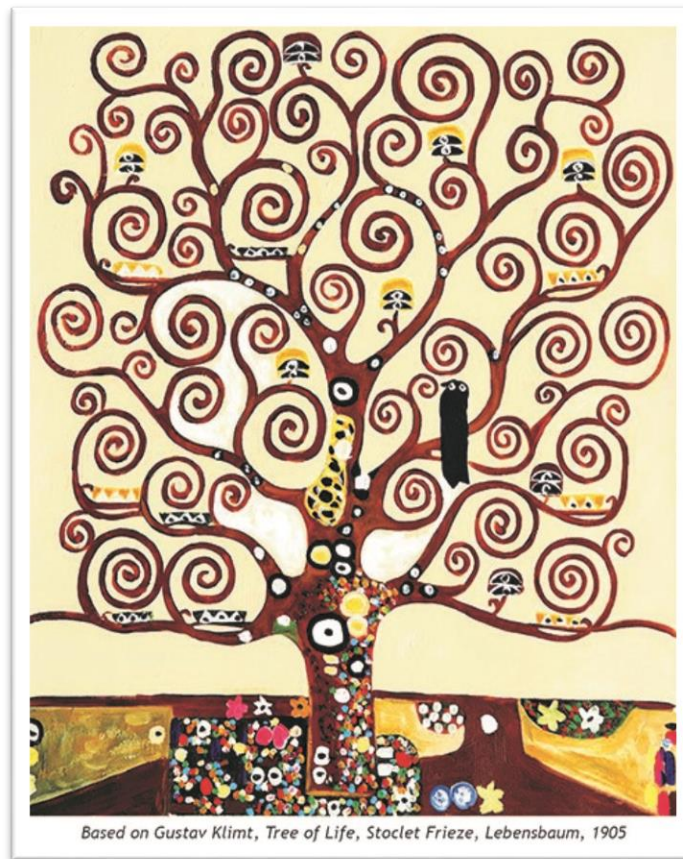




Allen Power: Dementia Beyond Disease

Interview with Dr. Allen Power



By Jean Galiana

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*ACCESS Health International, Inc.
1016 Fifth Avenue, Suite 11A/C
New York, New York 10028
United States*



Elder and Long Term Care

An ACCESS Health International Program Area

Background

In this interview, Dr. Allen Power shares his experiences as a geriatrician that led him to become an international speaker about the practices of person directed dementia care in the home and senior living community setting. Dr. Power provides insights into models of care partnerships that do not require antipsychotic medications, and other chemical or physical restraints. He details the need for dedicated staff assignments where care partners do not rotate. It is his belief that dedicated staff enables an environment of relationship and connection that meet the needs of those living with cognitive challenges in a holistic and more effective way. Dr. Power supports a warm, home like setting where residents of long term living are given more autonomy and respect. In this interview, he shares his thoughts about how behaviors can be translated into the communication of needs by those who have lost their ability to communicate clearly with words.

About Dr. Allen Power



Allen Power, M.D. is a board certified internist and geriatrician, a clinical associate professor of medicine at the University of Rochester, and a Fellow of the American College of Physicians and the American Society for Internal Medicine. Dr. Power is a certified Eden Alternative® Educator, a member of the [Eden Alternative](#) board of directors, and an international educator on transformational models of care for older adults, particularly those living with changing cognitive abilities.

Dr. Power's [book](#), *Dementia Beyond Drugs: Changing the Culture of Care* won a 2010 Book of the Year Award from the *American Journal of Nursing*, a Merit Award from the 2011 National Mature Media Awards, and was listed as a “must have” title in *Doody's Core Titles* list for 2013. He has co produced two DVDs with Dr. Richard Taylor and [Brilliant Image Productions](#): *Living with Dementia* and *20 Questions, 100 Answers, 6 Perspectives*. Dr. Power was interviewed for the film [Alive Inside](#), winner of the Audience Award for Best U.S. Documentary at the 2014 Sundance Film Festival. His two day Eden Alternative course, "*Dementia Beyond Drugs*" has been taught in nine states and five countries.

Dr. Power was awarded a [Bellagio Residency](#) in Italy in 2012 by the Rockefeller Foundation, where he worked with Dr. Emi Kiyota on developing guidelines for sustainable communities that embrace people of all ages and abilities. He is a consultant for Dr. Kiyota's non profit organization [Ibasho](#), as well as a member of the Leadership Council for the Dementia Action [Alliance](#), and serves in an advisory capacity for the Music and Memory project, Dementia Care Australia, and the South Africa Care Forum.

Dr. Power recorded introductory material for the new Centers for Medicare and Medicaid Services' educational package, "[Hand in Hand](#)," designed to help hands on staff better care for people living with dementia. He has served in an advisory capacity with the Centers for Medicare and Medicaid Services and worked with the National Dementia Initiative to produce a white paper about new approaches to dementia for the U.S. Senate Special Committee on Aging.

Dr. Power is a featured contributor to Eden Founder Dr. Bill Thomas's weblog at www.changingaging.org. He has been interviewed by the *BBC*, *The New York Times*, *The Washington Post*, *The Los Angeles Times*, *The Wall Street Journal*, *The New Yorker*, Singapore's *Straits Times*, ABC Radio (Australia), WHY radio, WXXI radio, many other publications and radio shows, and for the book *Old Age in a New Age: The Promise of Transformative Nursing Homes*, by [Beth Baker](#).

Dr. Power is also a trained musician and songwriter with three recordings, including *Life Worth Living: A Celebration of Elders and Those Who Care for Them*. His songs have been recorded by several artists and performed on three continents. Peter, Paul and Mary performed his song of elder autonomy, "If You Don't Mind," and Walter Cronkite used his song, "I'll Love You Forever" in a 1995 *Discovery Channel* profile of American families.

Interview

Jean Galiana (JG): Please share the journey that led you to becoming an author and speaker about dementia.

Allen Power (AP): I started as a geriatrician in private practice as an internist. After about seven years of working as an internist I became a little burned out. I was drawn into long term care and worked in a large nursing home complex. Over time and mostly due to the [Eden Alternative](#), I discovered the culture change movement that was beginning to form. The nursing home where I was practicing did not want to embrace culture change, so I moved to [St. John's Home](#) in Rochester, where I worked for almost fourteen years. I was always concerned with the use of antipsychotic medications and similar drugs in people with dementia. I tried not to use them whenever possible. I continually spoke about out against them and challenged co workers to find other solutions. I received a lot of pushback, as you can imagine. This was well before anyone was talking about the high usage of these medicines.

It remained a challenge for me because I had a view of culture change with a bigger vision than I could not yet articulate. I did not completely understand it myself. I often say, when you do not understand a subject as well as you would like, the best thing to do is write a book about it. That belief is what led me to write my first book, *Dementia Beyond Drugs*. It took me three years to write it. The book was my attempt to explain what was wrong with only using medications when people are stressed. I knew that we needed to find new ways to interact with people with dementia that challenged the existing view of dementia care. I also delved into some of the transformational principles of culture change to care for people living with memory challenges. This type of person centered care is based in the work of [Tom Kitwood](#), the psychologist from the United Kingdom. He introduced person centered thinking approximately twenty years ago. My book is the first person centered dementia care guide written by a medical doctor. I received some nice reviews after its publication. Not much else happened for a couple of years until the Centers for Medicare and Medicaid Services began to focus on reducing the use of antipsychotic medications. More and more evidence came out against the overmedication of people with dementia in long term living. My book gained in popularity, and I was regularly asked to speak and to consult. I migrated out of working in the medical setting and became a culture change specialist at St. John's Home, traveling around to speaking engagements. Three years ago, I made the shift to full time speaker and consultant. That is a long way

from where I started back in private practice. Life takes us to surprising places sometimes.

JG: Please describe your book, [*Dementia Beyond Drugs*](#).

AP: *Dementia Beyond Drugs* challenged the entire paradigm of dementia. It presented different ways to conceptualize living with dementia and proposed better options to transform our approach to care. My second book, [*Dementia Beyond Disease*](#), was meant to further the thoughts of the first, but I was not really sure what to write about. I had not been practicing at that point, so I did not have many more of my own stories to tell. I decided to tell stories of best practice that I witnessed during my travels. I also decided to focus on a model of wellbeing that a handful of culture change specialists had designed. I thought it would be nice to write a book that examines dementia through the lens of the seven Eden Alternative [*Domains*](#) of Well-Being. I originally planned it as an addendum to my first book, but it turned out to be forty pages longer. That is how the second book originated. It led me to create a strengths based approach to people with dementia, where instead of just trying to mitigate problems, you are actually enhancing wellbeing proactively. The strengths based approach has enabled care partners to successfully address certain challenges that were insurmountable before. It really opened the door to new ways of thinking.

After *Dementia Beyond Disease* had been out for two years, my publisher came back to me and said, “The first book is still selling well. I think it is time to come up with a second edition and update it.” I did not want to rewrite my second book into my first. When it came to revising the first book, I tried to keep the same format, even though my view of dementia had moved a little bit. I kept the format and updated some of the stories. The main thing I changed was the language. I thought my language was enlightened when I wrote the first book. Six years later I looked at it and cringed, so I changed a lot of wording and updated some of my terminology. That second edition came out in October 2016.

Then, as things often happen, my second book went to a reprinting at the same time. The publishers told me that they were not going to print a second edition but wanted me to read it through for words I thought could be replaced by better words and other minor changes. When I read what I had written about the dedicated staff initiative my friends implemented at Arcare in Australia, there were many new outcomes they had tracked since the book was published. I wanted to add those along with a couple of quotes. Because my new book was

coming out as a new edition with a new copyright date, we decided to release the second book as a revised edition. It is essentially the same book.

JG: Please discuss the transformational principles you mentioned.

AP: The Eden Alternative informs much of my work, but also I work with the Green House Project and the Pioneer Network. There are many people I work with who are involved with culture change. In the case of dementia, I look at transforming three aspects. Personal transformation consists of the intrapersonal, which is changing the way we see dementia, changing how we view people living with dementia, and understanding their needs; and the interpersonal dimension, which is changing the way we communicate with those living with dementia. That comprises one aspect of transformation. A second is the physical living environment. Does it support people who live with dementia or does it not? We examine what policies and practices help or hinder wellbeing for people with dementia, including medical and physical restraints and alarms. We also examine how homey and warm the setting is.

Then the third aspect, which I consider the lynchpin, is the operational transformation. As I say in the book, neither a holistic mindset nor a beautiful building will matter if you do not change day to day operations. This includes how decisions are made and how staff interacts with the residents. In the case of community based living, it includes how family members are adjusting to the rhythms and needs of the person. [Sundowning](#) is a result of forcing people to conform to our rhythms. That is why it happens in the home as well as in the long term living homes. Family care is challenging because it is difficult for one person to meet another's needs twenty four hours a day. Caregivers need to sleep and run errands. It is very hard to individualize care around the rhythms of someone. Long term living residences often have the goal of person directed culture, but they do not adapt to the personal rhythms including eating, sleeping, toilet use, and bathing. Providers build nice buildings but do not make the important cultural shift necessary to achieve person directed lifestyles for their residents.

JG: You mentioned sundowning and the relationship to neglecting personal rhythms. Have you witnessed light adjustments that also lead to a decreased incidence of sundowning?

AP: There is no question that we all need cues. If you live in a place like I do with little light for six months a year, you see many people who experience seasonal depression. There is no question sunlight is important to people. I think that

lighting could be helpful, but to affect circadian rhythms, the light must be strong. I am not sure if just having indoor incandescent lights that dim or brighten would be useful. With Seasonal Affective Disorder, you need to shine a bright lamp about twelve to eighteen inches from your face, the first thing in the morning for a half hour to an hour. To me, the answer is to bring people outdoors. Even on a cloudy day, the sun is still much brighter and broad spectrum than anything available indoors. Why not have people go out and sit or build a snowman like they do at the Green Houses at St. John's in Rochester?

JG: They have residents build snowmen at St. John's Home?

AP: Yes. All it takes is fifteen minutes of good sunlight to make a big difference. You can do other things like design with skylights and big windows and things that bring natural light into the environment also. Organizing practices to adjust around the resident's changing rhythms reduces or eliminates sundowning most effectively. The best option is to support the changing rhythms of the residents and create an environment that is flexible enough to accommodate those rhythms as much as possible. A good example of creating opportunities that honor the rhythms of the resident can be found at [Hebrew Home](#) of Riverdale. Residents who are up at night can go to their nightclub. Rather than requiring people to go to bed at a set hour, they offer other options. Normal aging causes changes in our sleep architecture and sleep duration that are difficult to fix with sleeping pills. The drugs tend to do more harm than good. The goal of person directed living is working around the rhythms of the residents and not trying to force ours on them.

JG: Does it require more staff to adjust to the personal rhythms of the residents?

AP: This is why I emphasize the third part the operational transformation. It may appear that person directed culture would require more staff, but it requires fewer than the traditional siloed culture that is that built upon a hierarchical environment model. Fewer staff is needed when you remove silos and create flexibility with dedicated staffing. Staff that is dedicated knows each resident so deeply that the care is easier and the connection more fluid. The practice of rotating staff assignments means the roster changes, the order in which you do things changes, the personalities you deal with change, the way you interact with your coworkers changes because you are interacting with different people who do things differently. Rotating staff adds many layers of inefficiency. It sounds convenient but it is not. The institutional model is not efficient. I am one of the people who has been guilty of spreading the myth that institutions have thrived

because they favor efficiency over people. The truth is that there is nothing efficient about institutions.

JG: Please give an example of best practice in dedicated staff assignments.

AP: Daniella Greenwood of [Arcare](#) in Australia led her team to dedicated staff assignments. They made the shift because the residents and their families who participated in a survey asked for improved connections and continuous relationships. If you believe in consumer directed care, then you give the customer what they want. They had no idea of the profound health outcomes the choice would produce. Those things were icing on the cake. Any good business will adapt themselves around the needs of people.

JG: Did their shift from rotated staff to dedicated staff assignments take Arcare a long time?

AP: It took them six weeks in their first community before they could claim that the staff was spending more time with the elders and were also able to complete their tasks. The entire process was rolled out sequentially over their twenty seven communities over a three year period.

JG: What outcomes did moving to a dedicated staff assignment produce at Arcare?

AP: The results from one early adopting community of thirty eight residents saw a sixty nine percent decrease in chest infections, ninety percent decrease in pressure injuries and five percent increase in family satisfaction. They have many other impressive outcomes for both the residents, family members, and the team members as well, such as increased satisfaction and decreased turnover.

JG: The concept seems simple.

AP: Yes, but change is difficult. To change an organizational culture, you must engage everyone. Most systems reinforce the old industrialized ways of thinking and acting. An example that I added to the new edition of *Dementia Beyond Disease* is that in New York state, insurers pay a per bed premium to anyone who has a nursing home with more than three hundred beds. They are incentivizing warehousing of older people by building these huge institutional buildings. In order to create a person directed culture, the organizations will have to adapt to a badly built environment. These large buildings offer little access to the outdoors. They also have long clinical hallways that make too much distance for residents

to easily access the common areas. There is inefficiency getting from one resident's room to another.

JG: When was that policy enacted?

AP: In the 1960s and 1970s. The policy presented me with a wonderful opportunity to learn. Most small homes have a doctor who comes once or twice a month. St. John's Home was so large that it gave me the ability to be a full time doctor in a nursing home community. I was there every day getting to know the staff and residents and working on culture change. As a physician, I was able to deeply understand culture change. However, warehousing older adults is not the best way to care for people.

JG: Do you have an opinion about whether staff should or should not wear uniforms?

AP: Uniforms reinforce the medical model. We try to create a home, particularly for people who may be somewhat confused about what home is. They need all the cues we can give them. Regular clothes are as much a physical cue as a nice living room. Uniforms give two messages. One is the message of power and control. Uniforms represent power, whether it is the uniform of a police officer, a member of the military, a nurse, or a doctor. The other message of uniforms in long term care is, *you are here because you are sick*. This tends to promote dependency among residents. You sit back and become a patient when you see everyone walking around in uniforms. We have witnessed that response to uniforms. I have heard stories of communities where when they change from wearing uniforms to street clothes, they see the residents becoming much more independent and doing more for themselves. Providers who do not use uniforms give the employees a clothing budget. Some people worry whether the residents will know who the care partners are. St. John's is a leading example with regard to person directed care without uniforms.

JG: I was there and at first I could not tell whether they were staff or family.

AP: The interesting thing is that the residents do know who the care partners are because the staff does not rotate. They are there every day. The relationships between the care partners and the residents are close and loving. You do not see people trying to get out the front door. You do not see people walking into each other's rooms. Many dementia related behaviors are triggered by the environment. They are triggered when we create confusion and desire to find

something that the care partners are not providing. It is possible to cure these things with the culture of care partnership.

JG: Please tell me about your speaking tour.

AP: I travel around the world [speaking](#) about dementia. I updated my geriatrician certification exam a couple of years ago, but my talks are mostly non medical. My talks and books are mostly nonscientific. I made that choice intentionally for a couple of reasons. Doctors use a lot of technical language and to me that is another entrapment of power. If you can baffle people with the technical talk, they have to defer to what you say. I also am determined to communicate a model that is easily understood and makes sense. We need a model that people can apply to all residences, no matter what form of dementia or other challenges their residents face. If someone is teaching an approach to dementia that requires a certified nursing assistant to know that a resident has a particular type and stage of dementia before they can respond, the care model is worthless. That is what I love about truly person directed; it is universal. It is universal across cultures, ethnicities, and abilities.

I also consult with organizations to help them understand how to fully operationalize person directed long term living. I consult often with [Schlegel Villages](#) in Canada. The [Research Institute for Aging](#) partnered with Schlegel Villages to research and measure outcomes of their relational living model.

JG: In one of your talks you mentioned the existential, spiritual experience of dementia. Please describe what you mean.

AP: In [Christine Bryden's](#) first book, *[Who Will I Be When I Die?](#)*, she wrote about how people go through existential questions when they are struck with a new illness. The diagnosis makes them think about their mortality and their abilities. In *Dementia Beyond Disease*, I wrote about how people who lose easy access to memories or to language sometimes become hyper attuned to other senses such as non verbal communications. People living with dementia can view things in symbolic or metaphorical ways instead of literally. We need to understand this to be able to hone our communication skills. We are communicating with our whole bodies and our tone of voice.

JG: What are your thoughts about touch for those living with dementia?

AP: When you cannot connect through language or reminiscence, touch is a way of connecting that is powerful. It is powerful from infancy. There have been many

studies about the need of touch for children to develop normally. We know how important touch is throughout life. Touch stimulates other pathways in the brain that continue to function. There is a massage therapist who has worked at St. John's Home who has seen massage free people's ability to speak and remember after they had a session. There are many ways to stimulate people in areas where their brain can still connect. Learning which methods work for each individual and applying them is a perfect example of person directed care partnering. Music also has the power to find its way into a brain that may have some challenges.

JG: Would you discuss your blog [series](#), *The Hidden Restraint*?

AP: We tend to view the idea of safety and security from a narrow lens. It is a lens of physical safety. It is the litigious lens of preventing the worst case scenario. I do not want to minimize anyone being hurt, but we are only seeing one side of the security issue. I define security as supporting both emotional and psychological security. Many restraints, including locked doors, have the opposite effect. They actually make people much less secure because they cannot get out and cannot move freely. They feel trapped and often also feel that they need to get away from something that is there. As a result, we are trading one kind of safety for another kind of security and, in many cases, making people feel worse instead of better. Is the locked door really helping the residents or the providers?

[Bill Thomas](#) speaks about the downside risk of surplus safety. Risk is not good or bad. Risk is just the chance that something will turn out differently. Different can be better. If you go outside, you might fall... or you might sleep better. You also might not experience sundowning. You might have better strength and balance. You might be less likely to take a swing at somebody when they get in your space. There is no way to enable quality of life and eliminate all risk. We have to continually negotiate risk. That is what I write about in the *Hidden Restraint* blog. If you have people wanting to leave all the time, before you unlock the doors, you must eliminate all of the stressors that make them want to leave. That is the important place to start. In the book, I gave stories about providers who were successful at unlocking the doors. I have a great story from Heather Luth at [Schlegel Villages](#) in Ontario. They had a gentleman who was constantly at the door. It is a perfect example, because he was stressed every day. He was either medicated or about to be medicated because he was at the door trying to get out. He said, "I just want to sit outside. I want to get some fresh air and see people." They negotiated and decided with staff to give him the key code. When I went to visit the home a few months ago, the resident was greeting visitors at the door and pushing the code to let them in. When I left, he was sitting outside on the

bench and watching people come and go. Heather said that in the four years since they have done this, he has actually caught the bus three times. People have had to bring him back. Fortunately, he had no injury, but three days of getting away versus four years of daily pounding on the door and being medicated with dangerous drugs is a perfect example of risk versus quality of life.

Those are the concepts a provider must balance. Which is better? Which is worse? There is no zero risk. Bill Thomas says that the only risk in a human environment is a coffin. We have to understand that, for every person who leaves the home, there are hundreds of people who are being put on antipsychotics, who are distressed and traumatized every single day behind a locked door. They are withdrawing and giving up on life. That never makes the news. We have to balance those two. You cannot just help that one person and damage the other hundred.

JG: In balancing risk and quality, should the providers involve the wishes of the family and the resident?

AP: Providers must involve everyone in the care circle, including everyone in touch with the resident and their family. We all must explore people's values and understand what their tolerance for risk is, because each individual has a different risk tolerance. Some residents would say, "I do not want anything bad to happen to me, I just want some fresh air from time to time." Other people may say, "I do not care if I get run over by a truck tomorrow. I have to be able to go outside."

Everyone needs to be brought to the decision making table, including management, staff, family, and the resident. The resident must be kept in the loop, no matter their cognitive abilities. No one should be surprised by not being informed of the plan because this is where lawsuits arise. As a practicing doctor, I have gone to medical malpractice seminars for years. Most lawsuits come from poor communication, not from true malpractice. If a provider does not communicate, they are setting themselves up for trouble because people need to understand why the provider makes the choices they do. On the surface it may not make sense. It is also important to document all conversations for the regulators. Legally, if it is not written in the chart, it never happened. I have asked many regulators, and they have told me that they do not expect that nothing bad will ever happen in a nursing home. They just need to know that there is a valid thought process in the planning and operations.

JG: Is there a fine balance between mitigating risk and facilitating wellbeing?

AP: We try to prevent the one terrible thing from happening, but in doing so, we cause daily distress, which results in overmedication. In this scenario, wellbeing needs are completely ignored and the aspect of meaningful life is nonexistent. This is not because providers are bad people. Their system is focused on tasks and excess surplus safety while well being and quality of life are ignored.

JG: Do restraints make a person safer?

AP: That is a good question. I used to talk about how restraints create safety at the expense of wellbeing. Studies show that they were not even creating safety. With restraints, people are more likely to be injured and more likely to have serious falls when they were allowed to stand than those who were not. Restraints were making people feel less emotionally secure and less safe. Once again, one has to ask the question, can you even make that argument for locked doors? I do not know whether you can go that far, but if people are becoming distressed and falling down because they are constantly at the door, you can make the argument that locked doors create less physical safety as well as more emotional insecurity.

JG: Do you see a trend for unlocking doors?

AP: Not yet. That is why I maintain such a vigorous speaking calendar. Some organizations, like the [St. John's Green House homes](#), do not lock the doors. They are out there on the fringe. Unfortunately, some of the brightest leaders are waiting for a study to prove that unlocking the doors is morally the right thing to do. Other providers have just unlocked the doors because they know it is the right thing to do. They are using their moral compass to direct their thinking. This is a personal challenge for me because I have never been a confrontational person by nature. If anything, I am just the opposite. As I try to construct an ethos around dementia that works, I start noticing the practices that contradict the philosophy. I have two choices: either be a hypocrite or speak up. The practice of locking people in is one of those areas. If you truly care about wellbeing, autonomy, and security, you have to understand that locking doors is not helping. It is making things worse.

JG: Have there been studies regarding chemical and physical restraints and safety?

AP: Yes. They proved that restraints increase the risk of serious injuries, increase emotional distress, and increase many other types of morbidity such as bedsores,

incontinence, and muscle wasting. Those studies drove the big push by the government and most of the providers to end the use of restraints. Surprisingly, there are still a few organizations that have not made the change.

JG: Does the same apply with chemical restraints such as antipsychotic medications?

AP: Yes. People will ask me, “What about people with dual diagnoses such as dementia and lifelong schizophrenia? We do not really feel we can stop their antipsychotic.” That is acceptable because the person has another condition. Possibly they cannot stop using an antipsychotic medication, but the person with the dual diagnosis still needs wellbeing. If you are showering them and they hit you, it may not be due to their schizophrenia. The reason may be where, how, or when you are showering them. The method or time of showering may challenge their autonomy or security. Maybe the staff rotates and the person assisting in the shower is a stranger. Just because a person has another diagnosis does not mean that person directed commitment by the providers is not important. I also emphasize that autonomy is important with staff and family members. If you do not have autonomy or meaning in your job, how are you going to bring it to anyone else?

JG: Do you mean wellbeing for the staff?

AP: Exactly. I think that lack of wellbeing is a key contributor to burnout and caregiver turnover. New employees mean new people around the residents, and added training costs to the organization.

JG: What would you say to a nursing home administrator who is hesitant to desegregate those living with dementia from the rest of the community?

AP: The most important factors to maintaining a successful desegregated community are education, education, and education. The antidote to any kind of fear or concern or improper interaction is to educate people. There is too much stigma around dementia. There is so much fear that people do not how to respond and react to someone who has difficulty thinking. Providers need to learn the many good evidence based communication techniques. All the instruction we give to staff members should also be given to the other residents and to family members.

Why, when someone has a memory challenge, are they treated any differently? When I was with St. John’s Home, we had residents who did not have dementia

provide companionship to people with dementia. It gave the residents who were helping a purpose. It also created a community connection for the person who was living with dementia, rather than ostracizing them for being different. It is a great benefit to the whole community.

It boils down to the need for education and modeling, which leads to the crucial aspect of relationship and connection. When someone who has been living in a neighborhood, a nursing home, or assisted living for a long time develops dementia, their neighbors who know them almost always accept them. When a new person living with dementia moves in to a community, the fear and resistance arise. I have seen these dynamics over and over again. Relationship is the key. This is where the importance of modeling enters the scene. Providers need to educate the staff and the community about the new resident. The resident is no longer able to tell their own story, but their families can offer insights and details. The residents and staff can meet the family and learn about the life, hobbies, and unique characteristics of the newcomer. Was he a doctor? If so, possibly he should be referred to as doctor. Was she a professor? Maybe we should use professor before her name. This puts the person in front of the challenges. If you share the whole person with their neighbors, that helps decrease the fear of unfamiliarity as well.

JG: Does segregating those living with dementia contribute to the stigma?

AP: People living with dementia should be given the respect and dignified attention that they deserve. In many ways, we are reinforcing those stigmas and fears by locking up people whose brains have changed. That sends the message to the other residents that they are right and people with dementia are dangerous or odd and do not belong around them. People with dementia deserve for us to see them for who they are beyond their limitations. If you start having trouble remembering, would you like us to take you away from your friends because we do not want you around anymore? How would you feel? The best providers to those living with dementia understand that it is about preserving people's humanity as much as possible. If you were the administrator, what would you say to angry residents and family members who told you that they do not want any African American or Jewish people on the unit? You would tell them that those are not your beliefs and that thinking does not align with the mission of your organization. It is the same for someone living with dementia, if you truly support inclusive communities. The big irony is that everyone is talking about dementia friendly communities, which are inclusive communities, yet the only dementia unfriendly sector now is long term care. I do not understand why long term care

providers seem to be giving up. Providers continue to lock people in. Challenging that practice would be a great initiative for life plan communities around the world.

JG: Do you meet with resistance when you advocate for desegregated living?

AP: Sometimes. This is a new concept, so it is understandable to a degree. It is mainly about appealing to our sense of humanity. I remember when we first built our [Green Houses](#). We planned to move the homes off campus and into a neighborhood. Charlie Runyon, our CEO, passed the idea by the town supervisor, who loved it, but he was afraid that the neighborhood council would not. We were faced with the “not in my backyard” thinking that many people have about group homes. In response, Charlie took the impressive Green House promotional [video](#), an urn of coffee, and a basket of homemade cookies to the neighborhood association. After that day, the neighborhood residents were enthusiastic and even offered to visit the residents and bring their dogs over. One offered to cook Thanksgiving dinner. Sometimes we sell people short. People want to be good. They want to help. When we emphasize that we all want to be accepted, no matter what happens to us, people understand. If you have a stroke and you start dribbling some of your food, would you want us to shut you away somewhere, or is that unfair? It is basic human values.

JG: How do the Green Houses support the Eden Alternative care culture?

AP: In culture change, we tend to deemphasize the physical structure of the building because too many people are building nice buildings and thinking they have succeeded in changing the culture when they have not. Organizations that build Green Houses come from all stages of culture change awareness. St. John’s was the largest Eden Alternative nursing home in the world for ten years before they opened Green Houses. They had the culture in place even in their existing, old fashioned, hospital like structure. The Green House environment served to support that culture. Others get excited about the Green House and begin building, but do not understand the culture that the structure was designed to support.

To quote my friend in England, a bulldozer is not a culture change tool. Having said that, the physical environment does matter, it does make a difference, it does cue people in good or bad ways. When you walk into a Green House home, you just relax. You do not feel like you are going into a hospital. Even as a clinician, you do not feel like you are going in there to do traditional doctor work. You just

feel like you are making a house call. It gives you a whole different feeling and it is a very powerful, different feeling for the people who live there. The residents do not feel they are in a hospital ward. They feel as though they are living in a home, not a long term care facility.

JG: What are your thoughts about the [potential support ratio](#)?

AP: I was researching the global aging demographic data and the potential support ratio changed my whole paradigm. The potential support ratio, for my purposes, is approximately the number of working adults as compared to the number of retired adults. Who is earning an income and who is not? Who is living on a pension? The ratio is striking; from a ratio of twelve to one in 1950, it dropped to nine to one in 2000. By 2050, with the aging of the baby boomer generation, the ratio is projected to be four to one. It made it clear to me that we cannot continue to move older people to any kind of segregated community such as assisted living, nursing homes, or dementia villages. It is impossible mathematically because there will not be enough people to build, staff, and maintain all the communities. There will still also be a need for police, firefighters, doctors, teachers, and every other profession. The only solution to global aging is to keep people living with dementia in communities by creating inclusive communities.

The only solution to skilled care is to integrate skilled care and congregate living into larger communities so we can tap into social capital, because we will not have the necessary financial capital. St. John's is moving in that direction now. We need social capital. We need to keep communities inclusive. We need to keep people engaged so that most of them are contributing. The contributions do not have to be directly financial. People can volunteer, mentor, babysit. There are many solutions such as time banking. We need to focus on supporting those types of communities rather than building more assisted living and retirement homes.

JG: The retirement communities appear to be expanding rapidly.

AP: That is a dead end, and the problem is that aging will overwhelm us if we do not start building different systems. It is an issue that no one is addressing. That is why I keep talking about it in my publications and presentations. Another aspect of the support ratio is how to capture the knowledge, wisdom, and ability of the community that is dependent on some sort of care. Otherwise, we are creating excess disability among older people by marginalizing them. Support has to go beyond family ties for the system restructure to be sustainable. We are a

mobile population these days, and families often live far away. An inclusive system will have to include neighbors looking after neighbors. My mother is almost ninety. She lives in the house I was raised in, which is about ten miles from me now. I visit her when I can. My daughter works at her house often and gives some personal assistance. It is great that one of her neighbors will run to the store for her if she needs something. The neighbors have a key and can check on her. Another neighbor will come over and do yard work for her or simple repairs when I am away. To me that is a healthy system. We need to start helping each other out more that way.

JG: Do you think it is important to create intergenerational connections?

AP: Yes. St. John's Meadows is the independent living campus and is about a mile from the home. Several years ago, Nazareth College began teaching a sociology course called Aging in Society in one of the common rooms at the retirement community. The residents who are interested attend the course. While the students and professors are talking about aging, they have the real aging experts in the room. Nazareth College won a national education award for this synergistic program. We hear more and more about moving older people to college campuses and moving students over to senior living and trying to blend those opportunities. They are wonderful ideas.

JG: Where do you give presentations?

AP: I present all over the world at conferences and seminars. I also teach a two day course based on my books , which I developed that is generally offered through the Eden Alternative. I have taught that course in seven countries. I've also taught it in Kentucky, Tennessee, Mississippi, South Carolina, Georgia, Texas, Illinois, and Oklahoma. I have received several Centers for Medicare and Medicaid Services grants to teach the courses in the U.S. Presently I am consulting with Schlegel Villages in Canada. They are committed to person directed living. They have residences around Ontario ranging from Toronto to Windsor. I provide ongoing consulting support with dementia education and culture change.

JG: Are the communities at Schlegel Villages designed to look like villages?

AP: Yes, they have interior streets, many types of gathering places and neighborhood areas. They are devoted to culture change for their employees and residents. They are for profit and are very mission based. I attended a marketing celebration dinner that they had in the spring and they were giving out awards for

occupancy. The village that won the highest occupancy award for 2015 had maintained an average annual occupancy of more than ninety nine percent. There were several others that were in the ninety eight and ninety nine range. They are highly respected.

JG: Please discuss the two day dementia course that you offer.

AP: I wrote the original course five years ago and have recently revised it, with the help of Sonya Barsness, Karen Stobbe, Denise Hyde and Laura Beck. It was based on my first book. I have expanded it to encompass a lot of the concepts in the second book as well. The course is two days, resulting in fourteen and a half contact hours. It is an intense course. Ideally it is great for twenty five to forty people, but with the national grants, we have had classes of two hundred. Eden educators in the room act as co facilitators and we break the tables into neighborhoods so we can work in semi large groups. We have ten modules over the two days, beginning with relationship and team building. We explore the different views of wellbeing from the point of view of the resident. We talk a lot about dementia and challenge the standard way of caring for those living with dementia. I share some basic medical information, but very little, because that is easily available elsewhere. I challenge the narrow bio medical view and introduce my experiential view. We begin talking about paradigm shifts and basic culture change.

Then day two really jumps in with detailed information about face to face techniques, including communicating and facilitating tasks with people. Then we explore other ways to understand distress. What does it really mean when people say they want to go home? What does it mean when people are removing their clothes? What does it mean when people appear to be hallucinating or delusional? Those actions are all a form of communication or expression. Then we have a wellbeing exercise where a participant explains a real life challenge they are experiencing in their residence. I break the class up into the Eden Alternative Seven Well-Being Domains and we determine which aspects of wellbeing are not being met. Then the participants work proactively to design a plan that only proactively provides each of those domains of wellbeing, without specifically trying to fix the distress at all. This enables providers a way around their blind spots that exist when one is focused on the behavior rather than the cause of the behavior. When behavior is considered communication, we look at it differently and we respond differently.

JG: Thank you for this interesting discussion.

AP: Thank you.

END