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THE FIVE TRAJECTORIES

Supporting Patients During Serious Illness

Jennifer Moore Ballentine

The Five Trajectories: Supporting Patients During Serious Illness

By Jennifer Moore Ballentine

Introduction

The opportunity to develop meaningful relationships with patients and families over the long term is one of the great rewards of primary care. In his 2012 article, “The Joy of Family Practice,” William Ventres, MD, called the work “rich, engaging, and fulfilling” (2012).

Accompanying the joys in practice, however, are the challenges that arise when your patients develop serious, chronic, or progressive illness. In those times, primary care clinicians are ideally positioned to provide support and guidance, not only medically, but also in psychosocial, and spiritual/existential dimensions. This whole person, patient-centered approach is the heart of primary care and the heart of palliative care.

The following reflection examines common “trajectories” of serious illness as patients approach death and provides a framework for how primary care providers can serve patients and families experiencing any one of them. Advance care planning is underscored as a key tool that draws upon the clinician-patient relationship and helps primary care practitioners profoundly and effectively support patients through the end of life, along whatever path that takes.

Additional palliative care information and resources are listed on Page 12.

What Is a Trajectory of Dying?

“Trajectories of dying” were first articulated by researchers at the Institute of Medicine in the late 1990s as a conceptual framework for understanding the experience of illness and dying in America today. The trajectories map the course of decline in terms of “shape” and “duration” – the particular path the illness takes toward death and the speed with which it progresses (Field & Cassell, 1997).

Trajectories are also often predictive, though not determinative, of where a patient will die, and they have significant influence over the opportunity for and timing of advance care planning and palliative or hospice care. Different trajectories of illness require different preparations, coping strategies, and responses. An understanding of the trajectories offers insights into the lived experience of people who are ill and those providing care for a loved one, and helps clinicians and their patients anticipate and plan for the challenges posed by the trajectory.

As articulated by the Institute of Medicine, and augmented by researcher and palliative physician Joanne Lynn in the early 2000s, there are four commonly recognized trajectories: Sudden Death, Terminal Disease, Major Organ Failure, and Frailty (Lynn, 2004). In a 2013 chapter of a textbook for Certified Senior Advisors, I identified an additional trajectory, not fully accounted

for by the well-established four: the “Catastrophic Event.”¹ This fifth trajectory presents unique and particularly acute challenges for planning, coping, and palliative support.

This eBook will briefly explore the five trajectories and offer concrete suggestions for how advance care planning and palliative care can enhance patient autonomy and caregiver coping, informed decision making, better end-of-life preparation, and timely access to palliative services.

Sudden Death Trajectory

Case Study

Tessa was 69, working a few hours each day in her photography studio and teaching online for the local community college. Her children were grown and married. To her delight, her son Hank and his family, including his toddler son, had recently moved back to town and were living just a quarter mile down the road. Tessa had always been slender, a vegetarian since her 20s, never smoked, drank wine only on special occasions, walked the 2 miles to her studio in all but the most severe weather, and took regular “trekking” holidays with her equally athletic husband. She’d nursed several close friends through bouts with cancer – three had survived, one had died – and was both thankful for her good health and committed to maintaining it.

¹ In 2015, researchers at the University of Rochester identified brain injuries (including traumatic, vascular, and inflammatory brain injury) as occupying a possible “fourth trajectory,” not counting sudden death; they term these conditions “a distinct group of neurological catastrophes for which the patient and their families are typically unprepared” (Creutzfeld, Lonstreth, & Holloway, 2015). In this, they are correct, but other catastrophes follow a similar path.



One morning, when her husband was out of town, Tessa woke feeling unusually tired. As she showered and had breakfast, she felt a growing throbbing sort of ache in her chest and upper back. Feeling that something just wasn't right, she called Hank and asked him to take her to the emergency room. He was slightly annoyed, already late for work and unprepared for a big meeting that afternoon. Still, he had never known his mother to complain, so he picked her up and took her to the hospital. He realized, when they arrived, that he'd forgotten his briefcase. Once Tessa was settled into a bay and waiting for the doctor, he kissed her on the forehead and said he'd be right back.

About a half hour later, as he returned, walking briskly toward the bay where he'd left Tessa, he was intercepted by one of the physicians. "I'm so sorry," he said, "We tried to get her in to surgery, but it just happened too fast. There was nothing we could do." Shortly after Hank had left, an aneurysm in her aorta had ruptured and Tessa was dead in minutes.

The Sudden Death Trajectory (see Figure 1) – as exemplified by Tessa's story – was the most common throughout human history until very recently. The vast majority of deaths prior to the mid-20th century were instantaneous from accidental injury, or swift following brief episodes of acute illness (e.g., infection, pneumonia, gastrointestinal disease and diarrhea, nephritis, diphtheria).

Sudden Death

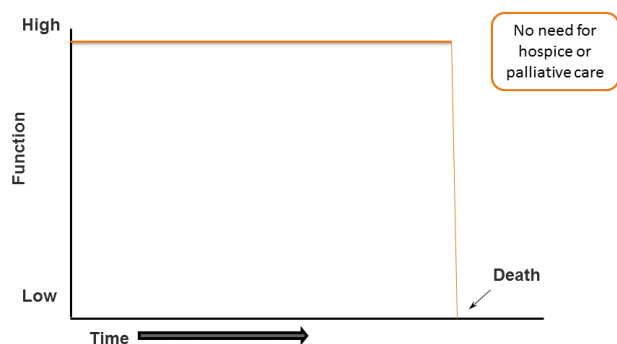


Figure 1: Sudden Death Trajectory. Adapted with permission from Lynn, 2004.

This type of death is still extremely common in less developed parts of the world, but in the United States, only about 10% of deaths in any year are sudden deaths from a health condition such as cardiac arrest, stroke, aneurysm, a fall followed by brain bleed, and so on (i.e., not including homicide, suicide, substance abuse, fatal motor vehicle injury, which together constitute only about another 6%) (Lewis et al., 2016).

Often, these deaths take place outside of any healthcare facility – at home, at the mall, at work, on the basketball

court or golf course. Interventions, such as CPR or defibrillation administered by EMS or bystanders, are unlikely to result in even short-term survival. A meta-analysis of studies of persons experiencing out-of-hospital cardiac arrest found that only about 6 to 7% of those receiving CPR survived to hospital discharge (interestingly, the rate was slightly higher, at 6.7%, for those receiving CPR from bystanders rather than from EMS, at 6.1%) (Anon., 2010).

In the Sudden Death Trajectory, there is no chance to prepare, tie up loose ends or personal/business affairs, or say goodbye to loved ones. Survivors are shocked, even if the person's health had not been robust prior to the fatal event. Obviously, there is no opportunity or need for hospice or palliative care, but there is comfort in knowing that such deaths often entail little pain and suffering.

The lesson in the possibility of sudden death, however, is to prepare your patients for death even while they are in the peak of health.

Advance care planning

Healthcare practitioners can assist in general preparation by encouraging all adults, starting at 18, to identify a surrogate healthcare decision maker (also called a "healthcare agent" or "proxy"). There was no opportunity for decision making in Tessa's case, but some sudden-death events, through emergency interventions, place patients in situations that require decisions about sustaining life; some may entail decisions about organ donation. Such scenarios are much easier for family members and clinicians to manage when there is advance planning and appropriate documentation (see more in the Catastrophic Event Trajectory section below).

Key practice point

At minimum, it's appropriate to ask your patients at any stage of health if they have thoughts about their preferences, should a sudden crisis occur. Would they want CPR or other life-saving measures if their heart or breathing were to abruptly stop? Would they want to be intubated or receive other life-sustaining treatments, and, if so, which and for how long? And, most importantly, which of their loved ones – family or friends – would they want to make decisions for them if they're unable to speak for themselves?

Encourage patients to begin these conversations with their families. Refer them to helpful websites or forms to assist in these discussions (see the Resources section at the end of this book for some suggestions). Become educated and/or train your staff in how to lead advance care planning conversations. Group visits/discussions including a cohort of patients cared for by your practice is an intriguing, efficient, and potentially effective option; see Lum, et al., 2016.

Terminal Disease Trajectory

Case Study

Johnno was 57, celebrating a second year of semi-retirement and living his dream as a jazz drummer in New Orleans. He and his husband were getting ready for an empty nest, enjoying the last few weeks of having their son at home before sending him off to college, when Johnno was diagnosed with pancreatic cancer.



He managed the surgery well, and stoically put up with accelerating side effects and pain through six rounds of chemotherapy. He got his appetite and strength back for a few months, enough to celebrate Christmas in California with their son, but he was still losing ground.

His weight dropped, his lower legs and abdomen swelled, and pain in his side kept him from sitting or lying down comfortably. He couldn't sleep.

A scan showed the tumors enlarging again and new metastases to his liver and colon. A second line of chemotherapy caused rectal bleeding but had no discernable effect on the tumors. His doctor offered a different regimen with a "targeted biologic" that was newly approved. It might help, he said, but no guarantees. Johnno decided he'd had enough of all that.

The hospital palliative care team helped Johnno and his husband contact a hospice that served their neighborhood, and the nurse was there to meet them when they got home from the hospital. Johnno was able to stay at home with his symptoms mostly managed – he even played a couple of gigs – until in June, just a few days after his son returned home from freshman year, he died.

The Terminal Disease Trajectory (see Figure 2) was not unknown prior to the 20th century: Cancer followed this trajectory, usually over a matter of weeks or at most months, while the years-long decline associated with tuberculosis was a harbinger of our modern way of dying.

The duration of many eventually terminal conditions has stretched to match and exceed that of tuberculosis, and the degree of function maintained during the duration can be much higher now due to modern treatments.

Course Recommendation:

[***Essential Palliative Care Skills for Every Clinician***](#)



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As in Johnno's story, however, at some point in the terminal trajectory the disease outpaces available treatments or the treatments lose effectiveness, and the decline to death accelerates.

Terminal Illness (Cancer)

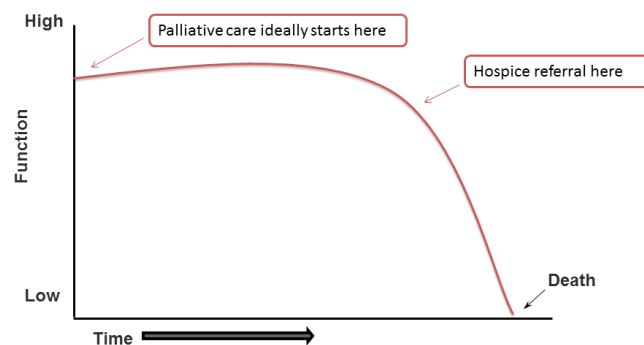


Figure 2: Terminal Disease Trajectory. Adapted with permission from Lynn, 2004.

An illness with a terminal trajectory is one that unequivocally should be accompanied by advance care planning and palliative care, ideally starting at diagnosis. Disease progression, while delayed almost to a standstill in some cases by effective treatments, will eventually result in the person's death.

There is time, typically, to prepare mentally, emotionally, spiritually, and practically, and to document the person's preferences and decisions so that they are well known to family members and professional caregivers. Throughout, palliative care can maximize comfort, increase coping, manage side effects of treatment, and support family and loved ones.

The Terminal Disease Trajectory in its final stage is the one for which hospice was originally developed. The philosophy entails "neither hastening nor impeding natural death," and the interventions are designed primarily to maintain comfort and quality of life throughout the progression of the illness, but especially in its final stages. Hospice focuses support on the patient and family as the "unit of care," even extending beyond the patient's death with family bereavement support.

In the United States, hospice services are defined and constrained by the Medicare Hospice Benefit. One of the requirements is that patients must be certified by two physicians as having a prognosis of 6 months or less, most readily met by those with a terminal disease. For example, cancer generally speaking is well understood and predictable within a range of individual variation (and the occasional surprising outlier).

Even allowing for the well-documented difficulties in accurate prognosis (e.g., Christakis, 1999), attentive clinicians can usually identify the turning point in the Terminal Disease Trajectory from management to accelerating decline. At this point, hospice services can appropriately be involved, assuming patients and physicians are open to the option.

One of the continuing barriers to providing hospice care, even in a Terminal Disease Trajectory, is the reluctance of both patients and providers to transition from curative or disease-modifying strategies to a wholly palliative approach, as enrollment in hospice requires.



This reluctance has many sources, among them a lack of accurate knowledge of the role and extent of hospice services, federal and individual hospice

enrollment policies, discomfort on both providers' and patients' parts with discussing terminal disease, cultural and ethnic features, certain physician characteristics, and even the location of care prior to referral (Aldridge Carlson, et al., 2012; Casarett & Quill, 2007; Dillon, Roscoe, & Jenkins, 2012; Obermeyer, et al., 2015).

Still, a 2008 article in the journal *American Family Physician* cited research that showed "the majority of caregivers and families of patients who have received hospice care report they would have welcomed more information about hospice from their primary care physician when the diagnosis was labeled terminal" (Weckmann, 2008, pp. 18-22).

Palliative care, while free from restrictive enrollment requirements, is subject to many of the same barriers as hospice. In addition, access to palliative services – especially for home-based patients – is spotty at best. The Center to Advance Palliative Care reports that, as of 2015, 75% of hospitals with more than 50 beds have a "palliative care program" – however, the exact composition, activity, and effectiveness of such programs varies widely (CAPC, 2017). In-hospital palliative care services ideally entail patient-family-clinician consultations leading to clarification of goals of care and alignment of treatment plans with goals.

Rarely do inpatient services follow patients past discharge into the community or a post-acute setting. The prevalence of community-based palliative care services – whether offered as transition-to-hospice programs, in clinics, or by home health or concierge medical practices – is unknown, although CAPC and the National Coalition for Hospice and Palliative Care have recently launched [an effort to identify programs](#).

Quality standards for such programs have been proposed but have not been universally or reliably met. Patients or providers attempting to identify such



services, let alone evaluate their quality, can only resort to word-of-mouth, provider networks, or laborious website-by-website research.

Even with such frustrating barriers, patients and their professional caregivers facing a Terminal Disease Trajectory have time (usually), motivation, and opportunity to plan ahead and assemble resources ahead of crises and the late-stage acceleration toward death. Primary care clinicians who are [educated in palliative care](#) can provide invaluable comfort and support to patients and families on this trajectory.

Advance care planning

To paraphrase an old saying, [advance care planning](#) begins at home. In this age of the "continuum of care," healthcare practitioners in all settings need to create treatment plans informed by the patient's own goals of care and the likely paths their illnesses will take. Advance care planning helps patients articulate and document those goals and preferences, and is most effective when clinicians work with each other and with patients so the goals are accurately reflected in the treatment plan.

Key practice point

Diagnosis of a potentially terminal disease should be an unequivocal trigger for a discussion between patients and providers, and between patients and their family members, of values, priorities, treatment choices, and surrogate decision maker documentation.

Primary care physicians and other providers can offer generic descriptions of how the disease might progress, what decisions might be necessary, and what options



are available. PCPs can encourage patients to identify surrogate decision makers and have candid conversations with family members and caregivers about their choices. You can assist with completing documentation such as medical powers of

attorney, CPR directives, POLST (or other POLST-like forms for your state), and living wills and distributing them to all clinicians and locations involved in the patient's care.

Palliative care

Hand-in-hand with curative or disease-modifying approaches, palliative care is focused on maintaining

Course Recommendation:

[Effective Advance Care Planning: Skill Building for Everyone](#)



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comfort and quality of life, easing symptoms of disease or its treatment, and supporting patient choice and independence. In comprehensive palliative care services, attention is paid to caregivers, offering instruction and support to enhance coping and adjustment to the patient's increasing care needs.

Key practice point

Ideally, palliative care should begin at diagnosis of any serious illness that may eventually prove terminal. Over time, as curative treatments cease to be effective or symptom burden ramps up, patients may begin to focus more on palliative goals, perhaps leading to hospice enrollment without an abrupt or disorienting shift.

Such an approach requires close coordination between PCPs and specialists and with community-based palliative care services and/or inpatient palliative care teams. PCPs can be of invaluable assistance to patients by becoming knowledgeable about the palliative and supportive services available in the area, identifying specific inpatient resources and quality [community-based](#) services ahead of crises.

Major Organ Failure Trajectory

Case Study

Anna Marie was 75, a recent widow, mother/stepmother of six, grandmother/step-grandmother of 10, active community volunteer, and die-hard football fan. She'd been "feeling crummy" since the New Year, but figured she was just worn down from having all the family in and out for the holidays.



When she finally got to the doctor, he immediately sent her for a chest x-ray. A large mass was detected in the upper right lobe of her

lung. Further tests ruled out cancer but pointed to an infection. After several days in the hospital, she was sent home with IV antibiotics and an order for in-home oxygen therapy. The "mass" shrank over time, but her pulmonologist diagnosed COPD, and Anna Marie continued on the oxygen.

Over the next two years, she did pretty well – continuing most of her activities and enjoying family visits – but her children noticed her slowing down. She didn't feel like planting summer annuals as she had for 35 years; her refrigerator was emptier and her freezer more full with microwave dinners; she asked her daughters to pick up the grandkids sooner on Saturdays and even begged off the annual trip to the zoo.

She had several panicky trips to the ER and stays in the hospital and rehab. Each stay was a little longer, and each one seemed to take a little more out of her.

Once she had to be intubated for a few days. She swore she'd never do that again. Her pulmonologist recommended hospice, but she insisted she wasn't ready for that either.

Soon her daughter, Janna, asked her to come stay with her family, wedging a hospital bed into the "craft room" behind the kitchen. Anna Marie alternated between being disoriented by her new surroundings and delighted by being with her grandchildren. Her doctor ordered a regimen of several inhalers and several times-a-day nebulizer treatments. She was able to manage this on her own at first but soon it fell to Janna to keep up the schedule.

One morning Janna found Anna Marie unconscious on the floor of the family room, with bruises on her right leg, arm, and a bump on her head. A visit to the ER found no broken bones, or serious head trauma, but the fall had frightened everyone. Janna took to sleeping on the pull-out couch in the family room just to be closer to Anna Marie at night.

A few weeks later, Janna woke to the sound of Anna Marie wheezing and coughing. She was wide-eyed with panic and couldn't speak between heaving breaths. This time, the hospital admitted her straight into the ICU. She swatted and fought when they tried to intubate her but agreed to an oxygen mask. Over the next several days, she was in and out of consciousness as the ICU team tried to keep her comfortable with morphine, suctioning, and sedation. Finally, about a week in to her stay, just after the family left after watching the Super Bowl in her room, Anna Marie died.

The Major Organ Failure Trajectory (see Figure 3) is characteristic of chronic and progressive heart, lung, liver, kidney, and some neurological diseases: Onset and progression of the illness may be gradual, slowly eroding function, and often punctuated by crises, "exacerbations" of the underlying disease or caused by some accompanying acute illness such as pneumonia or flu. As in Anna Marie's case, these crises typically require acute intervention, likely a trip to the emergency room followed by hospitalization and rehabilitation.

Any one episode might result in the person's demise; or the person might recover but never quite to baseline, only to have the next crisis erode function further. As time goes on, persons on this trajectory become more dependent on others for activities of daily living and functional activities of daily living.

Organ Failure (COPD, CHF, Renal Disease)

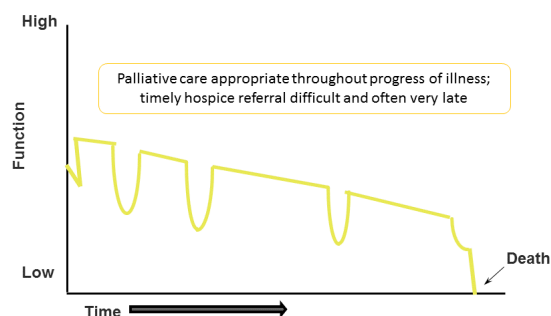


Figure 3. Major Organ Failure Trajectory. Adapted with permission from Lynn, 2004.

Increasing medication loads and debility can interfere with executive function, leading to confusion and disorientation. The cycle of home to hospital to rehab to home may eventually require that the discharge from rehab be not to the person's private home but to a family member's home, assisted living, or nursing facility.

Persons on this path rarely think of themselves as "dying," and their family members are often shocked by the death, experiencing it as sudden even after years of an accelerating pattern of crisis-recovery-decline-crisis (Field & Cassel, 1997). Because any one crisis could be "the end," progression of the disease to an end or terminal stage can be imperceptible, even to alert clinicians and family members.

Thus, timely involvement of hospice care is challenging, and if hospice is involved at all, it may only be very late in the trajectory resulting in a length of stay of only days or even hours. Still, a number of the characteristics identified as indicators for palliative care in widely used assessment guides such as the SPICT™ (Supportive and Palliative Care Indicators Tool), include features of accelerating organ failure:

- Performance status is poor or deteriorating (the person is in bed or a chair for 50% or more of the day); reversibility is limited
- Dependent on others for most care needs due to physical and/or mental health problems
- Two or more unplanned hospital admissions in the past 6 months
- Significant weight loss (5–10%) over the past 3–6 months, and/or a low body mass index
- Persistent, troublesome symptoms despite optimal treatment of underlying condition(s)
- Patient asks for supportive and palliative care, or treatment withdrawal. (SPICT, 2015)

Course Recommendation:

[Effective Advance Care Planning Fundamentals](#)



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Advance care planning

As in terminal disease, diagnosis of any chronic, progressive, or seriously life-limiting disease should prompt planning ahead, including the same issues and factors as previously discussed.

Key practice point

Because this trajectory is characterized by crisis, it is crucial to have choices made, discussed, and documented and surrogate decision makers informed and empowered from the get-go. [POLST](#) and POLST-like forms are especially helpful because they are portable medical orders. The POLST paradigm, whether enacted by statute or regulation, typically requires adherence to the orders by any physician treating the patient if the patient cannot speak for themselves. At the same time, POLST forms are intended to be updated to stay current with changing health conditions and goals.

Palliative care

Here, too, ideally, palliative care would begin at diagnosis and accompany the patient and family through the progression and crises.

Key practice point

Exacerbations and hospitalizations offer excellent opportunities for consultation with inpatient palliative care teams and coordination with [community-based programs](#) and PCPs for ongoing support. While hospice eligibility may be elusive, continued outpatient palliative care can significantly improve coping and quality of life for patients and families along this trajectory and avoid repeated hospitalizations and emergency room visits.

Frailty Trajectory

Case Study

Perry was 82, living by himself in a basement apartment near downtown. His son, Rafe, lived about an hour away, and visited every weekend.



Perry helped out the apartment managers by showing vacant apartments to prospective tenants, keeping a spare master key to the laundry and storage areas and front door, collecting mail for tenants on vacation, and accepting package deliveries. He enjoyed his job and enjoyed the discount off his rent even more. With just a small army pension and Social Security, he needed all the extra cash he could get.

The first thing Rafe noticed was that Perry didn't seem to be dressing himself as well. His clothes were often soiled, mismatched, and wrinkled – shirt buttoned askew or inside out. Then there was the

time when Rafe was visiting and a tenant stopped by to ask Perry to let him in to the laundry room. Instead of cheerfully helping like he always had before, Perry yelled at the young man, cursed him out for being careless, and slammed the door in his face. Then, when Rafe turned up one Saturday at 11 in the morning like always, Perry was surprised to see him, asking what he was doing visiting when he should be at work.

After Rafe coaxed Perry into seeing the doctor, he wasn't too surprised to hear her say she suspected Perry was developing dementia. She offered to run some more tests to confirm the diagnosis, but she admitted there wasn't much available in the way of treatment. She said Rafe should start thinking about making other living arrangements for Perry and ensuring supportive care.

Perry resisted all Rafe's efforts to organize extra help, refusing to let any of the nonmedical caregivers in his apartment, throwing out the Meals-on-Wheels, and accusing Rafe of hiding his clothes and stealing his money. Only when he'd nearly set the apartment building on fire when he left the stove on did Perry allow Rafe to move him to a subsidized senior apartment with provided meals and regular visiting nurses. It wasn't long before the management told Rafe that Perry really needed closer supervision and 24/7 nursing care. The next move was actually easier, because Perry seemed pretty "checked out" and didn't resist or seemingly even notice the move.

Over the next 5 years, Rafe regularly visited Perry at the nursing home, watching him slowly fade, becoming more and more dependent and disoriented. Eventually, the nursing staff told Rafe they'd have to put in a feeding tube because Perry wasn't able to swallow without choking and so wasn't eating enough to "keep his strength up."

Rafe shared his ambivalence about this with a colleague at work who put him in touch with her sister, a hospice nurse. She explained that a feeding tube at this stage of Perry's dementia would likely only make things worse, increasing his suffering and not necessarily prolonging his life. The loss of the ability to swallow, she said, indicates that his disease is entering a final stage. She recommended that Rafe refuse the feeding tube and instead enroll Perry in hospice, which would keep him comfortable through the final stages of his dementia. The nursing home resisted this plan at first, accusing Rafe of "starving" his father and threatening to report him for abuse. Rafe held his ground, supported by the hospice team, and eventually the nursing home staff agreed to his request. Perry was kept comfortable and clean, and Rafe was with him when he died a week later, almost 6 years after his diagnosis.

Debility/Failure to Thrive (Dementia)

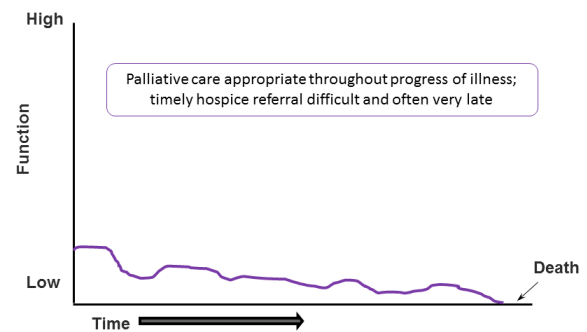


Figure 4. Frailty Trajectory. Adapted with permission from Lynn, 2004.

As noted above, the Frailty Trajectory (see Figure 4) was identified by Dr. Joanne Lynn (2004): This trajectory is characteristic of Alzheimer's and other dementias, some neurodegenerative diseases such as multiple sclerosis or Parkinson's, "failure to thrive," and "debility." In this trajectory, decline sets in very slowly and may be well along before any formal disease diagnosis is made. Sometimes the diagnosis may simply be advanced age (or, as is sometimes said with mordant humor, "TMB" for "too many birthdays").

The decline continues its inexorably downward path, but crises are rare; changes can be almost imperceptible and take many years to ultimately conclude in the person's death. This is the trajectory that exacts the most toll on caregivers, especially spouses, who are at significantly higher risk of disease, disability, and even death themselves as a result of the emotional, physical, and often financial burdens of protracted, intensive caregiving (Beeson, 2003; Christakis & Allen, 2006; Pinquart & Sorensen, 2003; Schulz & Sherwood, 2008; Vitaliano, Zhang, & Scanlon, 2003; Zarit, 2006).

Deaths from Alzheimer's disease increased by an alarming 89% between 2000 and 2014, and continue to rise. Currently, about 5.5 million Americans have Alzheimer's disease, and the number of cases is expected to double by 2050. Persons suffering from Alzheimer's live an average of 4 to 8 years from diagnosis and as long as 20, depending on a number of factors (Alzheimer's Association 2017).

While the specter of Alzheimer's disease and other dementias is particularly frightful, many other conditions can be just as debilitating. "Cognitive disability and frailty are rapidly becoming dominant elements of dying in old age" (Lynn, 2004, p. 9), and both can gradually accumulate over years.

Residents in nursing facilities suffer from a median of 5.2 concurrent chronic conditions and 24% of all elders die in nursing homes (CDC, 2016). Elders can expect a minimum of 2 years of significant disability prior to death, even in the absence of major disease: Instability and weakness, hearing and vision loss, reduced lung

capacity and muscular strength, and some degree of cognitive decline are typical (Byock, 2012; Field & Cassel, 1997; Lynn, 2004).

Frailty is also the trajectory that is most likely to present very difficult determinations of the effectiveness of treatments or therapies, assessments of quality of life, and perhaps agonizing decisions over withholding or withdrawing life-sustaining treatments. While palliative care from diagnosis would certainly be appropriate, hospice enrollment can be forestalled by nursing facility resistance or simply by the difficulty of identifying the end stage. As Perry's story illustrates, inability to swallow may be a clear signal of end-stage disease, but feeding tubes can continue to deliver hydration and nutrition.

In the Frailty Trajectory, death often comes about only as a result of a surrogate decision maker deciding to stop or not start some life-saving or -prolonging intervention, just as Rafe refused the feeding tube for Perry. These decisions can be agonizing for loved ones, and even for professional caregivers, especially if there is uncertainty about what the person would have wanted for themselves.



Advance care planning

A particular challenge of the Frailty Trajectory is that, if the decline is cognitive, the disease progression may be far enough long to compromise autonomous decision making before a formal diagnosis is made or a clear picture of the illness progression comes into view. If a person loses capacity prior to formally identifying a surrogate decision maker, decision making can be delayed and complicated. Some states specify a set, default hierarchy of decision makers, but some do not. Surrogates are then selected by consensus of "interested persons" or only via court ruling and guardian appointment.

Key practice point

Clinicians assisting patients with advance care planning must be knowledgeable about the laws and specific mechanisms in their state. Though advance care planning is ideally initiated early in adulthood, when all the person's faculties are intact, most people don't even think about it until a health crisis strikes or they reach an advanced age. Primary care clinicians can avoid crisis decision making by encouraging completion of advance directives, especially by their Medicare-eligible patients, well before the ravages of frailty begin. To facilitate such discussions, Medicare now will reimburse providers for advance care planning conversations (CMS, 2015).

Especially important in these discussions are decisions around life-sustaining treatment such as ventilators,

dialysis, tube-feeding, and CPR. Some living wills are only valid when patients are terminally ill or in persistent vegetative state, as determined by physicians, so they may not be helpful in guiding care for frail elders or those with dementia until the very end stages.

Pre-emptive refusal of life-sustaining treatments, and even antibiotics for potentially lethal infections, at certain points in their loss of cognitive or physical function, can be an option for those not wanting to extend a meaningless (to them) existence. POLST and POLST-like forms are especially effective for such decisions, as are printed, electronic, or even video decision aids offering descriptions of the purpose, likely outcome, and procedures entailed in each treatment (Vollandes, 2016).



Voluntary stopping eating and drinking (VSED) is gaining popularity as a choice a competent patient can make to hasten, or at least exert control over death legally (Ivanović, Büche, & Fringer, 2014). It should be noted that while VSED is legal, it is still controversial, and some providers may not be comfortable either suggesting it or supporting patients who choose it (Jox, Black, Borasio, & Anneser, 2017). (None of the major hospice and palliative care professional associations has issued an ethical position statement on the matter.)

At the same time, there are efforts under way to establish an advance directive to refuse hand-feeding when one becomes incapacitated, although the legal efficacy of such directives is untested (End of Life Washington, 2017). All such choices, however, are very personal and must be explored with skill and care by clinicians familiar with the laws of their state and comfortable having such discussions.

Palliative care

Dementia of any kind and progressive neurological or musculoskeletal diseases are certainly appropriate for long-term palliative care hand-in-hand with disease management strategies. In the absence of a diagnosis of disease – for instance, in cases of frailty, failure to thrive, debility, or TMB – accessing specialty-level palliative care may be more challenging.

Key practice point

Primary care providers may be the only source along this trajectory to offer palliative care, whether within your own practice or as a referral to an appropriate home-based or outpatient palliative care provider. Even when specialty palliative care is not available or suggested, PCPs can offer resources and services geared toward advance care planning, a focus on quality of life, and support for caregivers.

Course Recommendation:

[*Integrating Advance Care Planning into Your Medical Practice*](#)

Catastrophic Event Trajectory

Case Study

Veda was 89 and had been living with her son and his family for 14 years. After her granddaughter had joined the military, her son and daughter-in-law then decided to “downsize,” and Veda moved out to an independent senior apartment a few blocks from their new condo.



Given her age, she was in excellent health. Her only major problem was a double-whammy to her vision – glaucoma and macular degeneration – which had gradually rendered her legally blind. She figured that by giving up her car at 67 and walking everywhere since, and having to rely on her memory rather than reading, she had probably added years to her life. Her vision was just good enough to still get around in familiar surroundings.

Her teeth were bad, too, and she found it difficult to chew anything firmer than a slice of canned peach. She knew she’d lost weight, but didn’t think anything of it. And her blood pressure was a little high; she’d grudgingly agreed to take medication once the doctor said she might have stroke if she didn’t. She visited him once a year to renew her prescriptions and politely declined any other tests or treatments. She’d been a navy nurse on Guam during the “Second War” and worked in critical care throughout her career. She’d seen what doctors and medicine could do – good and bad – and preferred to handle her own health her way.

A few days before Christmas, her son took her shopping. She wanted to get a gift for her granddaughter who was coming home on leave for the holidays. It had snowed a few days earlier, but the walkways and store entrances were mostly clear. As she and her son entered the store, however, she didn’t see the slightly curled up edge of the entry mat. Her toe caught the edge and she went down hard on the cement floor of the store.

The emergency room confirmed what she feared – she’d broken her hip. They transferred her to the floor. When the surgeon came in to discuss the procedure, she insisted she didn’t want the surgery. The surgeon explained that hers was a kind of break “we repair even if the patient is on hospice.” Otherwise, it’s too painful, he said, and she’d be bed bound. With surgery and rehab she would have a chance to walk again and maybe even return home.

The surgery went well, and she transferred to rehab a few days later. She worked hard, even through a bout of norovirus, and returned to her apartment with a walker by the end of January. Even after her hard work to get home, she couldn’t really cope, although she didn’t like to admit it. She still had pain, and she found herself breathless and tired. Not able to even get down to the dining room for the evening meal with the residents, she felt trapped and useless. The days and weeks went by and instead of getting stronger, she found herself feeling more and more tired and less motivated. In April, when her ankles and abdomen got swollen and she developed a wheezing cough, along with a fluttering heartbeat, she knew her heart was failing. She asked her son to arrange a hospice evaluation. Six months after her fall, and 2 months shy of her 90th birthday, Veda died of congestive heart failure at the hospice inpatient facility.

The Catastrophic Event Trajectory combines aspects of the Sudden Death and Frailty trajectories: A sudden health event occurs – heart attack, stroke, aneurysm, brain injury from a fall or accident or illness, a hip fracture – but is not immediately fatal, either on its own or because of some emergency intervention. (See Figure 5)

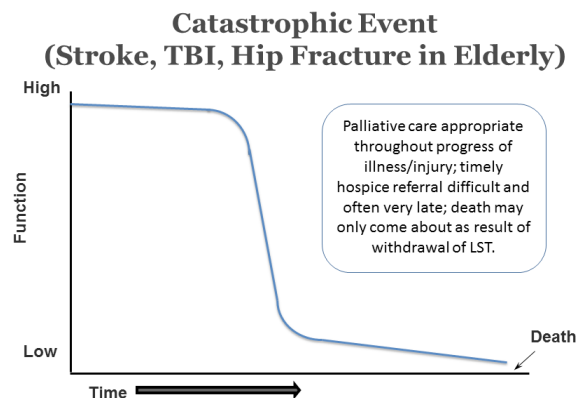


Figure 5: Catastrophic Event Trajectory (reprinted with permission of the author from Ballentine, 2013).

The person survives, but is rendered extremely impaired – suddenly plunged into a state of frailty and dependence of an uncertain, but likely permanent, duration.

Sometimes the person is left unconscious and dependent on long-term life-sustaining treatments such as a ventilator or tube feeding or both, sometimes for years. As of 2010, an estimated 100,000 persons in the United States were chronically dependent on ventilators and cared for in long-term acute care hospitals (Nelson, Cox, Hope, & Carlson, 2010). Likely the number is significantly higher now; the better we get at rescuing patients from cardiac death, the more often we condemn

them to severe brain or other physical damage that slowly limps toward death. As in the Frailty Trajectory, often death only comes about when surrogate decision makers withdraw life-sustaining treatment.

The exemplar case of this trajectory is Terri Schiavo, whose end of life tragically played out on the public stage in the context of a bitter family squabble and contentious national debate in 2004 and 2005 (Quill, 2005). In brief, Terri was in her mid-20s when she suffered a massive heart attack triggered by an eating disorder. She was successfully resuscitated but never regained consciousness.

Able to breathe on her own, she was kept alive by tube feeding for 15 years, 12 of which provided the context for successive litigations between her parents and her husband over the authority to make decisions for their incapacitated loved one, particularly on the issue of continuation or withdrawal of life-sustaining treatment.

Her husband finally won the legal argument, and Terri survived for 13 days following withdrawal of the tube



feeding, while protesters and supporters loudly rallied outside the inpatient hospice. She was sufficiently young and physically strong that with continued tube feeding she

could have lived for decades, barring an untreated or uncontrolled pneumonia or other infection.

Schiavo's case did not establish any new points of law, but two preceding cases with similar outlines significantly impacted, even established, the legalities of advance care planning and surrogate medical decision making: In the 1970s, the case of Karen Ann Quinlan, who at 19 lapsed into a coma for unknown reasons and never regained consciousness, established the rights of surrogates to make decisions on behalf of incapacitated patients (Zucker, 1999). The case of Nancy Cruzan, who never regained consciousness after being resuscitated following a car wreck in the 1980s, established the concept that tube feeding is a medical treatment and, as such, could be withheld or withdrawn like any other treatment (Colby, 2002).

In all three cases, young women suffered near-fatal catastrophic events; all three were resuscitated but suffered permanent brain damage; all three were dependent on life-sustaining treatments, which their loved ones had to seek permission from the courts to

remove; all three efforts were ultimately successful. Nancy died 12 days after her feeding tube was removed (New York Times, 1990). When Karen Ann's ventilator was withdrawn in 1976 after the New Jersey Supreme Court granted her parents' petition, everyone was surprised that she was able to breathe on her own. She lived for another 9 years, with tube feeding, until finally succumbing to pneumonia in 1985 (New York Times, 1985).

These cases stand out in our national consciousness because they were controversial, sparked vigorous debate, established or reinforced important points of law, and because of the tragedy of the lives of three young, vivacious women cut short. Similar "catastrophic events," including motor vehicle or recreational accidents, heart attacks and strokes, and falls resulting in broken bones or brain injury, however, are experienced by elders and others daily. In fact, according to the National Council on Aging, one in four older Americans will fall each year, and every 11 seconds an older adult is treated in an emergency room following a fall. Falls are the most common cause of nonfatal injury-related admissions to hospitals among older adults (NCOA, 2017).

A broken hip, especially one that can be surgically repaired, isn't immediately the picture one gets from the phrase "catastrophic event." However, as in Veda's case, mortality following hip fracture and repair



in elderly patients is high: One study found that excess mortality in patients within the first year following the fracture was more than 43% and overall 5-year mortality was 75%. Mean time to death was 767 days, or just a month or so longer than 2 years (Stewart, et al., 2011). Whether the "excess mortality" is due to the fracture itself, by some unknown mechanism, or due to the attendant stresses of surgery, hospitalization, rehab, diminished activity and function, pain, isolation, and loss of independence is not settled, but hip fractures often are the proverbial last straw that breaks down an elder's tenuous hold on quality of life and health (Frost, et al., 2013).

Advance care planning

Given the frequency of falls, as well as the risks of other health- or accident-related catastrophic events, older

Course Recommendations:

[Facilitating an Advance Care Planning Conversation](#)
[Billing for Advance Care Planning Conversations](#)

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patients and families should be gently prepared for the possibility and encouraged to have advance directives and contingency care plans in place.

Key practice point

The primary care practice can provide information and resources to patients and family members to access quality reviews and information on nearby rehabilitation, assisted living, and nursing facilities. As a primary care provider, you can incorporate palliative care services into your practice, including advance care planning discussions, follow-up, completion of documents, and insertion into patient records; clarity about the responsibilities of caregiving among family members and/or resources available to pay for professional help, and more. You can also discuss fall prevention strategies to help prevent injuries in the home.

Palliative care and key practice point

Palliative and supportive approaches can be very helpful past the initial crisis, keeping a focus on comfort and quality of life, maximizing remaining cognitive and physical function, and supporting caregivers. As in the Frailty and Major Organ Failure trajectories, timely referral to hospice might be difficult.

Conclusion

For primary care physicians, connecting with patients over a lifetime of care can be one of the most rewarding aspects of your work. There is joy that comes with helping patients manage disease or prevent a future health crisis, and sadness when sudden death or life-limiting illness strikes.

The framework for the “five trajectories of dying” presented in this eBook demonstrate how primary care clinicians can better guide patients and families experiencing any of these pathways. The advance care planning tips and resources highlighted with each trajectory offer a deeper understanding of how clinicians can provide compassionate, appropriate care that reflects a patient’s goals and wishes.

Primary care is already closely aligned with the patient-centered, whole-person approach of palliative care – an approach increasingly in demand as our population ages. Primary care clinicians are perfectly positioned to provide this transformative kind of care, or work with palliative specialists, to truly support patients through the end of life.

Resources:

[Essentials of Palliative Care for Every Clinician](#) – Comprehensive online course that provides palliative care education geared toward primary care clinicians, with instruction that includes advance care planning, physical aspects of care, and on how to incorporate palliative care into a primary practice

[Caringinfo.org](#) – A website dedicated to advance care planning and caregiver support. It hosts a database of downloadable, easy-to-use, legal advance directive and medical power of attorney forms for each state. Healthcare practitioners can download the appropriate forms and introduce them to patients at annual well-patient visits, revisiting choices and updating documents as health conditions and life circumstances change.

[Conversation Project Starter Kit](#) – A tool for families designed to foster open and honest discussion, before a medical crisis happens, about what matters most at the end of life

[Serious Illness Conversation Guide](#) – A framework for clinicians that shows how to broach difficult subjects in a sensitive and respectful way

[National Hospice Locator](#) – A searchable online directory of all hospice agencies in the United States, with detailed information on each one

[Primary Palliative Care Guideline](#) – A handout of quick and practical approaches for any clinician treating a person with serious illness; includes guidelines on when to involve specialty-level palliative care or refer patients to hospice

[POLST.org](#) – A website that explains the POLST paradigm, a voluntary approach to end-of-life planning that emphasizes documenting and honoring the preferences of the seriously ill using a POLST form. The website includes information and guidelines specific to each state

[ACP Decisions](#) – A nonprofit foundation working to create a library of short, easy-to-understand, evidence-based videos of important medical procedures to assist patients in their decision making

[Nursing Home Compare](#) – A Medicare tool that allows users to find and compare nursing homes certified by Medicare and Medicaid

[Hospice Compare](#) – A Medicare tool that allows users to search for hospices by specific geographic area, and compare them based on quality of care and other factors

[Alzheimer’s Association](#) – An organization that offers abundant resources for patients and caregivers living with Alzheimer’s disease, including information and forms to assist with end-of-life planning

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