advance care planning integrates financial, legal and medical decision-making within a cohesive process tailored to individual goals and values. End-of-life care can be expensive and unpredictable. It’s essential to link investments and insurance with appropriate legal documentation. When assessing their medical risk profiles, individuals should evaluate the following:

- Likelihood of a prolonged chronic disease, such as Alzheimer’s
- The adequacy of existing investments to cover future medical expenditures
- Strategies for minimizing tax obligations while paying for medical treatments
- The cost and relative benefits of long-term care insurance
- The availability and cost of transitioning a home into a care center
- Asset protection strategies, e.g. for individuals considering Medicaid-funded nursing home care (guidelines are state-specific)



Advance care planning integrates end-of-life treatment preferences. Engage with Grace's "One Slide Project" challenges "individuals and their loved ones" to answer five questions:

- 1 On a scale of 1 to 5, where would you fall on this continuum? 1 is "Let me die without medical intervention" and 5 is "Don't give up on me no matter what, try any proven and unproven intervention possible."
- 2 If there were a choice would you prefer to die at home or in a hospital?
- 3 Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
- 4 Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
- 5 Have you completed any of the following: written a living will; appointed a healthcare power of attorney or completed an advance directive?

Talking about death doesn't cause death. Instead, answering difficult questions about death creates a framework for end-of-life wellness. It enables individuals to design their end-of-life care plans well before they decline. This is as it should be. As the adage goes, "The best time to fix the roof is when the sun is shining."

Establishing a durable medical power of attorney is essential. No checklist can cover all contingencies. Individuals need informed and trusted advocates to act on their behalf when they lack the capacity to make important medical decisions.

End-of-Life Wellness

We all get older. We just die once. We don't get to practice. We want to get it right. Getting it right requires courage to do the following:

- Accepting medical realities
- Determining priorities for the time remaining
- Being pro-active

Individuals weigh hopes (attending a wedding) and fears (not being a burden) in determining their priorities. When given the choice, most people care more about end-of-life quality than longevity.

Key decisions are whether and when to receive palliative care, sometimes called "comfort care." Palliative care does not negate medical treatment, but shifts focus to making patients more comfortable. Interestingly, several research studies have found patients receiving palliative and hospice care live longer than patients receiving standard care.¹⁴

Numerous organizations offer tools to assist individuals make informed medical decisions. For example, Advance Care Planning Decisions produces short, disease-specific videos that guide patients through end-of-life care decisions. Ninety-five percent of patients viewing these video guides recommend them.

In seventeen states, individuals with terminal diagnoses can translate end-of-life care plans into actionable medical orders through POLST — Physician Orders for Life-Sustaining Treatment Paradigm. POLST emphasizes advanced care planning and shared medical decision-making (between patients and their doctors) to ensure caregivers follow pre-determined care plans.

Final Words

Near the end of *Being Mortal*, Jeff Shields speaks to the Frontline cameras a final time,

"These last couple weeks, I've been surrounded by family and friends. It's been terrific. Some of the best days of my life, I must say... so, I'm still a happy guy."

These were among Jeff's very last words. He died later that day. "Death be not proud."¹⁵ Jeff Shields' legacy is strong. His shining example of living and dying well endures.



David W. Johnson, CEO 4sight Health

David Johnson is the CEO and founder of 4sight Health, a boutique healthcare firm specializing in thought leadership, strategic advice and venture investing. Mr. Johnson's new book, *Market vs. Medicine: America's Epic Fight for Better, Affordable Healthcare* will publish in April 2016. He is the author-in-residence at the Health Management Academy, writes the widely-read "Market Corner" commentaries each week and contributes regularly to *Modern Healthcare*. He is director and/or advisor for several early-stage healthcare companies, Bienestar, Curate Health, GaussSoft, Link Capital, HealthiPass and MultiScale.

Mr. Johnson's extensive work within healthcare economics has been featured in numerous news outlets including *The New York Times* and NPR. He is a frequent speaker at industry events, most notably at Chicago Council on Global Affairs, Harvard School of Public Health, and will be a Keynote Speaker at this year's HFMA Annual National Institute. Mr. Johnson holds a Bachelors of Arts degree in English Literature from Colgate University and a Master's degree in Public Policy from Harvard University.

Resources for further information:

PBS—*Being Mortal*

<http://www.pbs.org/wgbh/frontline/film/being-mortal>

Engage with Grace

www.engagewithgrace.org

Respecting Choices

<http://www.gundersenhealth.org/respecting-choices>

Advance Care Planning Decisions

<https://www.acpdecisions.org>

Physician Orders for Life Sustaining Treatment

<http://www.polst.org/about-the-national-polst-paradigm>

¹ MedPAC, *Spending in the Last Year of Life and the Impact of Hospice on Medicare Outlays*, June 2015, p. 9

² Ibid.

³ *The Dartmouth Atlas*

⁴ *Money Magazine*, "Cutting the High Cost of End-of-Life Care," Penelope Wang, December 12, 2012

⁵ *The Dartmouth Atlas*, "Trends and Variations in End-of-Life Care," April 12, 2011

⁶ *Huffington Post*, "Top 10 Reasons People Go Bankrupt," May 24, 2015

⁷ *Time Magazine*, "A Kinder, Gentler Death," John Cloud, September 18, 2000

⁸ Centers for Disease Control, *Deaths by Place*, 2005

⁹ *The Dartmouth Atlas*

¹⁰ Kaiser Family Foundation, Kaiser Health Tracking Poll, September 30, 2015

¹¹ Gundersen Health System, *Respecting Choices*, "Return on Investment"

¹² Family Caregiver Alliance, *Women and Caregiving: Facts and Figures*, February 2015

¹³ "Financial Experience & Behaviors Among Women," 2014-2015 Prudential Research Study

¹⁴ NPCO, "Research Shows Patients May Live Longer with Hospice and Palliative Care," August 19, 2010

¹⁵ John Donne, *Sonnet X*, 1609

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