

Helping Patients with Life-Limiting Illnesses

Chronic and life-limiting illnesses like cardiovascular disease affect nearly 90 million people in the U.S, according to the Centers for Disease Control and Prevention. Patients and their families may feel all alone trying to find their way in the complicated health care system. These challenges can cause panic, anxiety, frustration, confusion, anger, and hopelessness.

Experts have found that seriously ill patients whose pain and symptoms are well managed can better handle treatments, and improve their quality of life. “Palliative care” is the term medical professionals use to describe management of seriously ill patients. Unlike hospice care, palliative care can help patients move forward with treatments that either cure their illness or help them live longer.

Palliative care is a growing medical specialty in which a team approach is used to care for the patient. Without this type of care, patients with life-limiting illnesses may:

- end up in the hospital for long periods of times
- have to repeatedly return to the hospital after being discharged
- have symptoms that get worse
- pay more money for their care.

People think of palliative care as an “end of life, hospice type” of service. ICSI sought to add elements of this “specialty” palliative care into routine primary care. That would ensure that such things as pain and symptom management, care coordinating and shared decision-making were introduced much earlier in the patient’s care.

ICSI created the LiLLIE (Living with a Life-Limiting Illness Effectively) model—a different way to delivery care--to describe the important parts of palliative care that can be delivered to the patient to primary care. LiLLIE also encourages doctors to partner with the patient and family to create a plan that addresses the patient’s physical, cultural, psychological, social, spiritual and financial needs. When doctors listen to the desires of the seriously ill patient, patients can receive high-quality, patient-centered care that relieves suffering, improves quality of life for both the patient and the family and reduces health care costs over the long term.

The doctors, health plans, employers and patients who collaborated within ICSI to design the LiLLIE model believe it holds great promise in improving care delivery. Elements of LiLLIE are being adopted by primary care and specialty care clinics, and are supporting efforts to improve the health and care experience of patients while lowering their health care costs.