

Making life decisions at the end of I-5: Ramping up to National Healthcare Decisions Day

Change AGENTS Initiative

The John A. Hartford Foundation's Change AGENTS Initiative was a three-year effort dedicated to improving the health of older Americans, their families, and their communities through practice change. The initiative harnessed the collective strengths, resources, and expertise of the foundation's interprofessional community of scholars, clinicians, and health system leaders. The Change AGENTS Initiative was managed by The Gerontological Society of America.

The 34 projects funded through the Action Awards grants program showcased the improvements that interprofessional teams can bring to light by implementing evidence-based programs into targeted care settings in local environments.

These one-year grants for up to \$10,000 were available to interprofessional teams led by Change AGENTS for the purpose of achieving meaningful change to practice or policy that will improve the health and wellbeing of older adults and/or their families.



The people of Whatcom County, Washington, have a good feel for what life is like at the end of the line. The county sits in the northwest corner of Washington State, which is the northwest corner of the contiguous 48 states of the United States.

Interstate 5 leads travelers north to the Peace Arch, which marks the 49th parallel—the border between the United States and Canada. The Pacific Ocean laps at the western edge of the county.

What those in Bellingham and other Whatcom towns were not so familiar with, though, are the decisions people face at the end of long life, when disease processes lead to decline and ultimately death. That's where Casey Shillam, PhD, RN-BC, Catherine Bree Johnston, MD, MPH, FACP, and their colleagues in Northwest Life Passages

[<http://whatcomalliance.org/northwest-life-passages/>] came into play, developing a communitywide blueprint for how to improve palliative care and educating local workers and their families about the need for advance directives.

Seeking to work through the county's largest employers, Shillam acted on her passion of "getting people to start understanding that goal-directed conversations of care are needed before the onset of life-limiting illness so people are not going through high-intensity procedures, taking high levels of medications, or having interventions they never wanted." Knowing that the needed community engagement effort would not be funded through traditional grant sources, Shillam and Johnston applied for and were awarded a Hartford Change AGENTS Action Awards grant. They used this award as seed money to start a ramp-up event preceding the annual National Healthcare Decisions Day, when national organizations encourage people to make sure they have advance directives in place that express their wishes for a time when they are not able to speak for themselves.

Administered by The Gerontological Society of America, the Hartford Change AGENTS Initiative accelerated sustained practice change to improve the health of older Americans, their

families, and communities. The initiative harnessed the collective strengths, resources, and

expertise of the John A. Hartford Foundation’s interprofessional community of scholars, clinicians, and health system leaders so they could learn from and support one another while they adopted, evaluated, and sustained changes in practice and service delivery. The Change AGENTS Action Awards grants program was designed to support Change AGENTS in implementing promising ideas in practice change.

The situation

Leaving a position at Baltimore’s Johns Hopkins Center for Innovative Care in Aging, Shillam in 2013 brought a background in nursing care and a research interest in pain management and end-of-life care to Western Washington University in Bellingham. There she founded the Palliative Care Institute [<https://pci.wvu.edu>] and began working with PeaceHealth and with Johnston, director of palliative health at the PeaceHealth St. Joseph Medical Center. Based on work done at the PeaceHealth acute-care facility, Shillam and Johnston engaged with the Whatcom Alliance for Health Advancement, which already had an advance planning initiative.

“All three of these organizations came together in 2013 to recognize that collectively we really could raise awareness in the community,” Shillam said. “We had efforts that could align what we were doing. Over the course of a couple of years, we wound up creating Northwest Life Passages and developed a communitywide blueprint for how we wanted to improve palliative care in our community.”

Community members involved in the Palliative Care Institute brought up the challenges of getting more people to take action on National Healthcare Decisions Day [<http://www.nhdd.org>]. First begun in 2006, the event has been held on April 16—the day after tax returns are due; it is now being expanded to a weeklong effort. The community members had great ideas about engaging with large employers in Whatcom County and holding information sessions with employees about a month before Decisions Day. Their goal was to contribute to the “60 by 65 Campaign”: to have 60% of those 65 years of age or older in the region with an advance directive on file in the local hospital by 2017.

What they lacked was money and expertise on how to run a large event. For that, Shillam and her colleagues were more than willing to help. The institute already had the needed conference infrastructure, having started an annual summer event with a keynote speaker and breakout sessions. “All of our events were tailored to draw together community members and health providers,” Shillam said. “Our goal on the provider side was to draw a wide variety of disciplines—medicine and nursing, social work, clergy, pharmacists. Really anyone and everyone that you can think of in an interdisciplinary team approach. We made sure that we had speakers who would draw those different professions and have applicability to their practices.”

The solution

Shillam and other leaders of the Palliative Care Institute were familiar with the highly successful Respecting Choices model in La Crosse, Wisconsin [<https://www.gundersenhealth.org/respecting-choices/>]. “As we began to write the grant

proposal, the central question was how can we achieve a really high rate of advance care plans on file—how can we be the next La Crosse?”

Talking through what the options were, the group kept coming back to how to engage with employees at the county’s large employers—BP Cherry Point Refinery, Raptor Group businesses, and the county, as well as those working at PeaceHealth. Shillam recalled, “Instead of trying to get invited to those organizations, we said, ‘Well, if we invited the employers from those larger organizations to come to a ramp-up event, and invited community members and health providers as we always do for the summer institute, wouldn’t that be a great way to try to get their interest and to get them on board with having workshops held onsite?’”

Using funds from the Hartford Change AGEnts Action Awards grant, the ramp-up event was organized and held in March 2016. “It was a remarkable day,” Shillam said. “We had a lot of amazing panelists. The speakers talked about why do we need to have advance directives in place and how to do that. We were able to get buy-in from employers to have the Whatcom Alliance for Health Advancement provide onsite workshops. These sessions go step-by-step showing employees how to prepare an advance directive. The outcome is exactly what we had hoped for—we are seeing a ripple effect with many of the large employers in Whatcom County.”

Not only are the workshops being presented at more and more worksites, but employers have also decided to encourage their workers through financial incentives. “If employees attend the workshops and get their advance care directives on file with their primary care providers in the health system, the employers give them a reduction in their insurance premium,” Shillam said with satisfaction.

How the grant improved outcomes

Washington is one of a growing number of states that introduce a lot of variables into end-of-life care: death with dignity, medical marijuana, and even the use of psychedelics in some situations. Shillam said the Palliative Care Institute is working through these issues in Whatcom County: “We’ve really tried to embrace many ways of looking at end-of-life care so that our providers and our community members are educated in knowing what options there are out there. That means sometimes we have to talk about controversial issues.”

Those community members are anything but passive recipients of institute messages, Shillam emphasized. In many ways, activist community members have driven institute activities by conveying their needs, helping create responsive services, and even serving as the institute’s best public relations voices. “We have two PeaceHealth critical care nurses who do a very needed presentation of the realities of resuscitation,” Shillam said. “One of our very motivated community members heard them speak at a senior center, talking about the realities of resuscitation and what it really means to go through that.”

That community member has become close to being the publicist for the nurses, Shillam said. Because of an experience with her husband, the woman is very passionate about resuscitation and advance directives, and she is booking the nurses to do this presentation all around the community.

The Hartford Change AGEnts Action Awards grant—even though it is a small amount of money—gave Shillam, Johnston, and their colleagues the opportunity not only to “do something as important as this,” Shillam recalled, but also to gain access to the Change AGEnts network and, she hopes, the proof-of-concept research data needed to get larger grants. “The gratitude I have for the Hartford Foundation and its providing opportunities to do this kind of work is very heartfelt,” Shillam said.