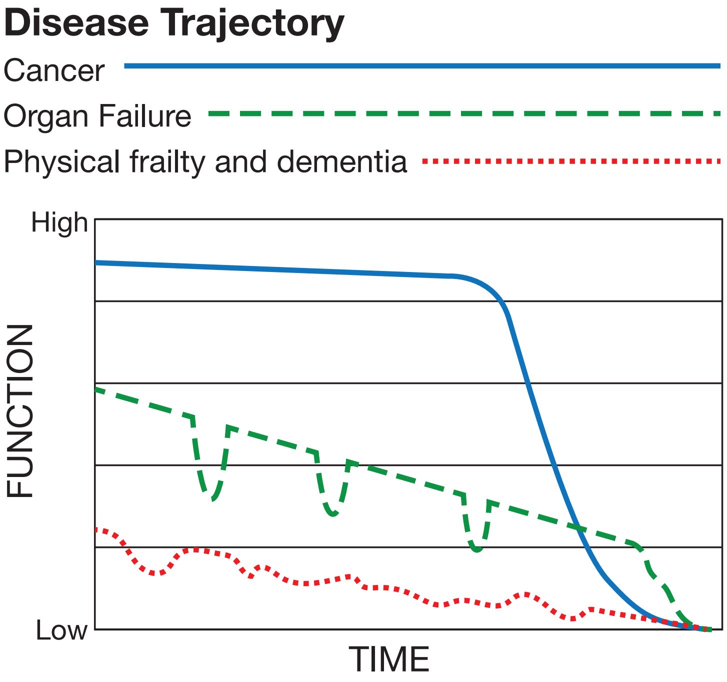
A **Common Practice** White Paper

Advanc*ing* Serious Illness: How Words Can Help or Hinder Needed Actions

Annie, a 75-year old woman with advanced lung disease, was nearing the end of another hospitalization that had brought her almost to death's door. A bout of bronchitis had nearly put her on a ventilator, something that had occurred to her several times in the past year. As our team met with her to talk about discharge planning, we learned from her that she thought of herself as being "pretty healthy." Yes, she needed oxygen 24/7 but she had been able to live independently in her home. But it seemed to us that Annie was very ill and getting worse. How could we bridge what seemed to us to be a big gap between our perspectives about her present and future health, so that Annie could get the care she wanted and needed?

Much has been written about the role of conversations for patients with advanced serious illness. Actually, for the purpose of this and future white papers, I'll be modifying the term advanced serious illness to advancing serious illness. The reason for this modification is the central tenet of this white paper: namely, that people living with worsening diseases that will lead to their deaths carry different mental models of those diseases and their future impact on themselves regarding quality and quantity of life. Referring to their illness as "advanced" suggests that it may be serious but static, while referring to the illness as "advancing" captures the progressive nature that can be useful for them in making sense of their past and present and planning for their future.



Adapted from: *Living Well at the End of Life*, Rand Health White Paper WP-137 (2003)

Figure 1

Chronic diseases have different patterns of decline as they progress through their final stages towards end of life. In a widely quoted article in the British Medical Journal in 2008, Murray and Sheikh describe three different "clinical archetypes" with regard to pattern and trajectory of functional decline in the months before death.[1] (Figure 1)

Patients with advanced cancer seem to do well until their disease exceeds a threshold at

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[1] Murray SA and Sheikh A. *Care for all at the end of life*. BMJ 2008;336:958-959.

which there is a steep and steady decline towards death. Patients with worsening organ failure (e.g., heart failure, advanced lung disease, end-stage liver disease) have a decline punctuated by episodes that bring them closer and closer to death. Recovery from the episode brings the patient back towards the functional level they were at prior to the episode—towards, but not quite there. Finally, patients with dementing illnesses and/or physical frailty live with a low functional level for an extended period of time, with little margin for decline into their death.

The same researchers have interviewed people within these three clinical archetypes, their family caregivers, and their health professionals, asking them to reflect on their recollections about their initial diagnosis, living with their illness, and approaching end of life. They specifically were interested in how thoughts about their own mortality intersected with their thoughts about their illness. Just as the trajectories differed between the three archetypes, the narratives about living with their illness and how thinking about death intersected with that experience over time (or not) were also quite different (Table 1).

The pattern reflected in the advanced cancer archetype is the one most familiar to us. The very diagnosis itself triggers concerns about mortality. As active treatment dominates the patient's attention, death goes into the background, though it at least briefly resurfaces any time a new symptom arises. Finally, when the steep decline into death begins, many patients at least internally recognize that the end of life is near and preparation for as good a death as possible becomes central.

However, the other two archetypes have very different patterns and present significant challenges for supporting person-centered care for people with advancing illness. People living with organ failure are understandably influenced by their successful recoveries from episodic flares. While they might not recover fully to their pre-episode state, the difference between pre- and post-episode functional state is quite small compared to the difference between either pre- or post-episode functionality and functional level during the episode. People feel so much better after the episode that they may not realize they're sicker than before the episode started.

People living as frail elders and/or with advancing dementia often live for extended periods (months to years) at a very low functional level. They typically require assistance from others for one or more activities of daily living, such as eating, bathing, or going to the bathroom. Over time, they often become entirely dependent on support from caregivers. These caregivers could be trained healthcare staff such as those employed

Phase of Illness	**Cancer**	**Organ Failure**	**Physical/Cognitive Frailty**
Becoming ill	Sudden memory	No clear event	Functional decline
Death	Real threat	Rarely considered	Not a concern
Living with Illness	Cancer treatment experience	Uncertainty, exacerbations, frustrating limitations	Normalizing, adapting, fear of nursing home and dementia
Death	Backstage, occasional appearances	Brushes with death during exacerbations	Concerns about fates worse than...
Dying	Focus on a good death	Keeping going	Slow, final decline
Death	*Center stage*	*Why discuss it?*	*Will happen in due course*

Table 1

by a long-term care facility, but more and more they are untrained family members and friends. People in this archetype have very little resilience and events/illnesses that might otherwise be relatively minor can be serious, even fatal. Death could literally come at almost any time.

Table 2 describes several areas of focus for conversations with people living with advancing serious illness in each of the above archetypes. I've included some words and phrases that I

	Progressive Cancer	**Organ Failure**	**Frailty/Dementia**
Types of Conversations Needed	Priorities, to treat or not, realistic goals of care	What's changing about the chronic disease(s), what is different about your life compared to previously, likely future scenarios (with decreasing chance of recovery and recovery only to lower functional status)	Likely future scenarios (from which recovery to baseline can't occur because of lack of resilience), what makes life worth living, scenario planning
Useful words and phrases	Serious, concerned, sicker, risk/benefit	Changing, getting even more serious, treatments no longer working like they used to, what does this mean	Frail, body has lost ability to bounce back, what might be fate worse than death
Examples of MGoG questions that could be useful *Numbers refer to Question Cards in the game*	21: Which is more frightening to imagine: suffering the worst physical pain of your life or not getting a chance to say goodbye to your family? 36: Do you want your doctor to be focused on maximizing: the length of your life, the quality of your life, other? 40: When you think about care at the end of your life, do you worry more about: not getting enough care, getting overly aggressive care, other?	29: What do you think happens to you after you leave this life? 33: If you had three months to live, what would you give yourself permission to do? Choose one per month. 39: Your will is a list of things you will give away after you die. What gift would you be better off giving today rather than after your death?	23: If you could control only one thing about the place where you spend your last hours of life, what would it be? 30: If you could write a note to the people who will care for you at the end of your life, to be delivered one year after your death, what would it say? 38: What habit makes your life worth living?

Table 2

think may be useful for anyone in conversation with the ill individual, be it a family member, friend, or someone from the clinical team. I've also included some questions from our tool, the game My Gift of Grace (MGoG) that might be helpful conversation starters.

Back to Annie and our conversation. We were interested in her perspectives about anything in her life that had changed recently that might be indicative of her changing clinical status. We asked, "You've told us about how you've been able to live on your own. Is there anything you've noticed that's different in the past few months, since your last stay in the hospital, that's concerning to you?" She acknowledged that her house was not as clean as it once was, as she no longer had the energy to sweep and vacuum for very long. She also was living more on canned or boxed foods, because she had a hard time cooking anymore. Mostly, she just sits around much more than she used to, because she feels she doesn't have the energy or desire to do very much anymore. We followed up with the question, "What do you think this means?" She was silent for a while, then sighed and said, "I guess I'm getting sicker." We nodded and said, "Yes, that's what we're concerned about too. Can we talk about that?" When she said "Yes," we asked, "Who else should we ask to join us in this conversation?" And that was the beginning to a different kind of conversation for her and her family.

People who are in their final years of life have gotten to that point through different pathways. What they've experienced, how they've thought about their illness and its impact on their life, and the conversations they've had so far are not the same. Helping people to appreciate what is different now can support the planning conversations that would likely be so useful for them, their loved ones, and the clinical team caring for them. The clinical archetypes mentioned above can be useful frameworks for clinicians to think about where their patients likely are so that they can meet them in conversation there. Certain phrases and questions, including some from My Gift of Grace, can be useful as bridges into the new and different conversations that need to start. Enabling the conversations to begin in ways that feel safe and comforting for patients and families will help them continue, as illness and life advances.

About the author: Jeff Cohn, MD, MHCM, is Common Practice's Medical Director. Jeff is a long-time change agent and student of behavior change. He graduated from Jefferson Medical College, did his Internal Medicine Residency at Einstein Medical Center and his fellowship in Hematology/Medical Oncology at Emory and Johns Hopkins. He received a Masters in Health Care Management from Harvard School of Public Health. For 11 years, Jeff was Chief Quality Officer and Patient Safety Officer for Einstein Healthcare Network in Philadelphia. He also served as Chief of Hematology at Einstein, and spearheaded the creation of the palliative care program at Einstein.

Common Practice is a healthcare innovation company that focuses on one of the most pervasive problems in healthcare today: the avoided conversations about serious illness and death. We believe that everyone does better at having these conversations when they are supported by simple tools such as our game, My Gift of Grace. We offer event kits that help organizations bring these conversations to their staff, patients, and communities, and we work directly with healthcare organizations to improve interactions between patients, families, and staff. **To find out more, visit common-practice.com.**

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