

PERSPECTIVES ON AGING WITH DIGNITY

A Series by The SCAN Foundation

Changing the Conversation: How Americans Talk, Think and Feel about Aging



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In my 25 years in medicine I've never heard anyone describe themselves as a "functionally impaired patient with chronic multiple conditions," a "long-term care recipient," or a "dual eligible." Yet these types of terms are used everyday among health care professionals, policy wonks, and advocates to describe the

very people on whose behalf we work. The result of using this vernacular is that we talk at people rather than with them, effectively turning living, breathing human beings into obscure concepts. Dehumanizing the most human of processes – namely, growing older with health needs – breeds fear and apathy among the public at best, and at worst, alienation from a health care system that is perceived as too cold to care, too complicated to understand, and nearly impossible to navigate.

Over the past year, The SCAN Foundation has embarked upon a process to renovate the way we talk about the care needs that most of us will have as we grow older. The dominant phrase, "long-term care," poorly describes the vast network of supports and services that older people rely upon for assistance, ranging from transportation to and from a doctor's visit, to help in the home with basic living needs, to care delivered in an institution. Currently there are not enough services to meet the needs of today's seniors, let alone the impending aging boom. Yet reform has been elusive largely because the vital role that these services play in allowing individuals to age with dignity and independence are unknown or misunderstood. Most people tune out when they hear the words "long-term care" for fear that it only means nursing homes. For elected officials, the phrase "long-term" sounds too expensive.

Bruce Chernof, MD, is President and CEO of The SCAN Foundation, dedicated to creating a society in which seniors receive medical treatment and human services that are integrated in the setting most appropriate to their needs. The SCAN Foundation Perspective Series serves as a venue for opinions and observations about transforming the way in which we age. For more information, visit www.TheSCANFoundation.org.

“Long-term services and supports,” a common alternative, is a mouthful and jargon-laden. In order get the public and policy makers to connect with a growing need for support as we grow older, the key questions are what do people call this kind of care when they need it and how do we help people to talk about it without eliciting fear or indifference?

To seek these answers, the Foundation began listening to people nationwide talk about aging, from the heart and in their own words. Through focus groups with diverse Americans ages 40 and up, we heard highly personal, detailed stories of caring for a parent, spouse, or other loved ones, including the challenges, the joys, the fears, and the indignities. Then they were asked to envision life as a healthy, robust older person proceeding to a time when they needed help with at least two daily living tasks, such as getting dressed or getting out of bed. Even with experiencing caregiving first-hand, most were unable to see themselves ever needing this level of support. We then informed people that 70 percent of people who reach age 65 will need some form daily support as they grow older. When faced with this reality along with their own personal experiences, people used words like independence, options, choice and dignity to describe attributes that are particularly important to them when thinking about a time in life when they might require help from others.

Almost as important as what words were used are the words that were not used: hospice, palliative, geriatric, advance, dependence, death, specific diseases, legal phrases (e.g., advance directives or durable power of attorney) or anything else with

those Latin or Greek derivations so beloved by the medical and other professional communities. People focused on their independence and the quality of life they want to retain, not functions that would be lost. What emerged was a model of wellness based on people’s needs, preferences, and desires, not the traditional medical, sickness-based, paternalistic model.

Through several rounds of polling work including a 2010 poll of California voters, we found that Americans are not prepared and do not know how to plan for having their needs met as they grow older. Most are also unsure about the availability and affordability of services that can be provided in the home or community. While the majority of Americans are not aware that they will likely need support as they age, they want to ensure there is a system available so loved ones are not left in isolation without a network of supports and services. They want this system to be more responsive to individuals and families who find themselves needing care. And most importantly, they are willing to vote for candidates who champion improving the system of care for people growing older with health and daily living needs.

Based on what we’ve learned, we will keep working to build a new lexicon for growing older with needs that reaches people through both the head and the heart. Focusing on older people as “people” instead of patients and emphasizing choice and self-direction even for those with severe limitations, these are the keys to a new public discussion about aging with dignity and independence.