

Revolutionizing the Experience of
Home by Bringing Well-Being to Life:

The Eden Alternative Domains of Well-Being®



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"Well-being is a much larger idea than either quality of life or customer satisfaction. It is based on a holistic understanding of human needs and capacities. Well-being is elusive, highly subjective, and the most valuable of all human possessions."

Dr. William Thomas, What Are Old People For? How Elders Will Save the World.

A question that has long-challenged those committed to changing the culture of care is:

What makes life worth living, and how do we measure it?

Pioneers of culture change contend that aging and living with unique health challenges need not be about decline and despair, but instead, a chance to joyously soar to new heights of human growth and awareness. We hold lofty goals for how we care for each other, seeking environments across the continuum of care that foster community rather than loneliness, meaningful activity rather than boredom, and self-reliance rather than helplessness.

The traditional model of health care has much lower goals – simply to mitigate decline. And despite the best efforts of thousands of highly skilled professionals and billions of dollars in government support, the system is failing us all.

Individuals accepting support often feel as though they need to give up their autonomy in order to receive the assistance they need. Family members agonize over the prospect of placing loved ones in long-term care environments. Employees, who give their hearts and souls to caring for others, experience the frustration of the broken system. 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. Service providers struggle to provide quality care and services in a tight market where competing demands often trump any efforts to reframe the priorities defined by the system and put the person first.

The Culture Change Movement Facilitates Well-being...

Culture change is the common name for a global initiative focused on transforming care, as we know it, for individuals as they age and/or live with different physical, developmental, intellectual, and psychological abilities. It advocates for a shift from institutional models of care to person-directed values and practices that put the person first. Person-directed care is structured around the unique needs,

preferences, and desires of the individual in question. Through this approach, decisions and actions around care honor the voices and choices of care recipients and those working most closely with them

The ultimate goal of culture change is well-being for all – all care partners (employees, family members, volunteers, and the individual accepting support), the organization, and ultimately the community. The Eden Alternative promotes the concept of care partnership, which affirms that care is a two-way street, focused on ensuring the growth and well-being of everyone involved in the care relationship. It acknowledges that the quality of our relationships is the key to our success, and that care and well-being is for everyone, not just the individuals accepting treatment or services.

While the person-directed model of care challenges us to change our attitudes, beliefs, and values, it also redefines how we measure the quality of outcomes – a need growing increasingly urgent, as more and more organizations begin the culture change journey. 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 someone is receiving appropriate physical care, but they fail to measure the nuances of a life worth living. To address this deficit, we need to define a new way to articulate and define our success.

So, what is quality of life? How do we define genuine caring?

As human beings, we are inclined to pay more attention to the negative rather than the positive, to see the limitations rather than the possibilities. Our language and our societal perceptions reinforce the view that aging and/or living with physical, developmental, intellectual, or psychological challenges equals decline or disability. Well-being, as a frame of reference, requires us to focus on the strengths, possibilities, dreams, and goals of each individual. Doing so, we define quality of life in terms of what each individual *can* do and what they have to *offer* their communities.

Many organizations believe they are “living culture change,” when in reality, they are just polishing the brass and shining up the glass. This kind of window dressing does not deeply impact the lives of the people who live and work in the home, wherever home may be. How will we know the difference? How will family members discern organizations committed to person-directed care from other options? How will professional care partners seeking employment know if they’ve chosen the right place to work? How will our government measure quality in the new model of care? How will providers be reimbursed? The answer to these questions relies on the development of a simple, well-articulated frame of reference that drives home what it is we all want for ourselves and for our loved ones: *well-being*.

The Eden Alternative recognizes the importance of measuring well-being among all members of the care partner team. It is our contention that in a true community, we can only experience true well-being, if those surrounding us are also.

Well-being can be simply defined as “a contented state of being.” Satisfaction, wellness, and happiness are concepts that are often used interchangeably with well-being. However, satisfaction is based on expectations. If others don’t meet them, we are not satisfied. Wellness implies healthiness, which may

peak and decline over time. Happiness, too, is a human emotion that comes and goes. In contrast, well-being evolves and develops over a life time, deepening as we grow into our full potential as human beings.

Well-being is the path to a life worth living. It is the ultimate outcome of a human life. It leads us to ask the following questions: What are the components of well-being? What do we need to experience contentment? Through a collaborative effort involving a task force of culture change specialists, The Eden Alternative has identified seven primary Domains of Well-being: identity, growth, autonomy, security, connectedness, meaning and joy.

The Eden Alternative Domains of Well-Being®

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

Nothing exists without identity. The healthcare system, as it exists today, strips away individuals' identities, leaving them virtually unknown and vulnerable. The medical model identifies people by their job title alone, their disease process, what they need assistance with, or how their food is prepared and served. If you need increased assistance with daily life, you find yourself compartmentalized and grouped with others in a similar situation. Your identity is now tied to others.

Becoming well-known is a hallmark value of The Eden Alternative. Part of knowing each other deeply involves acknowledging our strengths and what we each have to offer. How we bring forth these strengths each day is a powerful way to celebrate each other's unique individuality.

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

"...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 finale. 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 have become severed."

Carboni, Judith D., Homelessness Among The Institutionalized Elderly, Journal of Gerontological Nursing, July 1990.

Identity is socially constructed. One's identity, history, life, and sense of self are essential components of well-being. Without this, individuals cease to exist.

In our health care system, we use care plans as a way to establish one's identity in terms of what assistance they need and the deficits they live with. Defining care needs in terms of diagnosis or disease homogenizes individual experience in favor of a group identity. When we use well-being as our frame of reference, the care plan becomes very individualized, focusing on strengths, preferences, goals, and growth. Now that we have a full picture of an individual's identity, we know how to partner with her to highlight and strengthen her sense of individuality. This is true for everyone involved in the care relationship: the individuals accepting support, employees, and family members.

Exploring IDENTITY:

- How do we get to know each other in a way that highlights each person's unique identity?
- How do conversations among the team members reflect knowing the individual's identity?
- How do our care partners help people continue to become well-known to one another?
- In written language, how is each individual's identity revealed?
- How are strengths acknowledged as a part of each individual's identity?

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. Connectedness is more than being surrounded by people who are friendly or skilled in customer service. It is about being in meaningful, and sometimes deep, relationships with others. It is about being a part of something that is bigger than ourselves. It is about being surrounded by things that have personal meaning for us throughout our lives. It means knowing our history and looking forward to our future.

During our lives many connections can be lost – we retire, spouses and friends die, children, friends and neighbors move away, we are home-bound and don't get out as much – all of these place us at high-risk for feeling disconnected. Individuals can become disconnected from the past, by loss of familiar relationships, places and personal possessions, and from the future by loss of hopes and dreams. Thus, the present reality becomes endless days of loneliness, helplessness, and boredom. As this seeps into their spirits, many disconnect completely from the physical and social environment.

A person-directed model seeks to reconnect all members of the care partner team with the past, present and future, with their environment and with their hope and dreams. Consistent care partner relationships

is the beginning of this reconnection. Creating a home space that is filled with meaningful items, and not medical trappings, continues the connections. Restoring relationships and making peace with one's life can be another way to foster connectedness. The possibilities are endless as we get to know each other's stories.

Explore CONNECTEDNESS:

- How are members of the care partner team connecting with one another regularly?
- How are meaningful connections in the lives of different care partners identified and shared?
- What actions is the care partner team taking to sustain and strengthen connectedness for all?
- What role does a connection with the larger living world play in the individual's life, and how is the care partner team developing that connection?

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.

In his speech on the four freedoms, Franklin Delano Roosevelt touched on the right of human beings everywhere to feel secure in their ability to express themselves freely, to define their own unique relationship with spirit, to feel financially stable, and to be free from fear.

Security also expands beyond the basic need for safety to also include right to privacy, dignity and respect. A person receiving support services often finds their space becoming public space, forcing her into involuntary, intimate situations with strangers.

Another aspect of security involves ensuring that our commitment to safety doesn't infringe on someone's rights and choices. This is where Autonomy and Security are closely related domains. Eden Alternative Co-Founder Dr. Bill Thomas reminds us to consider surplus safety when optimizing, rather than maximizing, security for another. Our healthcare system is risk averse. Once an individual relies on the support of others on the care partner team, they find their safety maximized and opportunities to take risk diminished, if not removed entirely. To take away all risk and chances to make mistakes is to take away the right to be human. Maximizing safety actually creates insecurity. While safety is important, there is a range of risk tolerance. Optimizing safety with the individual, based on their risk tolerance, creates security.

Exploring SECURITY:

- How does the care partner team address anxieties and fears that members of the team possess?
- How do care partners protect the dignity and privacy of individuals accepting support?
- What does respect for one another look like on the care partner team?
- How comfortable is the physical space and do people feel at home there?
- In what ways is the care partner team optimizing the safety of its members?

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, is a condition which allows or invites sympathy, pity or invasive paternalism.

The key to grasping the depth of autonomy is balance. The right to folly is an important part of autonomy. If people are only able to choose between courses of action that are good for them or pre-selected then the true dimension of autonomy is greatly diminished. No one, with very few exceptions, has complete autonomy. It is an optimized concept, not a maximized concept.

Top-down organizational structures squeeze the life out of autonomy. These structures eliminate the creativity of those who are most familiar with the individuals accepting support. As a result, those who are likely to have the strongest impact on an individual's daily life experience are the least involved in important decision-making.

Principle Four of the Eden Alternative Philosophy reminds us that the opportunity to give as well as receive is the antidote to helplessness. People who identify as caregivers sometimes perceive good caregiving as doing everything possible for another individual. However, this well-meaning generosity can lead to learned helplessness and diminish individual choice. This imbalance of care ultimately destroys autonomy for everyone involved in the care relationship. In contrast, the concept of care partnership reminds us that care is not a one-way street, that opportunities to give as well as receive are abundant and available to everyone in the care partner team. Care partnership, as a way of relating to each other, helps us optimize choice.

Explore AUTONOMY:

- In what ways does the care partner team optimize individual choice?
- What assumptions have been made in the care partner team, and how do they limit choices?
- How does the care partner team handle situations, when they disagree with the choices made?
- Are mistakes an opportunity for punishment, or limitation, or an opportunity for growth?

- When engaging care partners, do team members truly empower each other to take an active role in daily decision-making?

Meaning – significance; heart; hope; import; value; purpose; reflection; sacred

The medical model of care strips away meaning in many different ways. The physical environment becomes meaningless for anyone except the decorator who designed it or healthcare professionals who access it. The sacred work of care partnering is reduced to a series of tasks and procedures delineated in the interdisciplinary care plan. The rhythm of daily life becomes repetitive and numbing, holds no meaning and inspires little motivation for the individual.

A person-directed approach infuses meaning into every corner, every act and every relationship. This way, all care partners share in a life worth living. Simple pleasures are brought to life for all. The rhythm of daily life is affirming and nurturing, drawing people together in meaningful ways. Meaning is generated because of the caring relationships we have nurtured with one another.

Creating meaning takes a lifetime of effort. Meaning thrives and grows in moments of time. It is more than fulfilling a life's wish. It is woven into our emotions, our feelings, and our need to be needed. Each individual experiences meaning in different ways. Meaning sometimes arises out of other life events; trying to rationalize trials and successes. Often meaning comes from the very act of searching for it. Food and shelter can be withheld, but meaning is something others cannot deny us. Regardless of our life situation, as humans we are always seeking meaning.

Explore MEANING:

- How are care partners learning each other's stories about what is meaningful in their lives?
- How is time for reflection and celebration woven into care partners' lives?
- How are individual's goals honored and achieved in meaningful ways?
- In what ways might care partners destroy meaning for one another?

Growth – development; enrichment; unfolding; expanding; evolving

The institutional model of care centers on mitigating decline and changes in ability. The person-directed model offers a radically different belief.

Longevity gives forth its own promise and potential. From the employee care partner'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, all members of the care partner team have every opportunity to

learn and grow. The opposite of growth is death – physical and spiritual. Individuals living with frailty continue to grow and teach us how to be human beings in a caring community. Everyone has the potential to be a “growth partner” to someone else.

We thrive when we have good medical treatment and appropriate care. Someone can benefit from several aspects of well-being, but may have a health condition that is out of control which significantly inhibits growth. Quality care enables growth, and medical treatment serves this process. Care (helping another to grow) and medical treatment are skillful partners. Care for the individual comes first and foremost.

Exploring GROWTH:

- How are the strengths, dreams and goals of individuals captured and shared?
- How does the care partner team promote growth, based on individual strengths and goals?
- In what ways are care partners exposed to new life experiences and knowledge?

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 that describes the best, most elusive dimensions of human experience. While people often identify joy with a response to a specific experience (for example the birth of a child) these moments are actually more accurately understood in terms of happiness. Joy is both deeper and more encompassing than happiness.

One of the best ways to understand joy, and how it plays a role in our experience of well-being, is to become aware of how often it sneaks up on us. Moments of joy often catch us by surprise. These joyful moments cannot be scheduled, structured, or commanded into existence. They can only emerge from the moment. No one can say, “I’m going to experience joy at 2:30 this afternoon.” Efforts to intentionally create joy for others are doomed to failure. The best soil for joyful moments is always found in places where relationships are deep, rich, and intensely meaningful. It is through the relationships we have with one another that we can discover ways to recognize and celebrate moments of joy when they occur.

Explore JOY:

- How is the care partner team sharing stories about joyful moments in life?
- How can joyful energy enrich the lives of members of the care partner team?
- How does each member of the care partner team define joy?
- How do care partners express the joy they experience with one another?

How to Use the Eden Alternative Domains of Well-Being®

We recommend weaving these Domains of Well-Being deeply into the systems and practices used to support individuals wherever they live. Here are some examples:

- Growth plans (care plans)
- Problem solving
- Developing new systems
- Guide personal, organizational, and physical transformation
- Woven into education, policies and procedures, handbooks
- Welcoming new care partners to the team
- Evaluating and developing new systems
- Team development
- Leadership development
- Assessment of the organization
- Assessment of the care partner team members

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