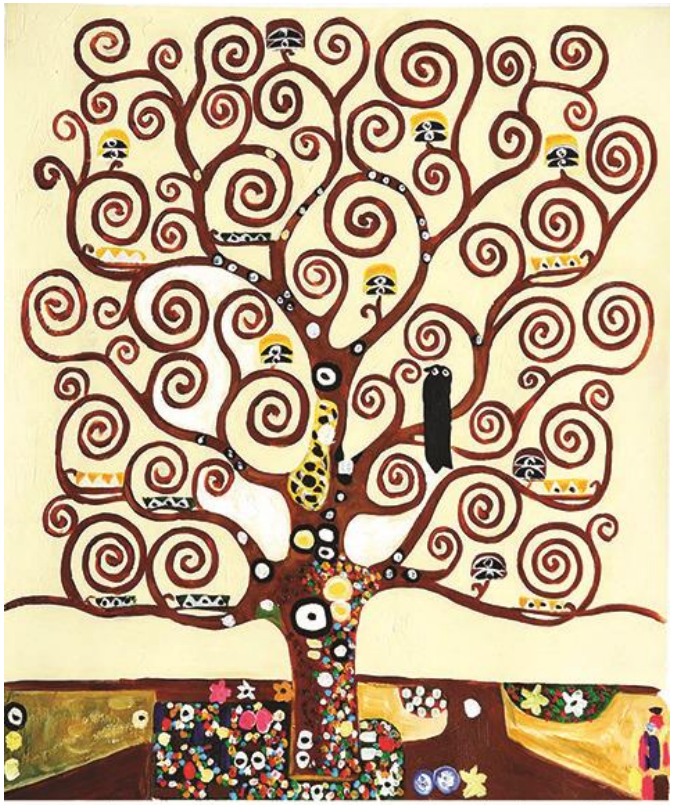
The Eden Alternative

Changing the Culture of Elder Care Since 1990

Interview with Christopher, President and CEO



Based on Gustav Klimt, Tree of Life, Stoclet Frieze, Lebensbaum, 1905

By Jean Galiana
ACCESS Health International

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Background

The Eden Alternative is a care philosophy based on ten core principles created by founders Dr. Bill Thomas and his wife, Jude. Bill Thomas was an early pioneer of person centered care, which he helped evolve into *person directed* care. The Eden Alternative is a not for profit organization that teaches the application of core principles to change long term care culture. The group educates through a combination of training courses, consulting efforts, and community outreach. Organizations that have adopted the Eden Alternative and achieved a sustained culture change have witnessed impressive results, such as lower caregiver turnover and higher quality of life for the elders. In this interview, Christopher Perna discusses the Eden Alternative philosophy and its impact on the culture of long term care. He also shares the details of their training and consulting efforts around the world.

About Chris Perna

Before Joining the Eden Alternative, Christopher Perna spent twenty five years in the insurance industry, most recently in long term care insurance as president of MedAmerica Insurance Company. His tenure at MedAmerica was marked by a combination of innovation and growth, including the introduction of a new line of long term care insurance products that revolutionized the industry and made MedAmerica an industry leader. Chris was active in advocating for the long term care insurance industry as a board member of America Health Insurance Plans for over eight years and as an organizing member of many industry events.

Prior to joining MedAmerica, Perna served as CEO of Blue Cross Blue Shield of Utica Watertown, New York for three years before leading that organization through a merger with Excellus Health Plan, based in Rochester, New York. Prior to moving to New York, Perna enjoyed a thirteen year career at Blue Cross Blue Shield of Massachusetts, where he served in a number of management roles.

Chris has also distinguished himself through his local service to elders as a past board chair for Lifespan and past chair of Family Services of Rochester. He currently serves on several not for profit boards in the aging services sector.

Interview

Jean Galiana (JG): Please give me a brief history of the Eden Alternative.

Christopher Perna (CP): Bill Thomas, the cofounder of the Eden Alternative, was working as the medical director of an upstate New York nursing home. He was treating a rash on the arm of one of the female residents. As he turned to leave her room, she reached up to draw him near and whispered, "Doctor, I am so lonely." Bill was shaken. As a Harvard educated physician and board certified geriatrician, Dr. Thomas searched his medical texts and found nothing to treat loneliness. He began spending his off hours watching and listening to life in the nursing home. He noticed three things happening in that environment that no one was acknowledging. He describes them as the three deadly plagues: loneliness, helplessness, and boredom. This observation was the genesis of the first principle of the Eden Alternative philosophy. Our other nine founding principles grew from there. Together, the ten Eden Alternative principles form the basis of our person directed care philosophy. The Eden Alternative approach to care is focused on putting the needs of the individual who is being cared for first.

Dr. Thomas began to envision a culture of care where people could thrive, not just survive.

Dr. Thomas began to envision a culture of care in which people could thrive, not just survive. He and his wife, Jude Thomas, launched a pilot program in 1991 that gave them the opportunity to operationalize the concepts of our philosophy. The Eden Alternative was incorporated as a 501(c)(3) not for profit organization in 1994. Today, we are an international organization reaching across fifteen countries and five continents. Our approach to care has moved beyond the walls of the nursing home and into the entire continuum of elder care.

Bill and Jude Thomas were also founding members of the Pioneer Network. This group of thought leaders was established in the 1990s, inspired in part by social worker Carter Williams. After witnessing the deplorable care that elders were receiving, Carter became determined to change the culture of long term care. Many people will tell you that Carter inspired the culture change movement that remains alive today in long term care.

JG: Please tell me more about the Pioneer Network.

CP: The Pioneer Network has members from across the United States and Canada. The network focuses on advocacy and education and operates as a convener. The Pioneer Network does not embrace any particular approach or model of culture change. The network is committed to person directed principles and care practices. The Pioneer Network has been influential with the federal government, and it has maintained a good working relationship with the Centers for Medicare and Medicaid Services. In the past, the Centers for Medicare and Medicaid Services

funded the Pioneer Network to engage in various research projects. The Eden Alternative is an active part of this vital network. I currently serve on their board of directors.

JG: How is the Eden Alternative connected to the Green House Project?

CP: The Eden Alternative and the Green House Project share a common heritage. Bill Thomas created both initiatives. The Green House Project builds on the philosophical foundation of the ten principles of the Eden Alternative by reimagining long term care environments from the ground up. Green House homes combine the experience of a rich and meaningful daily life with high quality clinical care. Each home is designed to house ten to twelve elders, which allows for a focus on relationships and daily life that is flexible and responsive to individual needs. Each home is warm, nurturing, and focused on growth—just like a greenhouse. The Green House Project and the Eden Alternative are completely separate organizations, but the Eden Alternative philosophy is at the heart of the Green House model.

JG: Has the government recognized the beneficial outcomes of implementing the Eden Alternative?

CP: Absolutely. Over the past few years we have received several sizeable government grants to deliver large scale projects sharing our philosophy and training with thousands of professional care partners. Governmental bodies have recognized the Eden Alternative for our performance and excellent track record, which has garnered us credibility and a broader audience. Recently, we have received a number of grants that enable us to package our educational offerings in combination with data analysis. The federal offices of the Centers for Medicare and Medicaid Services funded one of these grants. The grant enabled us to bring our Dementia Beyond Drugs training to nearly five hundred care partners across five states.

JG: Please tell me about the education, consultation, and outreach activities at the Eden Alternative.

CP: Education is at the core of everything we do. We often describe education as the antidote to fear. This is relevant to our work as change agents because change can be scary for people. Once people are empowered through education, implementing person directed care is much less daunting. Care professionals face the reality of a health care system that is not prepared to meet the needs of a growing aging population. Care professionals need practical tools and meaningful approaches that empower every member of the care team to become part of the solution. Our mission is to provide precisely those tools and approaches. We accomplish this in a number of ways. We provide materials and resources founded on our Ten Principles and the Eden Alternative Domains of Well Being. Our educational formats include several forms of interactive training, both in person and online. We offer webinar education, online learning collaboratives, topic specific resource guides, peer to peer networks, newsletters, and our website and blog. We also host a biennial international conference that draws participants from around the world.

One size does not fit all with person directed care.

JG: How do you assist in the implementation process?

CP: Organizations may choose to become a part of our Eden Registry. This is like an honor roll for organizations who demonstrate an exceptional commitment to consistently practicing our philosophy. With the ongoing support of our Eden Registry Team, registry members follow the Path to Mastry. The Path to Mastery is a flexible, guiding framework for implementing culture change through our philosophy. It is composed of four milestones that are outcome focused. This way, each organization can strive for the outcomes that reflect the unique individuals who live and work there; this aligns with our mission to provide highly individualized care. You cannot create person directed care through a prescriptive program. The beauty of a principle based approach like ours is that it provides both clear direction and a shared language to operate from. Principle based approaches ensure the flexibility to respond quickly and effectively to unique needs and circumstances as they arise. One size does not fit all with person directed care. Stepwise approaches do not work because they do not acknowledge how different each individual and each organization is. Implementation looks different from one organization to another. The key for all person centered care is that the decisions around care remain in the hands of the elders or those closest to them.

We have consultants called Eden Path to Mastery Guides. A guide works alongside the management and staff as an accountability partner. “Consulting” is a term we do not often use. The word implies someone who comes in and tells you what to do. An Eden Path to Mastery Guide assists and empowers an organization to customize the Eden Alternative philosophy to their unique operations, practices, and culture.

We have seen turnover for registered nurses and licensed practical nurses in organizations practicing our philosophy at only nineteen percent, as compared to a national average of thirty six percent for licensed practical nurses and fifty percent for registered nurses.

JG: How does the Eden Alternative affect the employees?

CP: Organizations working with the Eden Alternative are generally able to reduce staff turnover by increasing employee satisfaction and engagement. When people are given a voice and their perspectives are valued in problem solving and decision making, they are more likely to enjoy their jobs. When they are given the opportunity to deepen what is meaningful about the work they do, they take pride in their jobs. At the Eden Alternative, we have a golden rule: *As management does unto staff, so staff does unto the elders*. This means that it is simply not

possible to empower the elders we serve without first empowering the people who support their care. The epidemic turnover characteristic of long term care can be mitigated by the organizational culture that the Eden Alternative fosters.

We have seen turnover for registered nurses and licensed practical nurses in organizations practicing our philosophy at only nineteen percent, as compared to a national average of thirty six percent for licensed practical nurses and fifty percent for registered nurses. The turnover for certified nurse assistants in the same organizations has been reduced to fifty percent less than the national average. Staff stability is important in assuring quality care for elders. They need stable care partner relationships. It is also a critical financial consideration for providers. Staff turnover is very costly due to recruitment and training expenses for new hires. Care partners benefit from helping to create positive change.

We say, "elders rule." And we mean it.

JG: How would you describe that culture change?

CP: Culture change is about changing how an organization functions. It begins with the leadership team. Without leadership commitment, it is virtually impossible to succeed. Once leadership has agreed to move ahead with the change process, their job is to educate widely and engage all organizational teams in embracing the plan. Once teams begin to function as empowered teams, the organization looks and behaves differently. Hierarchy begins to flatten and decision making moves closer and closer to the elders and their care teams—no matter where the elders live. We say, "elders rule." And we mean it. They need to drive the course of their own care, no matter what their abilities are. If they cannot advocate for themselves directly, then those working most closely with them are engaged to speak on their behalf.

The language we use has powerful implications for the culture of care. The Eden Alternative is known for pushing the envelope in that respect. We use the phrase *words make worlds*. What you say conveys a lot of meaning. It is not just about being politically correct—it's about literally shifting how your brain perceives things.

Care partnership sees the elder as an active partner in his or her own care.

JG: Is that why you use the term care partner instead of caregiver?

CP: The idea of care partnership is central to what we teach. By our definition, care partners include family, friends, neighbors, volunteers, care professionals, and most importantly the

elders themselves. Care partnership promotes a culture that does not see the needs of caregivers as separate from the needs of care receivers. Care partnership sees the elder as an active partner in his or her own care. This seems like common sense, but institutional models of care rarely position the elders to direct the course of their own care. Caregiving is often a one way street. Care partnering is a two way street. This shift in thinking is powerful.

This kind of thinking shifts us from focusing on disabilities to focusing on abilities.

JG: How do word choices affect the care of someone who lives with dementia?

CP: We insist on using language that puts the person first. For example, we say someone is living with dementia, rather than suffering from dementia. Traditionally, health systems focus on managing deficits rather than supporting existing strengths. Instead of focusing on what someone cannot do and making care decisions based on this, we suggest focusing on what they can do as a more appropriate marker for care decisions. This kind of thinking shifts us from focusing on disabilities to focusing on abilities. We all have different abilities, no matter who we are or how old we are. Individualized care makes it possible to build on those abilities to maximize quality of life for each person on a daily basis. This is an important distinction from institutional approaches to care.

Through our culture change process and training, we empower employee care partners to think about the richness of the relationships they have with the people they serve. The care partners extract benefits from those relationships. There are nuggets that the care partner can recognize and appreciate. It is our hope that this mind shift can act as an antidote to the ubiquitous caregiver burnout.

We have proudly reclaimed the term "elder," which we define as someone who, by virtue of life experience, is here to teach us how to live.

JG: Does changing language help curb elder abuse?

CP: Yes. Ageism, or prejudice against someone due to their age, plays a large part in poor care practices. When people reframe the way they perceive aging and older people by recognizing the gifts elders have to offer, the relationship shifts dramatically. We have proudly reclaimed the term "elder," which we define as someone who, by virtue of life experience, is here to teach us how to live. We believe all elders, no matter who they are or what challenges they face, have a

unique gift or legacy to offer their communities. Elders are a valuable resource to be cherished. This is yet another opportunity for words to make worlds.

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JG: You mentioned that the Eden Alternative applies to the full continuum of care. Do you train home care providers?

CP: One of the misconceptions about the Eden Alternative is that we only serve nursing homes. Over the past several years we have diversified beyond nursing homes and worked actively with assisted living and independent living communities. We also work with home and community based service providers as well. Years ago, cofounders Bill and Jude Thomas came to the conclusion that even home can feel like an institution. We adapted aspects of the philosophy to meet the needs of elders who live at home and their care partner teams. We named that area of our teaching Eden at Home. Our ability to adapt and modify our material to support different living environments speaks to the flexibility of our principle based philosophy. **JG:** What do you teach the provider who is delivering home based care?

CP: The Eden at Home curriculum helps create a shared language between different members of the care partner team. The care team includes the elder first plus their family members, care providers, volunteers, neighbors, and friends. Like all of our educational processes, this shared understanding involves teaching teams how to build on strengths rather than just remedy deficits. The empowerment of the individual who is receiving services and support is crucial. Building on strengths is what makes this possible. Eden at Home also helps providers see that their unique niche in the care continuum does not exist in a vacuum. All care settings impact each other. This is why culture change and person directed care is a community wide issue. To be truly successful these concepts need to be woven into all aspects of care.

We often hear from care partners that the Domains of Well Being humanize the experience of care and offer them a new lens to see the needs of the elders and their fellow care partners.

JG: Please tell me about well being.

CP: The concept of well being is an essential aspect of this discussion. Through a grant funded effort in 2004, the Eden Alternative convened a task force of culture change experts and identified seven primary domains of well being. These Eden Alternative Domains of Well Being

are identity, connectedness, security, autonomy, meaning, growth, and joy. A detailed explanation of these domains can be found in a white paper available for free on our website.

We teach care partner teams to practice anchoring all decisions, choices, and actions in the Ten Principles in combination with these Domains of Well Being. We often hear from care partners that the Domains of Well Being humanize the experience of care and offer them a new lens through which to see the needs of the elders and their fellow care partners. We all need well being to lead rich, meaningful lives together.

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JG: How do the domains filter into your model of care for someone living with dementia?

CP: I've just described the Domains of Well being as a set of essential human needs. If this is the case, imagine what can happen when the well being of someone is compromised but they cannot adequately express it. We agree with geriatrician Dr. Allen Power that what care professionals so often describe as bad behaviors are really attempts by someone living with dementia to express their unmet needs. The mistake that the traditional model of care so often makes is being reactive rather than making an effort to understand what the unmet need is. Gone unchecked, unmet needs can lead to distress, which can lead to the overuse of antipsychotic medications for those living with dementia. Care partners who practice the Eden Alternative are taught to know each person deeply. The care partners learn about the life of the resident and what experiences made them who they were in their youth and who they are today. This uncovers a wealth of information that can be used to maximize well being for someone. When we can identify and meet unmet needs, it supports a person's well being, and the need for psychotropic drugs decreases or vanishes completely.

We codeveloped a two day training called Dementia Beyond Drugs with Dr. Power, who is also the award winning author of a book by the same name. In that book, Dr. Power credits the Eden Alternative with his own personal approach to dementia care. The training has recently been the focus of some of our grant funded projects. One of our grant projects in Oklahoma featured *Dementia Beyond Drugs* training. Participants experienced an overall nine percent shift toward person directed perceptions of and approach to dementia care. This shift, which is almost double what we had anticipated, took place between the beginning and the end of the training. Our findings also showed that participants were not only thinking differently about dementia care by the end of the training, but that they also indicated feeling more confident in their ability to use the approaches they had learned. Confidence is important. New tools and ideas will not work if you don't feel comfortable using them.

Care partners who practice the Eden Alternative are taught to know each person deeply.

In his second book, *Dementia Beyond Disease*, Al Power uses the Eden Alternative Seven Domains of Well Being as chapter headings. In this book, Al does a deep exploration of each domain and how a person with dementia experiences it. He details aspects of the care environment that can hinder or enhance these domains.

Our federal level Centers for Medicare and Medicaid grant project that I mentioned earlier also focuses on the reduction of antipsychotic medications through training like this. The grant covers five states, and we are seeing trends similar to the Oklahoma project in the interim raw data for each state in the project.

JG: Do you teach the Eden Registry members how to measure success?

CP: We believe measuring outcomes is a very important part of the culture change process. We ask for proof of outcomes when organizations want to progress from one milestone to the next within our Path to Mastery framework for culture change. We also collect an annual data set from our Registry members that shows, on average, Registry members perform better than industry benchmarks for most key outcomes, including staff stability and quality of care. We believe this is a direct result of using person directed care principles to inform the care model and culture.

Because medication use is such a significant and widely publicized topic related to elder care, I would like to share some outcomes of a recent grant project. The project was based on the principle that we want to optimize medication use, not maximize it. The project involved six nursing homes in Colorado and resulted in a sixteen percent reduction in the average number of scheduled medications per individual per day. The number of people receiving psychotropics, antidepressants, and anxiolytics was reduced by roughly forty percent. The average amount of time spent each day administering medications was reduced by thirty nine percent, creating time for care partners to strengthen relationships. The results of this project help organizations understand that by optimizing all of the systems involved in administering medications, we can make truly sustainable changes that have a significant impact on the lives of the people we serve. We have now created a new training module called *Less is More: Well Being Before the Med Cart* based on the lessons of this project. We are hoping to share it with many more care partners online.

The Eden Alternative has withstood the test of time because it is built on timeless principles. When put into practice, these principles help people of all

ages and abilities, along with their care partners, to grow and experience well being. This is what creates a life worth living for everyone.

JG: Other than making measure reporting mandatory, how do you plan to increase your data collection and analytics moving forward?

CP: The grant projects I have mentioned all require extensive data capture and outcome measurement. We are working with consultants that specialize in data analysis. We are excited about the prospect of using their analysis to identify best practices. We then plan to develop detailed case studies combining the best of both quantitative and qualitative data in a single snapshot. We are committed to expanding our use of seasoned researchers for credibility of tangible evidence in the form of outcomes. These case studies and the outcome data contained in them will further prove the positive impact our philosophy can have on elders and their care partners.

JG: Do you use any surveys to collect measures?

CP: We have developed custom pre and post surveys for many of our educational offerings. We have also developed customized tools that help organizations measure the impact of the changes they are implementing. These include the Eden Alternative Well Being Assessment Tool and the Eden Alternative Warmth Surveys. The former measures the presence of the Seven Domains of Well Being for employees, family members, and the elders themselves. The Warmth Surveys measure the warmth of the organizational culture. Are people feeling cynical? Are they feeling positive? Are they feeling like the organization is listening to them or ignoring them? It provides a good indicator of how healthy or unhealthy the organizational culture is. Information about well being and warmth are essential for the leadership of an organization to know where to focus their efforts.

JG: What other countries have adopted the Eden Alternative philosophy and care model?

CP: We are active in at least fifteen countries right now through relationships with regional coordinators who act as agents for us under a licensing arrangement. The list of countries includes Australia, Austria, Canada, Denmark, England, Germany, Iceland, Ireland, the Netherlands, New Zealand, Norway, South Africa, Sweden, Switzerland, and Wales. There are other countries such as India and China where we have seen interest, but there are no formal relationships yet. We have representatives from Canada, Denmark, and Australia who serve on our board of directors.

We have a regional coordinator based in Australia and New Zealand who is building relationships in the Far East, including Singapore and Malaysia. She will gradually venture into China to start building relationships there. Two of our Eden Mentors, Dr. Power and Emi Kiyota have also worked in Singapore and Japan over the past three to five years.

Our regional coordinator in South Africa, Rayne Strobel, has also done great work with our philosophy. He is not shy about traveling around the country. He is on a mission to take the Eden Alternative to as many people as he possibly can. Two years ago, we held a holiday fundraiser for a South African nursing home that he works with. This home was washing all of their laundry by hand. We raised the money to buy them a commercial washer and dryer set. We also paid for the plumbing to have it installed. It made a world of difference to that care community.

Our regional coordinators could dazzle you with story after story. In Denmark, for instance, entire municipalities have committed to the Eden Alternative philosophy for their nursing centers.

JG: Are there other success stories you would like to share?

CP: How much time do you have? There are literally hundreds and the number keeps growing!

END