

## Anderson EW. Supporting Patients with Serious Illness: The LifeCourse Model. Minnesota Physician. 2017;30(12): 10-11.

Mrs. Olsen—your patient of 20 years—is back home after an admission for heart failure and COPD. She’s doing better now, partly because she is wearing oxygen all the time. She feels well enough to take care of her granddaughter two days a week while her daughter goes to work. When you ask, “Mrs. Olsen, how are you?” she answers, “I’m fine!” Has anyone talked with her about having a serious illness? How much time does she really have? What does her family think about her health? Is anyone worrying about this except you? This scenario of serious illness has become very, very common. It occurs in medical offices, emergency departments (EDs), intensive care units, and post-acute care. As physicians, we can diagnose and prescribe treatments for the multiple conditions presented by these complex patients. But we go home at night waiting for the call from the ED because of all the things we can’t control. Is there adequate support at home? Does the family realize how sick the patient is becoming? Is she developing cognitive impairment? Has the patient ever talked about her wishes for care? Is it important that Mr. Olsen died nine months ago?

### **The needs of the seriously ill**

Five years ago, a team at Allina Health set out to find a way to respond to the needs of patients with serious illness. The new approach addressed nonmedical as well as medical needs, it was co-created with patients and families, and it focused upstream of hospice. We used trained lay health care workers to deliver whole-person care in patients’ homes during monthly in-person visits. About 1,900 patients and family members were enrolled over a four-year longitudinal study. The results have been gratifying:

- Quality of life is better maintained.
- Patients spend fewer days hospitalized and more in hospice.
- The program saves total health care dollars far in excess of the cost to provide it.

Our patients and families picked the program name—LifeCourse. You can follow the stories of LifeCourse patients and the physicians who cared for them in a series of compelling late life documentaries from Twin Cities Public Television: [www.lifecoursemn.org](http://www.lifecoursemn.org). Picking the right patients was a challenge. Traditionally, palliative care in the community focuses on high utilizers, but LifeCourse sought out everyone with heart failure, cancer, or dementia who was sick enough that they might die in the next two to three years. We plumbed the electronic record, applied a few simple metrics for comorbid illnesses, and then did a brief chart review. Willing patients were enrolled into the study, along with their key family members. The providers in our chosen sites were supporters of LifeCourse from the start, and allowed us to enroll the appropriate patients.

### **Care guides**

The LifeCourse care guides are the heart of the program, providing basic nonmedical care. Our health system had already successfully used care guides in the primary care clinic setting, helping patients manage diabetes and hypertension (Adair et al., 2013). Recent college graduates, health system employees looking to get closer to patient care, and late career folks in search of meaningful work all applied for the LifeCourse care guide positions. We looked first for great interpersonal and communication skills. The LifeCourse care guides were then trained in a broad range of palliative care areas, communication skills, and advance care planning. Palliative care is all about the whole person, their values, and the family setting in which they live. LifeCourse care guides can provide whole person care because they develop a relationship by meeting with patients and families monthly in their home. They begin with straightforward questions, such as asking about a patient’s understanding of their medical issues and then gradually progressing over six months to include inquiries about social support, spiritual well-being, financial-legal issues, legacy, and eventually end of life and grieving. Along the way, patients complete self-assessments, for example a list of functional and symptom scores. This information can be shared with providers, particularly when patients identify new or changing conditions. Every

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encounter begins with an inquiry into what is most important. In reviewing a thousand of these goals in patients' own words, only 40 percent turn out to be strictly medical. The rest focus on family, work, housing, and other important nonmedical aspects of living. Knowing that anything can come up for discussion, the LifeCourse care guides use their concise set of questions as starting points to explore meaningful issues.

### **How it works**

How can a lay health care worker do all this? We now know the answer is, "Very well!" But we learned some important things along the way as we asked nonclinicians to do this complex work. LifeCourse care guides were there to help patients explore all areas of their illness experience. They did not assess or diagnose medical conditions. They did help patients connect to their clinics and care teams, acting more as mortar between the bricks than as a separate clinical service. Being non-experts, the care guides naturally helped patients and families seek out resources in the community. The tools we provided to LifeCourse care guides were those aimed at the knowledgeable public, such as the Alzheimer's Association website, or our metro area go-to service, Senior LinkAge Line. The LifeCourse care guides helped empower families to find and use these resources.

As part of this work, we intentionally studied the results of the LifeCourse intervention. We surveyed patients and families every three months. Over the course of time, quality of life—particularly social and emotional wellbeing—declined in our control group, but was maintained in the LifeCourse patients. And this occurred even as overall function was declining for both the intervention and the comparison groups. The overall experience of care in the LifeCourse intervention group was better as well.

### **The role of hospice**

Addressing short lengths of stay in hospice was a priority for LifeCourse. Currently the national median length of stay is only 17 days, hardly enough time to establish trusted, supportive relationships with the hospice care team. In our study, LifeCourse patients were more likely to get into hospice, and their median length of stay increased by over 50 percent to 28 days. Emergency visits fell 16 percent, hospital days declined by 27 percent, and ICU stays decreased by 57 percent. These substantial drops in unwanted aggressive care resulted in overall savings of almost \$1,000 per month for every patient. The full cost of providing a LifeCourse care guide is only about \$120 per month, so LifeCourse would easily pay for itself in a value-based payment environment.

### **Moving from research to practice**

So, with impactful results, where is LifeCourse being implemented? It is working in two primary care clinics, an advanced heart failure clinic, a brain tumor clinic, and within our care management team. One of the clinics is a community health care center in North Minneapolis, employing LifeCourse care guides hired from within the local community. When we present LifeCourse to our medical staff, physicians explicitly talk with me about wanting to reclaim the heart of medicine. This is a powerful phrase! We went into medicine to treat human beings, not diseases.

LifeCourse gives us a window into what is most important to our patients. It gives them another trusted relationship in the care team to talk about issues that affect their daily lives. LifeCourse care guides are often able to help patients bring well-formulated questions to their physician visits, or clue the provider into an important event in the patient's life. As one geriatrician said, "It allowed me to have just the right conversation with my patient." Person-centered, supportive care can make a real difference in how our patients experience serious illness. Attending to the whole person can also make our work lives richer and more meaningful. As LifeCourse seeks partners both locally and nationally, and as value-based care gains traction, this approach and initiatives like it will make more and more sense for every patient with serious illness.