

# A Design for Change

ISSUE NO. 5

CRITICAL ISSUES IN CARE FOR CHRONICALLY AND TERMINALLY ILL KANSANS



## *Living & Learning Together: Mining the Treasure and Wisdom of Kansas Elders*

Though Marianne's children invited her to live with them, she declined, choosing to remain alone in her home. After a fall, she held on to her independence by paying someone to stay with her. When she felt she could no longer afford to pay for help, she struggled to stay in the home she loved. Over time, staying at home became impossible, because Marianne needed help with daily tasks of living. Against her wishes and hopes, Marianne's children finally convinced her to move from her home. Marianne never again felt a strong connection to her friends, her community or the life that she so loved.

Marvel and Harry had lived in the same home for 48 years, raising five children and establishing deep roots in their community.

*Healthcare must work to extend the time that citizens remain engaged and active.*

As Harry's diabetes and arthritis progressed, Marvel offered more and more caregiving to him. When Marvel could no longer drive, their daughter, the only child who remained in the community, tried to help them as much as possible while still working full-time and raising three children as a single mother. Marvel and Harry's decreasing interaction with others lead to depression and anxiety.

Sam and Linda are in their Searly 50s and thinking about how and where they want to live for the rest of their lives. They are very active, in good health and still working full-time. Both Sam and Linda have been caregivers to aging and ill parents, and they would like to be a part of a community that is structured in such a way that

**Helping all Kansans with advanced, chronic and terminal illnesses live with dignity, comfort and peace.**

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assures them that their families will not have the full burden of caregiving for them -- when and if that time arrives. They would like to be part of a community that has designed support services that allow them to remain active and engaged in life for the rest of their lives.

Every day, people like Marianne, Marvel and Harry, and Sam and Linda are facing similar experiences all across Kansas. Valuing our independence and freedom, we tend to resist the acceptance of assistance until we have no other choice. We then face changes when our abilities to create new relationships and our energy to do so are limited. And, often, we are placed among others who face the same limitations.

Growing old and dying in America is fundamentally different than it was in the previous century. Baby Boomers will have profound impact not only on the process, but also on the complexion, of the aging and dying process. Advances in medicine and technology - from antiviral medications to custom-designed drugs, genome mapping

and genetic research - will continue to accelerate. We face changing definitions of prevention, detection, diagnosis, intervention, treatment, management, dependence, life support and futility.

How and where Kansans live as they age is an issue of great concern. We face a growing shortage of available caregivers – both professional and informal. Growing numbers of Kansans live with multiple chronic illnesses and with moderate to severe disabilities. Structures that have housed the very ill are not sufficient to care for the aging population of the future.

As Kansans age, most will face living with one or more chronic illnesses. The providers of health-care are trained “to diagnose, instruct, and take charge of the treatment process. But evidence increasingly shows that patients with chronic disease do best when they themselves take a leading role, making informed decisions about health goals and pursuing them confidently, with caregivers as partners, offering support, education and practical help in overcoming barriers.” (IHI.org)

*Where and how will the growing number of Kansas’s aging population live? What will be their quality of life?*

## *The Aging of America*

*In the next 25 years, the population of Americans age 65 and older is expected to be 71.5 million, a 100% increase from 2000. It is in the best interest of all Kansans that aging citizens remain healthy. We need to invest in this health through research, education and demonstration.*

*The growth will continue* and, by 2050 the 65+ population will jump to 86.7 million.

*Citizens over 65 will grow* in numbers from 12.4% of the US population in 2000 to 20% by 2030.

*The 85+ population*, the fastest growing age group, is projected to increase from 4.6 million in 2002 to 9.6 million in 2030.

*The tsunami of aging* will occur between 2010 and 2030 when the Baby Boomers become age 65. This is the healthiest generation our country has known, so aging does not have to mean decline. Healthcare must work to extend the time that citizens remain engaged and active. With the costs of treating disability, our efforts to support active and quality life may help reduce healthcare costs as well.

—Source: US Census Bureau

The LIFE Project shares with the Institute for Healthcare Improvement the belief that those who are aging and/or ill have a higher quality of life when they are empowered to identify and address their own needs and are provided support services to do this.

The LIFE Project, in working to help chronically and terminally ill Kansans live well, has been drawn to work with, empower and learn from and with those who are aging. We want to maximize the resource that these citizens are to our state and to identify and create support networks, processes and environments that facilitate quality of life. We want to face the challenges these citizens face, to imagine and create best possible solutions and to share what we learn with others all across Kansas.

For eight years the Kansas LIFE Project has been working to help chronically and terminally ill Kansans live well. The challenges of managing chronic illnesses in ways that enhance quality of life and address fiscal limitations are huge. Currently, three-quarters of us reach the end of life living with chronic illnesses, and 74% of health-care costs go to dealing with these chronic illnesses and their related outcomes.

Kansans from earlier genera-



tions have approached the end of their lives and moved from health to death in fairly quick ways. Now, that process is greatly extended. Resources—human and financial—are a challenge. The Baby Boomers, as no generation before, provide great opportunity – and need—for

learning to address the challenges of life and living as health and vitality slowly decline. These citizens are resources – not burdens—and opportunities for learning are tremendous.

While 80% of adults age 55 to 74 own their homes, the percentage of older

adults living in their home declines with age and

health status. (Source: AoA Aging Information Notes) Why not, the LIFE Project asks, create intentional community at a younger age, when health and vitality are rich? And, why not create these communities in ways that mean residents will almost never have to leave the community unless they choose to do so?

Aging-in-place, though often talked about, is seldom a reality for those who live long enough to become frail and ill. The LIFE Project plans to create such a community of elders.

This intentional community will benefit not only the residents who live there. The goal is to provide information, resource and support that helps to improve the quality of life for all aging and/or ill Kansans. The LIFE Project plans to collaborate with other groups to create such a community of elders—engaged in lifelong learning and research. Kansans will be able to age in place—almost never again having to move unless they choose to do so. Why wait until we are frail and seriously ill before creating meaningful communities in which we can age in place?

The LIFE Project envisions a transition into be-



*“...patients with chronic disease do best when they themselves take a leading role, making informed decision about health goals and pursuing them confidently, with caregivers as partners, offering support, education and practical help in overcoming barriers.”*

**- Institute for Healthcare Improvement**



coming the Kansas LIFE Center. The LIFE Center will include the following:

- An active community of residents committed to life-long learning;
- Active partnerships in research and exploration projects designed to learn about and improve quality of

- A practical research-based model that will test, measure and evaluate alternatives for elders. The research will include many perspectives and learn with and about those who are aging. Partnerships with a variety of academic, governmental and other agencies will be a part of the LIFE Center.

- Life-long learning opportunities by and for members of the residential and larger community.
- Sharing of resources and information, consultation, learning opportunities and publications that enhance the lives of other Kansans.
- Connections and communications with other similar communities across the country.
- Partnering with others to create myriad activities to support needs of ill and/or aging Kansans.

life;

- Dissemination of what is being learned in ways that impact quality of life all across Kansas and the nation.

Though much is yet to be determined, we do know that as the LIFE Project transitions into the LIFE Center, we will identify partners who share the goals of living, learning and sharing of information that are inherent in this effort.

The LIFE Center will strengthen Kansans ability to:

- Live well as they age.
  - Live well even when very ill.
  - Share information, learning and resources.
  - Identify challenges and opportunities and demonstrate practical solutions to common challenges.
  - Enrich and inform academic and research endeavors.
  - Enrich and inform governmental responses and systems.
- Key components of the LIFE Center include:
- An active and vital community of residents.
  - A rich life in a community structured in ways that enable almost all residents to remain in the community as long as they wish.

*The LIFE Center will be a living demonstration of the combined power of residents, public and private organizations and the government working together to improve quality of life while, at the same time, working to contain costs.*

## The Four “Rs” —

- Residents
- Richness
- Research
- Resources

### Residents and Intentional Community

The LIFE Project envisions a residential community of young, middle and older elders. We have been influenced in our thinking by ElderSpirit Community® in Abingdon, Virginia. The LIFE Project has been

selected by ElderSpirit® as one of six groups from across the country to benefit from their nurturing, utilizing funds from the Retirement Research Foundation.

Criteria for residence currently under development by potential



residents are modeled on those from ElderSpirit Community ®. In brief, residents will be persons who respect others, appreciate diversity, want to be active, want to be life-long learners, would like to give and receive support as they age, value the environment, are open to change, value a sense of community with others and are willing to face the mysteries of aging and death.

### **Richness**

The LIFE Project believes that elders can live richly in community and that resources that support quality of life can be most effectively utilized to support—rather than supplant—elders. The values that the community will be built on will shape this richness. Values of the community include mutual support, quest for meaning and purpose, spirituality, health, life-long learning, creativity, care during illness and dying and mutual assistance.

Life will be enriched for all residents as they share in living and learning together and in facing the joys and challenges of life. Residents will also share with others across the state.

### **Research Partners**

The LIFE Center sees, as an integral component of success, learning from and about aging Kansans. Of the six US communities being mentored by ElderSpirit ®, the LIFE Center is the only group that plans to incorporate research into the model. Incorporation of research into the LIFE Center is critical, because learning and



measured outcomes offer the greatest benefit to all Kansans.

*Residents will be persons who respect others, appreciate diversity, want to be active, want to be life-long learners, would like to give and receive support as they age, value the environment, value the creative life, remain open to change, value a sense of community with others and are willing to face the mysteries of aging and death.*

We expect partnerships to emerge with academic institutions, governmental organizations and private and public agencies.

Issues related to living near life's end are a public health issue. Public healthcare leaders are charged to understand the science of aging and living with illness, to increase awareness and engage in education of citizens and to develop programs and policies that lead to needed system changes. (American Journal of Preventative Medicine, 2002:23(3))

Together, we will learn from and with the residents of the LIFE Center. And what we learn will be shared with others.

*As we age, what enhances and/or diminishes the quality of life?*

*What health and non-health interventions are most helpful?*

*What solutions can be found to address challenges and concerns of real Kansans who live with chronic illness?*

*How do we maximize the utilization of wisdom and expertise held by our elders?*





What may we learn about:  
*Aging and society?*

*Living with illness in ways that maximizes quality of life?*

It is in the best interest of all Kansans that aging citizens remain healthy and we need to invest in this health through research, education and demonstration.

*What are low- and mid-cost interventions that reduce costs of long-term care and high-tech interventions?*

*What are critical components of housing, community, transportation, socialization, meaning and purpose, spirituality and best utilization of resources?*

*How do elders support and help other elders?*

*How do we address needs while still maximizing life as health fails?*

### **Resources**

The LIFE Project believes that Kansas elders are themselves a powerful and important resource within our state. The LIFE Center will share through learning opportunities, research findings, citizen materials, public speaking and advocacy. The LIFE Project's history of working collaboratively and serving as resource and support will continue.

The LIFE Center will be a living demonstration of the combined power of residents, public and private organizations and the government working

together to improve quality of life while, at the same time, working to contain costs.



*With the high costs of treating disability, our efforts to support active and quality life may help reduce healthcare costs as well.*

**If interested in receiving updates about the development of this project, please write [donna@lifeproject.org](mailto:donna@lifeproject.org) and ask to be added to the "LIFE Center email list."**

### **Living Initiatives For End-of-Life Care**

*Helping Kansans with advanced chronic and terminal illnesses live with dignity, comfort and peace.*



The LIFE Project addresses public policy, professional education, and public engagement. Visit our website at [www.lifeproject.org](http://www.lifeproject.org) or call us at (888) 202-LIFE (5433) or, in Wichita, at (316) 219-3059.