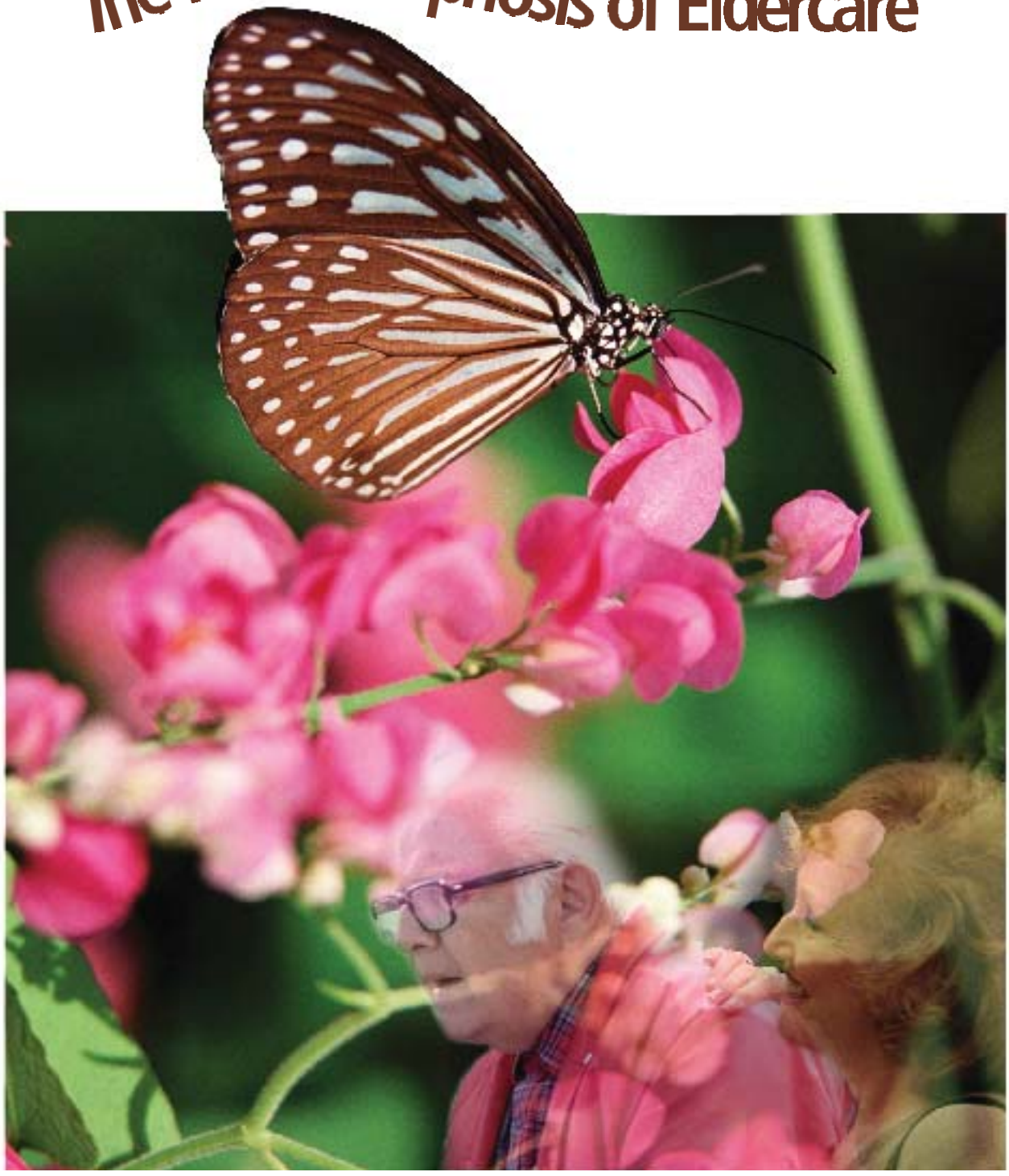
WELL-BEING: BEYOND QUALITY OF LIFE

The Metamorphosis of Eldercare



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Some organizations believe they are doing "culture change" when in reality, they are just putting wings on a caterpillar… How will we know the difference?

We cannot accurately judge the beauty of a butterfly by measuring the worn-out carcass of its caterpillar. Nor can we determine the true quality of life for residents and workers in long-term care by the way institutionalized nursing homes are currently evaluated.

It is a question that has long challenged pioneers of culture change: What makes life worth living and how do we measure it?

Old age, the pioneers contend, need not be a slow crawl toward decline and despair, but instead, a chance to joyously soar to new heights of human growth and awareness. They hold lofty goals for elder care, seeking environments that foster community rather than loneliness, meaningful activity rather than boredom and self-reliance rather than helplessness.

Like a caterpillar on its last legs, the current facility-based care system has much lower goals – simply to mitigate the decline of aging. And despite the best efforts of thousands of highly skilled professionals and billions of dollars in government support, the system is failing us all.

Elders dread the day they lose their freedom and move into a nursing home. Family members agonize over the prospect of "placing" parents or spouses. Staff members, who give their hearts and souls to caring for the elderly, seethe with frustration. Boards of Directors struggle to keep the doors open in the face of rising costs and inadequate reimbursement. A flood of litigation and losses overwhelms liability insurance providers.

Flaws in the Institutional Model of Care

The root cause of these troubles is a decades' long embrace of the institutional model of care in an archipelago of facilities serving 1.5 million of our frailest fellow citizens. Although a distinct improvement over what they replaced, these facilities are structured like military brigades with a strict hierarchy and a robust chain of command. Too often, the environment leads staff to place task assignments above residents' true needs. As a result, countless opportunities for genuine care are lost in the day's mad rush.

These shortcomings are abetted by a fear-based system of oversight extending from Washington D.C., to state capitals, to charge nurses on the evening shift. The result is a sterile institution where the sacred work of caring for elders falls prey to a bureaucracy no one wants and many despise.

The Culture Change Movement

Conventional gradualist approaches to this crisis are inadequate. We must brace ourselves for a complete transformation of the worlds we create for our frail elders and those who care for them.

We need a metamorphosis…

A marked change in the nature, function, appearance or condition of a thing/ especially a transformation that is not easily reversible.

- "The metamorphosis of a caterpillar into a butterfly."
- "The metamorphosis of the old house into something new and exciting."

How far do we have to go?
Just as the caterpillar must change into a butterfly to survive, the conventional long-term care institution must change into a place where:

- Elders feel at home,
- Family members enjoy visiting,
- Staff are respected and appreciated, and their opinions valued,
- The quality of care is beyond reproach,
- Life is worth living, and
- Legal action is unnecessary.

Thus is the goal of culture change, a movement that increasingly is gaining the attention of the long-term care industry. Motivated by the Eden Alternative®, the Pioneer Network, Action Pact, Wellspring and others, hundreds of long-term care organizations around the world are transforming the culture and physical environments of their facilities from an institutional to a person-directed model of care.

A Question of Measurement

The person-directed care model not only challenges us to change our attitudes, beliefs, and values, but to also redefine how we measure the quality of outcomes – a need growing increasingly urgent as more and more organizations begin the culture change journey.

The question is, "How will we know it is a butterfly, and not just a caterpillar in disguise?"

Some organizations believe they are doing "culture change" when in reality, they are just putting wings on a caterpillar. It may have beautiful wings, but it is still a caterpillar. How will we know the difference? How can a family know if it is a suitable environment for their loved ones? How can a caregiver seeking employment know if this is a good place to work? How will our government measure quality in the new model? How will providers be reimbursed?

The institutional model has well-defined measurements focused mostly around quality of care issues, with outcomes posted on our government's website for all to see. If used properly, they are effective for determining if an Elder is receiving appropriate physical care, but they fail to measure life worth living.

A Measure of Well-Being

"When we love a woman we don't start measuring her limbs." – Pablo Picasso

So, Picasso, what do we measure? What is quality of life, and what is true caring?

To help answer these questions and develop tools for evaluating the new person-directed model of care, The Eden Alternative put together a task force of experienced culture change leaders, educators and researchers. Our efforts were supported by the Jefferson Area Board of Aging and their representative, Arthur Rashap.

Eschewing the declinist's view of aging reflected in the institutional model of care, the task force worked from the perspective of old age as another stage of human growth and development. Accordingly, we defined the ultimate outcome of the person-directed model as WELL-BEING.

That is, the well-being of Elders, staff, families, leadership, the organization, and ultimately, the community. The task force recognized the importance of measuring well-being among all the members of the long-term care community, not just the Elders. It is our contention that in a true community, the Elders can only experience well-being if those surrounding them are also experiencing it.

Thus, the question becomes – What is well-being?

well-be·ing (wĕl'bē'ĭng)
n. A contented state of being.

Well-being is the path to a life worth living. It is what we all desire. It is the ultimate outcome of a human life. But what are the components of well-being? What do we need to experience contentment? The task force identifies seven primary domains of well-being: identity, growth, autonomy, security, connectedness, meaning and joy.

The Domains of Well-Being

- Identity – being well-known; having personhood; individuality; wholeness; having a history

Nothing exists without an identity. The nursing home as it exists today actively strips away our Elders' identities, leaving them virtually unknown and vulnerable.

In her research on the institutionalized elderly, Judith Carboni, RN, MSN, CS notes:

> "Elderly residents in nursing homes face non-personhood: identity becomes murky because they no longer have a special bond with a place that held a significant, personal meaning. Informants demonstrated a pervasive sense of uprootedness and non-belonging, as well as confused feelings about self and identity. What is significant in this feeling of uprootedness is its finality. In both instances, it appeared that the roots that fed each informant's identity and provided nurturance were more than merely pulled up; it seemed that the roots were actually severed. For example, how can one recover the roots of one's house if it is sold, how can one identify with a place that is no longer there? When possessions are dispersed among relatives or sold, they are no longer available to the individual for interaction and meaning; the relationship with objects and their memories become severed"
> - Carboni, Judith D., Homelessness Among The Institutionalized Elderly by Journal of Gerontological Nursing, July 1990.

One's own identity, history, life and feelings of self are essential components of well-being. Without this, our Elders "cease to exist."

- Growth – development; enrichment; unfolding; expanding; evolving

Conventional wisdom in our modern, industrial society regards aging as a process of decline. The institutional model of care centers on mitigating that decline. The person-directed model offers a radically different belief reflected in "The Live Oak Definition of an Elder". Live Oak cofounder and culture change movement leader, Barry Barkan, explains:

> An Elder is a person
> Who is still growing,
> Still a learner
> Still with potential and
> Whose life continues to have within it
> Promise for and connection to the future.

Longevity gives forth its own promise and potential. From staff's perspective, the institutional model offers little opportunity for personal growth in what are often considered "dead-end jobs". In a person-directed model of care, Elders and caregivers have every opportunity to learn and grow.

- Autonomy – liberty; self-governance; self-determination; immunity from the arbitrary exercise of authority; choice; freedom

Simply put, to be autonomous is to be one's own person…to be respected for one's ability to decide for oneself, control one's life and absorb the costs and benefits of one's own choices. Lacking autonomy, as children do, is a condition which allows or invites sympathy, pity or invasive paternalism.

The insitutional model assumes all decision making belongs with the organization, not with individuals. For the sake of "efficiency", personal wishes and choice are banished in the top-down organizational structure. Even the most basic personal choices of what, when, where, how much and in what order to eat is controled by the insitution.

The top-down organizational structure squeezes the life out of autonomy in "low-level" staff positions, thus eliminating the possibility of creative approaches by the staff who are most familiar with Elders as individuals and have the most frequent and meaningful interactions. As a result those who are likely to have the strongest impact on an Elder's daily life experience are the least involved in important decision-making.

- Security – Freedom from doubt, anxiety, or fear; safe, certain, assured; having privacy, dignity, and respect.

Abraham Maslow theorized that human beings are motivated by a hierarchy of needs, and that certain lower needs must be satisfied before higher needs can be fulfilled. For example, safety needs – the security of home and family, freedom from fear and anxiety – must be satisfied before we can grow toward self-actualization.

The institutional model provides Elders an environment fraught with fear and uncertainty. High turnover and shuffling of staff leave Elders in doubt of who will provide them with the most intimate kind of care. Personal belongings are not brought into the facility, as high rates of theft are the norm.

Security in this sense expands beyond the basic need for safety to also include right to privacy, dignity and respect. Lip service is often paid to the word "privacy" in the institutional model. Staff give a cursory knock on an Elder's door as they enter. A "privacy" curtain is provided between the beds in an "un-private" room. All space becomes public space, forcing the Elder into intimate situations with strangers. Sitting on a shower chair clothed in nothing more than a sheet, Elders are ungracefully whisked down public corridors, placed in a two or three-person shower room and "hosed" down. Such is the lack of security in the lives of

those who live and work in a long-term care facility.

- Connectedness – State of being connected; alive; belonging; engaged; involved; not detached; connected to the past, present and future; connected to personal possessions; connected to place; connected to nature.

"No man is an island, entire of itself; every man is a piece of the continent."
- John Donne

The idea John Donne brings forth in this meditation is not an unusual one – this idea of interconnectedness. Studies show physical and emotional benefits to staying connected with loved ones and with one's environment. As we age, many connections can be lost – we retire, spouses and friends die, children move away, we don't get out as much - all of these place us at high risk for feeling disconnected.

The risk increases dramatically for nursing home residents disconnected from the past by loss of familiar places and personal possessions, and from the future by loss of hopes and dreams. Thus, the present reality becomes endless days of boredom, helplessness and loneliness. As this seeps into their spirits, many disconnect completely from the physical and social environment, leaving a shell of a human slumped over in her wheelchair.

A person-directed model seeks to reconnect Elders and staff with the past, present and future, with their environment and with hope and dreams.

- Meaning - Significance; heart; hope; import; value; purpose; reflection; sacred.

The search for meaning is the primary human motivation, according to Logotherapy and Existential Analysis, the "Third Viennese School of Psychotherapy", developed by Viktor Frankl and first published in 1938.

Even in the degradation and abject misery of a concentration camp, Frankl was able to exercise the most important freedom of all – the freedom to determine one's own attitude and spiritual well-being. No sadistic Nazi SS guard was able to take that away from him, or to control the inner-life of Frankl's soul. One way he found the strength to stay alive and not lose hope was to think of his wife. Frankl saw those in the concentration camp who had nothing to live for were the first to die. Frankl found meaning even in the depths of horror, and with it, a reason to live.

The institutional nursing home strips away meaning in many different ways. Meaningful activity is withered into a program of mind-numbing, planned activities. The physical environment becomes meaningless for anyone except the decorator who designed it. The sacred work of caregiving is reduced to a series of tasks and procedures delineated in the interdisciplinary care plan.

A person-directed model infuses meaning into every corner, every act and every relationship. In that meaning, staff, Elders find life worth living rather than simply waiting to die.

- Joy – Happiness; pleasure; delight; contentment; enjoyment

"Joy seems to me a step beyond happiness-happiness is a sort of atmosphere you can live in sometimes when you're lucky. Joy is a light that fills you with hope and faith and love."
- Adela Rogers St. Johns

Joy is a short, simple word describing the highest possibility of human life. Joy is not a feeling in response to a fortunate event. That is happiness; and it fades away as quickly as the happy situation passes. Joy is not a momentary response to love or sky or water. That, too, is happiness, and it disappears when love is gone or the sky turns gray or the water hardens into ice. Joy is a condition of spirit that so fills a being that no amount of unhappiness can cast it out.

Find joy in a nursing home? It is possible, but only if the home is committed to creating a world where Elders, Families and Staff can experience identity, security, growth, autonomy, connectedness and meaning. That is a true community, marked by deep honesty and caring.

The work of the task force continues as we now must create tools which will measure well-being as the ultimate goal of a life worth living. We hope to soon be able to share these tools with hundreds of long-term care organizations that have come into this work of culture change - the work of transforming the caterpillar into a butterfly.

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