

The John A. Hartford Foundation Change AGENTS Initiative accelerates sustained practice change that improves the care of older adults. It does this by harnessing the collective power of The John A. Hartford Foundation's interprofessional community of scholars, clinicians, and health system leaders.

In December 2015, nearly 100 John A. Hartford Foundation Change AGENTS gathered in Philadelphia, PA to identify challenges and opportunities for improving care of older adults in several care settings and issue areas. Each group worked toward identifying actionable areas for John A. Hartford Foundation Change AGENTS, the Foundation, and colleagues in the field to pursue. The brief below represents the summary of the End of Life and Serious Illness group's proceedings and should inform future work to create widespread and systemic changes in the care of older adults.

End of Life and Serious Illness

Approximately 2.5 million Americans die every year with 73 percent over the age of 65. There is a gap between an individual's priorities and the medical treatment they receive. For example, 70 percent of Americans prefer to die at home, but 70 percent die in an institution among strangers, often receiving burdensome, harmful, and unwanted medical interventions.

Approaches to improve care of the seriously ill and at the end of life include efforts to strengthen palliative care and advance care planning. Advance care planning is a voluntary discussion about end-of-life treatment preferences between an individual and their care provider. This planning is vital as 75 percent of people are unable to make some or all decisions when the most critical treatment decisions need to be made.

As recently as 2009, the idea that Medicare would pay for clinicians to have conversations with patients about their wishes for end-of-life care was greeted with the howl of "death panels." The issue became toxic to policymakers. But in the fall of 2015, new Medicare proposals to **pay for these critical conversations** went through with little controversy. Beginning in January 2016, clinicians have started to be paid \$80 to have half-hour conversations with Medicare beneficiaries. If each of the approximately 2.0 million people on Medicare who die each year are served, this represents an annual influx of \$160 million toward improving care of those with serious illness.

The End of Life/Serious Illness issue group at the John A. Hartford Foundation's Change AGENTS Conference—comprised of clinicians, leaders and advocates—met against the background of this huge political and cultural change. Big questions, however, remain: Is the health care system ready? Are older people and families ready? Can we keep the person and his or her needs at the center of these critical conversations and interactions?

Challenges

Questions and issues to address. Several key themes—and more questions—emerged from the group's rich discussion, pointing both to the difficulties and possibilities that this dynamic environment suggests.

- *Education and training.* Clinicians need to be prepared for and made comfortable with these advance care planning conversations—not just paid or required to have them. The language used with patients and families needs to be clear and understandable. For

example, how many people know what an advance directive is? A health care proxy? Should clinicians and others talk about “informed consent” or “informed choice?” Are we clear about the difference between “care” and “treatment?” (We may end “treatment,” but should never end “care.”) There is much work to be done to clarify these and related communication issues, particularly in traditionally underserved communities who may have different attitudes toward end-of-life care and talking about death.

- *Checklists vs. conversations.* A related tension revolves around the values and limits of checklists. Does a checklist-style requirement to have an advance directive, for example, lead to a rich and meaningful conversation or to a perfunctory and meaningless (but reimbursed) encounter? How do we best measure the quality of these interactions to ensure the best possible conversations for those with serious illness?
- *Where do we start?* Should we assume or expect that it is the clinician’s job to initiate advance care planning? Or do we believe that people can have these conversations at the kitchen table and bring the subject into the clinician’s office? The group recognized that work needs to be done both inside the health care system and outside in the community. Those in the group working for institutional change inside health care noted the need to be responsive and connected to the larger community. Those working to change the culture outside the health care system were also aware of the need to influence the culture and the supports inside health care. There is much room here for a holistic, outside-inside strategy.
- *Accessibility.* It is not enough if people have conversations and sign advance directives. We must also create a robust and simple system to retrieve those directives from electronic health records and other places when the time comes. Otherwise, the directives will be “buried treasure,” useless to those who need them, when they need them.
- *Unfunded expectations.* While the new regulations and reimbursement are certainly positive, those working in the health care system, for example, noted that these policy changes come without the funding for implementation or the needed training noted above. And in low-resourced settings or clinics, clinicians are already overwhelmed and challenged to take on “one more thing.”

Opportunities

Moving Forward. Looking ahead, a number of hopeful ideas were raised:

- *Multiple conversations, multiple venues.* The work ahead requires a strategy that brings together institutional and cultural change, health care providers and people/patients and their families. It should follow the “conversation” from the kitchen table to the clinician’s office to the electronic health care record. Everyone—clinicians and families alike—clearly needs to build their communication skills and become comfortable with these interactions.
- *Building the field.* As this work is just entering a period of what we expect to be rapid growth, there will be the need for “more”—notably more time, resources, people, and funding for this work, as well as more support for innovations and innovators. This

includes support for working beyond well-resourced health systems and ensuring that advance care planning efforts serve all communities.

- *Getting everyone involved.* There was recognition of the tension between getting advance directives that are useful and clear for providers, while also including families and loved ones in the process and ensuring their needs are met. **POLST** and other such forms are fundamentally between seriously ill patients and clinicians. We need to have conversations around these documents earlier and with loved ones or caregivers, as well as with seriously ill people themselves.
- *Language matters.* Talking about these issues requires us to frame end of life in the way that people experience it. One member of the group ended with the thought that end of life should “be the dessert to a life well lived.” Another said the goal wasn’t so much a “good death” as “more good days.” Finding the right language will be critical to helping all of us have these needed conversations.

There is much work to be done, but there are tremendous opportunities for making needed change in this area. We are in the middle of a huge transition, with “one foot in two canoes” as one participant put it. No matter the current uncertainty, we should expect significant improvements in serious illness and end-of-life care in the months and years ahead.

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