“Every story tells a story that has already been told.”
— Umberto Eco, Postscript to the Name of the Rose

“I will tell you something about stories . . . They aren't just entertainment. Don't be fooled. They are all we have, you see, all we have to fight off illness and death.”
— Leslie Marmon Silko, Ceremony

At this point in my career, I have become somewhat of an expert in the issues of public policy and communications related to advanced illness and end-of-life care. And, I have always thought of myself as being well-equipped to navigate this terrain in my own life. But nothing prepares you for dealing with these issues with your own parents.

My mom died from cancer in 2011 and my father has been in and out of the hospital more times than I can count in the last five years. There are moments etched in my memory—in waiting rooms and exam rooms with doctors, sitting next to a parent on a gurney in the emergency room, late nights in surgery waiting rooms and recovery rooms, tense days in ICUs—where topics were avoided or not considered, where euphemisms were favored over directness, and where anxiety, fear and confusion prevailed. I found myself compartmentalizing. There was the daughter Nancy and the sister Nancy and these Nancys were quite distinct from the policy and communications professional Nancy.

Navigating serious illness and preparing for death is messy and complex. I have wished for “right” answers where none were available and clarity when it was not to be found. I have wanted to know what the future would hold and to have a thorough understanding of how a disease would progress. Five weeks before my mom died, she had cataract surgery. Two weeks before she died, she had a chemotherapy treatment.
Were these the right decisions given the progression of her illness? Maybe, maybe not. Did we have those tough conversations as a family? Or with physicians? No. Policy Nancy would have encouraged it, but daughter Nancy didn't touch it.

My mom had read Atul Gawande’s article “Letting Go,” and she understood palliative care and hospice care. She knew what she wanted. She was most afraid of being in pain, and she was particularly concerned about specific kinds of pain given her unique cancer. Her care team helped us through it all. She died a peaceful, pain-free death at home with a view of her beloved garden.

My father is also aware of the choices he faces and their implications. He talks often of quality of life in making those choices. He and I have openly discussed different scenarios for his future health, and he has expressed his wishes for those circumstances. These conversations have included some of the most meaningful and fulfilling moments out of a lifetime with my father. It took some courage to broach the subject, but after we got going—and with a martini to loosen things up—the exchange was easy.

I believe the landscape is changing, and stories like mine are being shared more often and more openly. The media covers end-of-life choices, over-treatment, coordination of care, and patient-centered care in a very different light from even ten years ago. My friends speak of their own parents. Politicians debate the issues with a greater degree of civility and respect. Communities launch campaigns. Organizations like C-TAC are created, with new members joining every month. People are realizing that this is an issue that transcends politics and ideology. We are, I hope, experiencing a culture shift. A culture shift that I hope will bring policy Nancy and daughter Nancy into a more comfortable co-existence.

One development that has helped change the landscape dramatically is the widespread availability of hospice care. While hospice care is often thought to be centuries old, modern hospice care actually began in 1967, with the first American hospice established in Connecticut in 1971 (see Appendix A for a brief history of hospice). Even though some hospices have their own inpatient facilities, hospice is a philosophy of care rather than a physical place of care. The hospice philosophy of care is based on an interdisciplinary approach to care that includes physician and nursing
services as well as social work; spiritual care; and occupational, physical and speech therapies. It emphasizes palliation of the pain and symptoms that result from a terminal disease, regardless of whether those symptoms are the result of physical, emotional or spiritual concerns.

Since that first hospice outside of New Haven, Connecticut, more than 5,000 hospice organizations have appeared and today serve more than 1.65 million people.¹ The success and growth of hospice care can be attributed in large part to its dynamic pioneers, the availability of the Medicare Hospice Benefit (enacted as part of the Tax Equity and Fiscal Responsibility Act of 1982) and the aging of the population. But the real catalyst for the growth and acceptance of hospice is that its philosophy and overarching principles are in tune with what patients and their families want and need. In short, they put the patient and family first by:

- Emphasizing patient self-determination and a desire to direct one’s own decisions about his or her care at the end of life, focusing on the quality of that life versus simply its longevity;

- Focusing hospice care on the patient and his/her family regardless of how that family is defined or identified. From their modern day beginnings, hospice caregivers knew and appreciated that the suffering of the patient is only compounded by isolating the patient from the family, and that the suffering of the family—for too long simply ignored by traditional medicine—only results in increased morbidity for those family members;

- Delivering on the promise of hospice care: assuring patients that they will not die alone, that they will not die in pain, and that their care will not become an unbearable burden on their loved ones.

Another part of this landscape change is driven by storytelling. Storytelling is an age-old tradition and one of the most effective ways human beings have to communicate. Stories create a shared experience. They connect us. Stories convey information in vivid and accessible ways, and stories can spark a deeper understanding of ideas and events.
Stories on the topic of illness and death are no exception. They are mixed in tone, sometimes triumphant and sometimes devastating. And, they are emerging from a dark corner in our public discourse. They less often seem a topic or a place to avoid. Stories about personal experiences with illness and the process of dying are now being shared more publically, more often, more easily and in ever more varied settings, from the kitchen table in a farm house in Iowa, to the patient room in a hospital in Seattle, and to the halls of Congress.

Why do these stories about dying and illness matter? They matter because we, as a society and as individuals, are reflected in the stories we tell. Stories test boundaries, explore norms and beliefs, shift perspectives, provide opportunities to learn, and ultimately create a national dialogue about an issue. In this case, the issue is a delicate one that includes declining health and well-being, pain and suffering, the last years of life, and death. Some of the stories also touch on the joy, humanity and connection that can reveal itself along that same path. And that is what we strive for—hoping that those stories of grace and dignity in the face of advanced illness and death will outnumber the stories of confusion, pain and suffering. In highlighting the intensely personal experience in the face of illness, we can identify the opportunities to improve that experience. We can create change.

At the heart of each story is the question of choices and how to ensure that one’s personal values are reflected in the management of illness, and in some cases, in decisions about how to approach death. These stories often include themes of confusion in navigating an illness and in trying to coordinate between physicians and hospitals and insurance companies. Getting a diagnosis is often a time-consuming process filled with misunderstandings and gaps in communications that contribute to an already stressful situation for the patients and families making their way through the process.

Different individuals will have different beliefs and preferences regarding advanced illness and what maximizes the quality of life in the final months or years. Each person’s preferences are unique. Therefore, an individual’s personal preferences, values, beliefs and cultural norms must be considered as part of any treatment plan. For that reason, it is critical that the patient and family are put first and that their values
are taken into account at every step along the way. Excellent care must be patient-centered care. Anything less than patient-centered care is less than excellent care. Dr. Don Berwick puts it elegantly in his 2009 article in *Health Affairs* titled, “What Patient-Centered Should Mean: Confessions of an Extremist.”

What chills my bones is indignity. It is the loss of influence on what happens to me. It is the image of myself in a hospital gown, homogenized, anonymous, powerless, no longer myself. It is the sound of a young nurse calling me, “Donald,” which is a name I never use—its “Don,” or, for him or her, “Dr. Berwick.” It is the voice of the doctor saying, “We think…,” instead of, “I think…,” and thereby placing that small verbal wedge between himself as a person and myself as a person. It is the clerk who tells my wife to leave my room, or me to leave hers, without asking if we want to be apart. Last month, a close friend called a clinic for her mammogram report and was told, “You have to come here; we don’t give that information out on the telephone.” She said, “It’s OK, you can tell me.” They said, “No, we can’t do that.” Of course, they “can” do that. They choose not to, and their choice trumps hers: period. That’s what scares me: to be made helpless before my time, to be made ignorant when I want to know, to be made to sit when I wish to stand, to be alone when I need to hold my wife’s hand, to eat what I do not wish to eat, to be named what I do not wish to be named, to be told when I wish to be asked, to be awoken when I wish to sleep. Call it patient-centeredness, but, I suggest, this is the core: it is that property of care that welcomes me to assert my humanity and my individuality.²
Americans have generally shied away from conversations about advanced illness and the process of dying, but a shift seems to be underway. Over the past few years, journalists and others have published their own stories and thoughts on the challenges in advance care planning, often in beautifully written and heartfelt pieces. In addition to Dr. Berwick’s article cited above, notable articles include: Atul Gawande’s “Letting Go: What Should Medicine Do When It Can’t Save Your Life?” from The New Yorker; Michael Wolf’s piece “A Life Worth Ending” from New York Magazine; and Charles Ornstein’s reflections captured in The Washington Post article “How Mom’s Death Changed my Views on End of Life Care,” to name just a few. These types of articles are shifting the public discourse. Along with organized initiatives like The Conversation Project (http://theconversationproject.org/), Honoring Choices (http://www.honoringchoices.org/), and television programs like the Frontline Series on “Facing Death,” they help move the conversation into living rooms and kitchens across the country. These initiatives are dedicated to encouraging individuals, families and communities to have discussions about their wishes and choices for end-of-life care. Because of these initiatives (and others like them that are emerging throughout the country), it is becoming more routine and more acceptable to speak of the difficult choices that we face. Under what circumstances should a feeding tube be inserted? How does one decide when to remove life support? What factors contribute to a decision to perform heart surgery on an 85-year-old with dementia? How does a family begin to make that type of choice?

At the heart of all of these stories are the patients and their families. There is the periodic story of the doctor as a hero, or medical technology as the hero. But more often, the physician is portrayed as a guide or partner, sometimes effective and sometimes not. Many people are realizing that they need and want to be more involved in the management of their care. They want to decide what works for them and what doesn’t. But not everyone desires that level of engagement—some like the idea that their physician or nurse will take the lead on important decisions. Either way, that choice is a preference that should be honored. For providers, figuring out those preferences and guiding a patient through difficult illness or end of life is a challenge,
but it can also provide some of the most meaningful and fulfilling aspects of the profession. For the patient, articulating those preferences in concert with loved ones can be difficult, and making difficult choices in the heat of the moment is even more harrowing. But this is an endeavor that can make all the difference in providing meaning and comfort to patients in a way that is also effective and trusted.

There is a small but growing body of research on the public attitudes about advanced illness and the patient and provider experience in caring for the elderly, or anyone with a serious illness. A thorough understanding of that research is important to designing care systems that can reflect those attitudes and to forming public policy that best supports the individuals in need as they move through this phase of life. This research tells us that a particularly difficult issue is confusion about the terminology related to advanced illness, primarily among patients but even among medical professionals. We don’t have a common understanding of some of the most basic terms. For example, many people—physicians and the general public alike—are under the impression that palliative care is, quite simply, end-of-life care. In actuality, palliative care is care that is designed to reduce suffering and enhance quality of life, regardless of whether a patient is undergoing curative treatments or is close to end of his or her life. In addition, there is a gap between the language that health care professionals use and that which patients are able to understand (or that matters most to them). For example, it is easy to find lists of the services that Medicare covers, but less easy to find a list of items that are not covered, which may come as a surprise to patients and their families.

Recent research shows that many people would choose a shorter, higher-quality life over a longer, lower-quality life. In addition, surveys indicate that the majority of people would prefer to stay in their homes with their families to support them and provide them with the care they need rather than to be in hospitals, nursing homes or other settings. Most patients indicate that their highest preferences are the desire to spend quality time with family and friends, to have their pain managed, to have their spiritual wishes and needs respected, and to be assured that loved ones are not emotionally and financially devastated by their illness or death. But even with these preferences—and knowing that they could be at risk—few people actually have the
conversations or do the planning required to make certain that these preferences are understood by their families or health care providers. It is a conversation that brings up uncertainty and difficult topics, and so more often than not, it becomes a conversation that is avoided. As a country, we need to put in place systems and controls that enable and facilitate these conversations early so that every individual can have those preferences honored and respected.

The research also shows that many elderly Americans articulate fears of being a burden on their families.\textsuperscript{xii} The cost of treatment is a key concern, ranking higher even than being unprepared for dying spiritually, according to a study reported in JAMA.\textsuperscript{xiii} There is a common theme of fear around creating huge financial hardship due to a serious illness—wiping out their own life savings and leaving large bills to be paid by their families.

Adding to the predicament, families often overestimate the coverage and support that will be provided by Medicare and private insurance. For example, many families are surprised to discover that help for bed-ridden patients is not considered a medical need and will not be covered by Medicare. Discovering these issues in the midst of advanced illness towards the end of one’s life creates additional stresses on an already difficult situation.

As an illness progresses, the communication between patients, families (who are often also caregivers), and providers becomes even more critical. The lack of a shared language combined with emotionally trying times make these communications progressively more difficult. Patients are looking for guidance in making decisions, and they increasingly count on their providers and caregivers as the disease progresses. Likewise, as family members provide more and more of the care for patients as illnesses progress, their information requirements change—they need more information and on different subjects. When their loved ones are in the early stages of needing care, family caregivers provide mostly personal care and do household chores. But as the illness progresses, family caregivers are called upon to provide more medical care more frequently. This is a much more complicated role. They are often coordinating the medical care among providers and communicating directly with physicians. They are also likely to be managing medications, IVs and injections, and wound care. They
are managing equipment use and ensuring availability of supplies. So not only do they need information to help them care for patients, they also need support for the many additional emotional and social burdens they now face.

Providers have equally challenging circumstances. They must gauge the preferences of each individual patient, understand the role the patient wishes their physician or nurse to play (and there is most assuredly variation in this regard), and they must assess the amount and timing of information to provide to patients. There is often a large gap between how much a physician may know about an illness and what a patient may know, but the most effective decision making in these instances is when that gap is effectively bridged and decisions are made jointly between all of the parties involved.

The challenges we face in addressing these communication gaps and honoring the preferences of patients are enormous. While we must continue to learn about these preferences and challenges through studies and surveys, we already know some things about what works and what doesn’t. Research shows that younger and healthier people resist discussing “end-of-life” treatments or completing advance directives, preferring to wait until such a discussion is “truly” needed, such as after an illness has been diagnosed. Even when advance directives have been completed, they often have little effect on treatment decisions that occur once patients have lost the ability to make their own decisions. For this reason, the recent focus of many health care systems on increasing completion rates of advance directives may be misguided or insufficient.

The POLST (Physician Orders for Life-Sustaining Treatment) paradigm appears to be a promising remedy to this situation. The National POLST Paradigm is an approach to end-of-life planning based on conversations between patients, loved ones, and health care professionals designed to ensure that seriously ill or frail patients can choose the treatments they want or do not want and that their wishes are documented and honored. A recent study published in the Journal of the American Geriatrics Society (JAGS) found that end-of-life preferences of people who do not want to be hospitalized as documented in POLST orders were honored.
We do know that once a patient and his/her family are in the midst of dealing with advanced illness, their information needs are significant, and those needs are not being well met. Patients and families want information about how an illness will progress and what types of symptoms to expect, how to best manage those symptoms and what the possible treatment options will be. And they want to know how to best prepare for and manage someone’s final days.

Given what we know about the challenges and the gap that we face, how do we build on the existing pockets of excellent work and the growing number of successful initiatives (see Chapter 5) to accelerate the pace of change and improve the nation’s efforts in addressing the problem? A critical next step is to create a common language and understanding that will work for all of the major stakeholders involved: patients, families, caregivers, and providers.

Another important approach is to provide the various stakeholders with the information they need in ways that reflect different stages along the way. Behaviors and needs change during the course of advanced illness, but some of the information to support end-of-life decisions does not keep pace with these changes. Several efforts are underway nationally and in local communities to address this need. In addition to the Conversation Project and Honoring Choices initiatives and the POLST Paradigm mentioned previously, C-TAC has developed CareJourney.org—a consumer based website aimed at helping patients and their caregivers understand their diagnoses, what those diagnoses mean for the future, and how to plan for their care and caregiving—medically, financially and spiritually. The information on CareJourney.org comes from C-TAC member organizations and is well documented and carefully crafted. The site provides information relevant to every stage along this journey and provides a comprehensive set of links to resources that will aid consumers in making important choices. C-TAC’s goal in this endeavor is to ensure that patient choice and shared decision-making are foundational in care.

That means serving “people” before “patients.” Many people with advanced illness want to avoid being patients, so it’s important to understand what they value and create a business model and metrics to ensure that personal goals drive clinical goals, as well as to focus on personal preferences when considering all available options for
care. This requires a shift in how we think about and approach care management, advance care planning and treatment and palliation.

As a first step, we need to provide care management through interdisciplinary teams supervised by an engaged leading physician and move the focus of care from the hospital to the home and community. These interdisciplinary teams should include the individual, the family, caregivers, physicians and other clinicians, other care managers and community partners (e.g., public agencies, churches and community navigators). And the structure of these teams should encourage coordinated care across all settings as the individual’s condition progresses.

At the same time, we need to promote advance care planning through continuing conversations over time at the ill-person’s pace in the comfort and safety of his or her home, as well as by documenting the stated preferences for care. Then, we need to ensure that those preferences are communicated to and implemented by clinicians at all points of care.

Once an individualized care plan is developed (driven by personal preference and clinical, psychological and spiritual needs), the clinical team can provide a customized blend of disease-modifying treatment plus palliative care and can fine tune the treatment to the preferred level of symptom control, managing the tradeoffs between analgesia and sedation. The team can then also alter the care plan as preferences evolve through the progression of the illness.

While this provides a broad process for putting patients and families first, much more can and should be done. We also need to enhance research efforts to collect the most recent information regarding public perceptions about advanced illness and end-of-life care. Additional resources and efforts are necessary to support improved communications. Improvements in advanced illness communications need to focus on in-the-moment decisions and support shared decision-making. Americans are calling for it. C-TAC has conducted an assessment of current practices in informed and shared decision making to identify best practices and develop tools that can be disseminated to both clinicians and consumers (see Chapter 5).

Additionally, all health professionals, policy leaders and consumer groups must be committed to developing and taking to scale research-based training programs for
health professionals on effective communications. Combined with a system to continuously update care treatment plans and integrate the ongoing conversation between patients, family members and physicians, we will most surely make progress in improving care and reducing the burden on the growing number of Americans struggling with these issues. Now is the time to find a common language that will close the communications gap among consumers, health professionals, the media and policymakers.

It is absolutely critical that we get this right. If we don’t, our chances of successfully transforming advanced illness care in America are greatly diminished. The increased involvement of patients and their families, hand-in-hand with providers, will help lead the way. If we do get it right, perhaps we will reach a place where Don Berwick’s fears of indignity, disrespect and humiliation will be a thing of the past; perhaps we will reach a place where daughter Nancy and policy Nancy will become one. That’s how I will know that we have finally succeeded.

The goal is daunting: to create an environment and a culture that encourages patients and their families to make their wishes known, to speak up when they don’t understand something, to voice their frustrations, to provide a personalized experience that includes an understanding of each person’s unique preferences and that treats everyone with compassion and respect, to honor their cultural needs, to provide them with the information they need when they need it and how they need it, and to ensure that care is coordinated across all of the different settings where it is provided and between the numerous physicians, nurses, caregivers and other health professionals involved. It is no small ask, but aren’t we each worth it?

Notes for Chapter 2


