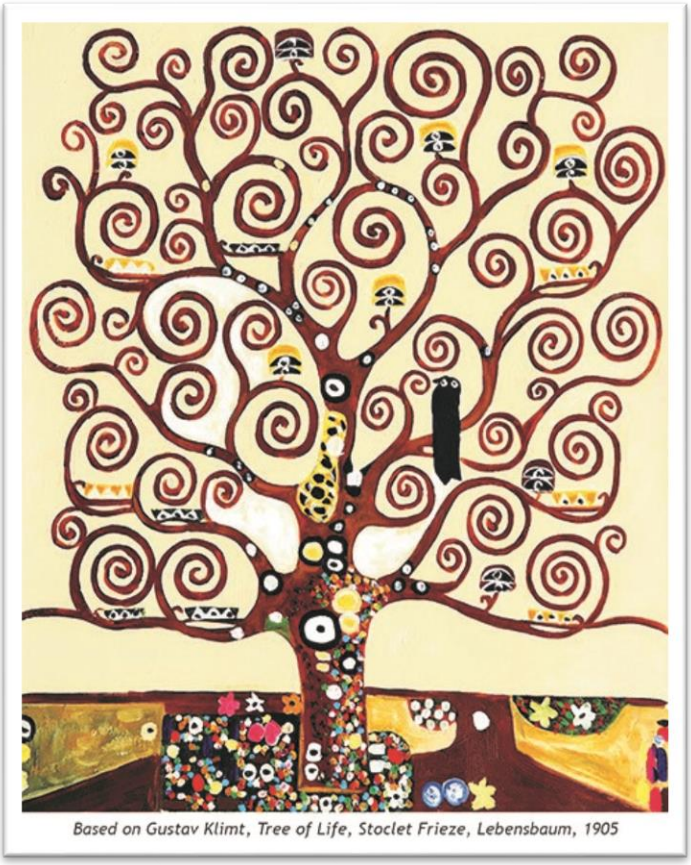
Beatitudes Campus: Person Directed Dementia Living

Interview with Karen Mitchell, Tena Alonzo, and Ivan Hilton



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

By Jean Galiana

ACCESS Health International

Phoenix, Arizona, January, 2017

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Background

Beatitudes Campus is a life plan community in Phoenix, Arizona. The twenty five acre campus is home to seven hundred residents. The campus has a host of amenities including a fitness studio, a swimming pool, a library, numerous restaurants ranging from coffee shop to bistro to fine dining, and even a lovely bar. The restaurants and bar are open to the public and are used frequently.

Bar at Beatitudes Campus

Other amenities on the campus include a hair salon, a bank, a chapel, arts and crafts and ceramics studios, a woodworking shop, garden areas, and walking paths. There is a doctor and medical staff on campus. Museum quality art can be seen throughout the community. There are over ninety clubs at Beatitudes that were all started and are run by the residents.

Beatitudes Campus has been conducting research into person directed dementia living for decades. Researchers at Beatitudes Campus have designed an evidence based model for dementia care called Comfort Matters™, a model that has been introduced to thousands of long term care staff, medical providers, and students throughout the world. Through the two year training program of Tena Alonzo, Karen Mitchell, and their team, the Comfort Matters concepts have been replicated in long term care organizations throughout the United States.

In this interview, Tena Alonzo, Karen Mitchell, and Ivan Hilton give examples of person directed living and share how they transformed the Beatitudes Campus into a fully person directed facility. They detail the philosophies and values of the Comfort Matters model and how the model was successfully operationalized, even in their late stage dementia residence, Vermillion Cliffs.

About Karen Mitchell, Tena Alonzo, and Ivan Hilton

Karen Mitchell, RN, BSN.

Educator of Comfort Matters.

Karen Mitchell has spent the past four decades improving the quality of life for older adults and their families in the long term care setting. Throughout her career, Ms. Mitchell has served in a variety of roles including nursing assistant, charge nurse, nursing instructor, nursing supervisor, assistant director, and director of nursing. Karen joined the staff at Beatitudes Campus in 1983 and has since been a driving force in developing and implementing evidence based, best practice care. Her work has been published in the *New York Times*, the *New Yorker Magazine* and the *Journal of Hospice and Palliative Nursing*. Ms. Mitchell received her Registered Nursing degree from Maria College in Albany, New York in 1975 and a Bachelor's of Science in Nursing from the University of Phoenix in 1989.

Tena R. M. Alonzo, MA

Director of Education and Research | Director of Comfort Matters

Ms. Alonzo is the director of education and research and the director of Comfort Matters at Beatitudes Campus in Phoenix, Arizona. She is also the education director for Palliative Care for the Advanced Dementia Training and Implementation Project in New York City in collaboration with Caring Kind (formerly the Alzheimer's Association New York City Chapter). She currently serves as a technical expert for the Initiative to Improve Dementia Care and Reduce Antipsychotic Medication for the Centers for Medicare and Medicaid.

Tena Alonzo's research focuses on developing comfort focused best practice for addressing dementia related behavior, decreasing antipsychotic, anxiolytic and sedative medications, enhancing pain management, eliminating physical restraints, preventing rejection of care, understanding behavior as a method of communication, addressing dining and nutrition concerns, enhancing fall reduction techniques, and educating caregiving staff in understanding the progression of dementia.

Ms. Alonzo's work has been published in more than twenty five books and scholarly journals. Ms. Alonzo speaks nationally and internationally as a keynote speaker, featured speaker, panel member, and facilitator on evidence based, caregiving practices for people with dementia.

Ms. Alonzo earned a Bachelor of Science in Psychology and Biology in 1983 and a Master's of Administration in Theoretical Psychology in 1985 from Northern Arizona University. She is currently pursuing a doctoral degree in biomedical ethics.

Ivan Hilton, MA, FACHE

Director of Business Development for Comfort Matters

Ivan Hilton has more than forty years of experience in development and implementation of best practices in acute healthcare settings. He has held a variety of roles including microbiologist, assistant hospital administrator, business developer and consultant. Most recently, in an acute health care setting, he served as vice president of ancillary and clinical support services for the John C. Lincoln Health Network located in Phoenix, Arizona.

Mr. Hilton has a Bachelor of Science degree in Medical Technology from the University of Utah and a Master's degree in Hospital Administration from Central Michigan University. He is board certified in healthcare management and is a Fellow in the American College of Healthcare Executives.

Interview

Jean Galiana (JG): What drew you to the long term care industry?

Karen Mitchell (KM): My grandmother. People are usually drawn to elder care because of a family member. My grandmother emigrated from England. Her father worked in a cigar factory. She was one of nine children. We lived in adjoining apartments. She was on the bottom flat and we were on the top flat. She was a nursing assistant in an oncology unit at a Hospital in Albany, New York. When she became ill, she was not dying quickly enough in the hospital so they told her that she had to move to a nursing home. Because she had seen the deplorable conditions in nursing homes back then, she was frightened about the prospect of living in a nursing home. This was in the 1960s, when nursing homes were scary places. She was terrified. She died before they were able to move her. That experience set my resolve to help create better care options for the other grandmothers.

Tena Alonzo (TA): My grandmother was diagnosed with early onset Alzheimer's around 1982. She was not yet sixty. It was the first time I had ever heard the term Alzheimer's. I was an undergraduate studying psychology and biology. I was planning to be a professor. From her diagnosis to her death was approximately eighteen months. Generally early onset Alzheimer's progresses more quickly, which is a blessing in some ways. I saw good aspects and bad aspects of healthcare during her experience with Alzheimer's disease. At the time of her death, I decided to be part of a team that enhances the quality of life for people with dementia. I changed direction and attained my master's in geropsychology. I spent the early part of my career in geropsychology trying to improve the quality of life for older people with dementia and other chronic mental illnesses. It was difficult to witness the way the care providers were treating people with dementia and mental illness. The individuals living with dementia and mental illness had their sense of autonomy undermined. The people with schizophrenia would receive more attention and more support than the person who had issues related specifically to Alzheimer's disease.

JG: By attention and support, do you mean medically or psychologically?

TA: Both. Those living with dementia were placed on the bottom of the priority list. It was a terrible situation for those who had dementia and mental illness such as a history of schizophrenia, schizoaffective disorder, and bipolar disorder.

Approximately twelve years into my career, I realized that I was in the wrong place to make the level of impact that I had envisioned. If I wanted to effect change I needed to be part of another system. My colleague, Jill Hamilton, who was the medical director here until recently, asked me to join the team at Beatitudes. When I arrived, it was clear that we had a good team comprised of people who cared about the residents. We struggled to develop the culture, policies, and procedures to become as radically person centered as we are today. I knew that we did not know everything we needed to know about serving those living with dementia. I began the journey of research and discovery. We wanted to learn what a completely person directed model of care looked like in action.

Initially we had a traditional model of care with a strong medical component. We had a wonderful clinical director, Dr. Gary Martin, who is a great geropsychologist, and Jill Hamilton as our medical director. She is an internist and a board certified geriatrician and palliative care provider. We had a good, but traditional team. We knew how to administer medicine and treat medical issues, but we were not yet caring for the whole person. In essence, a traditional model of care without the other components is hospital care. They send you into a hospital, fix your problem, and send you home. You endure some of the distress and upset associated with the short stay situation because they are going to make you better. They want to cure you as quickly as possible to get you back to your life. There is no quick fix or cure for dementia. This is long term living. No one is going home. We needed to progress beyond being solely focused on the medical to include the mind and the spirit.

JG: How did you begin progressing to include the mind and the spirit?

TA: We began to overlay a social model on top of the medical model. We discovered along the way that we did not know very much about taking care of people with dementia. That was not our fault. No one knew much about caring for people living with dementia twenty years ago. Today, many still do not understand the culture needed to create person centered dementia care.

JG: Did the board support your efforts to learn a new care model and implement a new organizational culture?

TA: We had support from the top management down to nearly everyone else. Beatitudes Campus is an organization that was founded in faith and is driven by innovation. The leaders of the Beatitudes organization have historically embraced

a strong sense of social justice. We are affiliated with the United Church of Christ, also called the Beatitudes Church, which supports social justice for all people.

JG: What is the history of Beatitudes Campus?

TA: Reverend Dr. Culver, the first pastor of the Church of Beatitudes, which is just down the street, was visiting one of his parishioners in a nursing home. He witnessed deplorable conditions and was encouraged by his wife to meet with the congregation to determine whether they could help. He rallied the church to create the Beatitudes Campus in the early 1960s. Many parishioners mortgaged their homes to contribute financially. The pastor and other church leaders chose to cancel plans to build their sanctuary and to contribute those funds to building Beatitudes Campus instead. Reverend Dr. Culver believed that older adults needed a place where they could live, learn, and grow every day of their lives. He lives on the campus now. His vision and mission established our foundation of innovation. Years later, our organizational culture of innovation enabled us to develop the Comfort Matters evidence based training.

KM: We hold that history and their commitment close to our hearts. We are determined to continue their mission.

JG: Did the church members volunteer to spend time with the Beatitudes residents?

TA: Yes, and they still do today. Advocacy and social justice are fundamental principles of the Beatitudes Campus because of our roots in the United Church of Christ. We began our exploration from those commitments and beliefs. We are dedicated to creating a community that is inclusive for our diverse residents. We strive to create a place of comfort for people who have trouble thinking, because they deserve a home as well. It was a labor of love for everyone involved. We knew we could design a new model of dementia care that was more person centered than anyone had yet conceived of. We did not know what the model would be, but we knew it would be different. Fortunately, there were not many egos in our way. The purity of our desire to make life better for those living with dementia made Comfort Matters possible.

JG: Do the Vermillion Cliffs memory residents have their own rooms?

Ivan Hilton (IH): We have single and double occupancy rooms. The double rooms are large. They were built to house three. The residents bring their own

furnishings and decorations. We find ways to arrange the furnishings to create a fair level of privacy. If roommates are not happy living with each other, we find roommates who are a better match.

The new center that we are planning will have private rooms only. The structure will be based on the small home model. It will be a multi story building with safe balconies for residents to experience fresh air and sunshine. We will also include places for safe wandering.

JG: How many rooms are you planning to build in the new structure?

TA: The need for memory living residences is great here in Phoenix. We could fill Vermillion Cliffs many times over today if we had the space. We are grappling with meeting the great need in our community and creating the small home environment that can house many. The average age of our seven hundred and twenty residents is eighty seven. Many will likely need memory residences.

JG: What are your thoughts regarding the built environment?

IH: Architecture is not critical to provide comfort for people. We are a perfect example. We will not go into organizations where we are conducting our two year training and demand that they build green houses or small homes. We do believe the built environment can help to support the care culture, but it is not imperative.

TA: We want environment to match program. That is one of the reasons we are preparing to build new residences.

JG: What percentage of your residents pay privately verses publicly?

TA: Sixty percent of our payers are private and forty are public.

JG: How are you able to remain sustainable?

TA: It is the mission of the Beatitudes campus to serve the broader middle class. Our business plan is designed to manage the margin to serve the many. We have a variety of housing options that make our campus accessible.

JG: Do you charge residents a buy in fee?

IH: Residents in independent living pay a buy in fee. That price can range from two hundred and fifty to three hundred and fifty thousand dollars. They pay a

monthly fee for services as well. We also have month to month rental units with no buy in requirement.

JG: When residents leave or pass away, do you reimburse any of the buy in fee?

IH: Yes. Ninety percent is reimbursed to the resident or their family.

JG: What is the gender ratio of your residents?

TA: The residents are approximately one third male and two thirds female.

JG: Do the residents who are not living in the memory residences have memory issues?

TA: Their average age is eighty seven. I estimate that sixty five percent have trouble thinking. They live independently, but they have some cognitive challenges. We have services available to them as they age and their cognition declines.

KM: I know two nurses diagnosed with dementia a few years ago who were heartbroken when they had to stop working. Luckily we have good diagnostic doctors in Phoenix. We are all or will all be touched by dementia in one way or another.

TA: We are designing a care model that will change many lives, including our own. The genetic make up of my children makes them more likely to develop dementia. My life's work will hopefully help them if need be. I want them to be treated with a sense of autonomy and to be allowed to fulfill their purpose.

JG: Do you think that it is a benefit for people to know if they have dementia?

TA: Yes. My family member was diagnosed early. It is a part of the human experience to be born to die. Believing that you can go on indefinitely is a fallacy based in denial. If a person is diagnosed, they can make a plan and lay out their priorities.

JG: Do you think that people do not want to be tested because of their fear of suffering?

TA: Maybe a person with dementia does not have to suffer. That is what Comfort Matters is about. If people are suffering, we are not doing our job. We have person centered interventions that alleviate suffering.

IH: Tena believes that we give Alzheimer's too much credit and too much power. There is no reason a person cannot be comfortable, even with dementia, through the end of their life.

TA: We know that dementia impacts your ability to think. That is unfortunate, and we all hope that we will eventually find a method to at least arrest its progression. Hopefully, one day we will eradicate dementia from the population entirely by treating everyone proactively in some way, such as immunization. Our work and training is focused on how to make a comfortable life for someone who has already been diagnosed. We know that the brain is resilient, even with dementia. Parts of the brain, such as the emotional connection, are not as impacted as others. This is the reason that the way someone with dementia feels is far more important than the way they think. This is why we see such pronounced emotions in people living with dementia. The emotions lead the behaviors. The behaviors serve as communication when the words are difficult to find. If we can find ways to provide someone the ability to feel good, it does not matter that they cannot think.

IH: That is why music and art work so well. Music brings pleasure and often triggers memories. Music is a simple and powerful form of comfort.

TA: We know that the part of our brain that tells us when we are comfortable and when we are not is intact until our last breath. Our emotions are primarily intact. We can use that knowledge. If we know what makes someone comfortable and feel like they are in charge, they live well. We have done this and we can teach it. We have witnessed it being operationalized around the country.

KM: The reverse also holds true. Knowing what irritates people and eliminating it is a form of support. Irritants can include making a resident adhere to our schedule of waking and sleeping, making them eat food that we think they should eat, having a television on, using overhead pagers, requiring them to shower how and when we want them to shower, and using medical, emotional, and alarm restraints.

IH: That is why we do not have staff turn over in our dementia residences. They have positive and peaceful interactions with happy, comfortable residents.

Lady Waddell by John Waddell – Beatitudes Campus

JG: Please discuss staff turnover a bit more.

TA: We have employees who retire. We have people who are diagnosed with dementia. We have people who go back to school. That turnover is natural. Beatitudes Campus is a good place to work because our culture supports the employees.

IH: That is the empowerment piece of our culture. A few months ago we had guests from the Department of Health and Human Services. They were interested in learning about our Comfort Matters program at the Vermillion Cliffs memory residence. We had just finished telling the visitors that we empower our staff to engage and give comfort to the residents. When we arrived at the Vermillion Cliffs residence, an employee was stacking the laundry closet. Our resident, Terry Lee, was walking around with her earphones in and listening to music. As she passed the laundry employee, he turned around and took the time to dance with

her and twirl her around. She had a big smile on her face. She was in heaven. We thanked the employee for taking the time to interact and connect with Terry. He responded, “I dance with her every day. I love it. That is why I come up here.”

That is part of the culture at Beatitudes. The empowerment of individuals. The laundry employee added joy and happiness to Terry’s day and also to his own.

We have a resident who is not able to pronounce words. She is Hispanic. One day she appeared to be having a tough time and was sitting at a small table with her head down. A Hispanic maintenance man walked over, got down on his knees, looked her in the face, and started talking to her in Spanish. Her face lit up immediately. He chose to spend a little time to be with her and talk to her in her familiar language. Those interactions happen here regularly.

JG: What influenced the design of Comfort Matters?

TA: We began researching and designing the Comfort Matters program in 1997. The publications[1] of Tom Kitwood were our early foundation and inspiration. Tom Kitwood promoted the concept of autonomy by identifying people as individuals, knowing them well, helping them to be comfortable, and recognizing that their behavior and their actions are their communication. Through our work, we learned that each member of the team must have the autonomy to help our residents to be comfortable, celebrate who they are, and feel a sense of wellbeing. If this responsibility is left to a couple of people or to part of our organization only, it does not work.

We began with weekly team meetings at Vermillion Cliffs, our advanced memory residence. We discussed each resident to determine their individual needs and preferences. We explored systems and structures that would support meeting those needs and preferences. Initially we learned that we were waking people at 4:30 or 5:00 in the morning for a 7:00 breakfast. Most of the residents are

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[1] Kitwood, T., (1997). Dementia reconsidered: The person comes first. Buckingham: Open University Press.

Kitwood, T., & Benson, S., (Eds.) (1995). The new culture of dementia care. London: Hawker Publications.

Kitwood, T., & Bredin, K., (1992). Towards a theory of dementia care: personhood and well-being. Ageing and Society, 12, 269-287.

vulnerable and frail. This schedule was not focused on the needs of the residents. The schedule was built around our organizational goals. We examined and broke down some of those systems. We did this process as a team, including everyone from the housekeeper to the director. We compared our systems to the needs and preferences of the residents. We know that people with dementia generally do not sleep like everyone else; they must be afforded the opportunity to rest and relax when it makes the most sense to their body. If we honor their schedule then when they wake up they are in a much better mood, they are able to think more clearly, and they are able to do other activities more easily than they would if they were tired.

The team meetings were an important component to our research. We were able to design new systems and policies that supported each resident individually.

JG: What other challenges did you encounter in your culture change process?

KM: We had to challenge territorialism, not just the hierarchy and the chain of command. An example would be an employee thinking, "This is housekeeping. This is my realm. You cannot decide that we are going to readjust our schedule because people want to have access to food twenty four hours a day." We examined all of the systems that we had in place that supported territorialism and redesigned them. As we began implementing the new culture, we realized that it would take a total buy in from every employee and board member. Everyone had to recognize that the needs and preferences of the residents were directing our policies and procedures. The residents are guiding us by how they respond to issues. Who knows the residents the best? The housekeeper who is in the room every day—not the management or the board.

Our job as managers is to support the entire staff in doing what they know to be best for the residents. Everyone understands that culture. There is no dictating downward. Management offers education and empowerment. I taught a senior staff member in class yesterday. I also had caregivers. The only top down sanction was that senior staff should encourage all of the employees in their department to bring any issues forward, to innovate, and to find special ways to connect to and create comfort for our residents.

We also have a fluid partnership with the families of our residents. We are continually exchanging information and collaborating with them to design a plan for their mom or dad. Situations change. Family members are an important part of our care team.

The business world does not naturally operate this way. This model demands one hundred percent employee participation and accountability. When we have discussions about changing a system and we hear, “It is going to interfere with my break” or “I will not be able to finish showering five residents,” we are not happy. We want staff to understand that the choice was made for the comfort of the residents. Staff should adjust their schedules around the individual schedules of the residents. That is person directed culture.

JG: Why do you refer to yourselves as a campus?

TA: We were named Beatitudes Campus for a reason. This is a learning environment. We trial and we trial again. Sometimes we get it right. Sometimes we do not. The beauty of healing and medicine is that they incorporate art and science. Often providers are so focused on the science that they forget that art has to be considered in equal measure. We are elevating the art portion to the position it needs to be. There is an art to learning how to collectively develop ideas that keep the resident comfortable, autonomous, and in control.

JG: Was elevating the art portion a difficult process?

TA: We were able to develop beliefs and philosophies that did not necessarily support people. Why can we not develop policies, philosophies, and beliefs that do? We have experienced success in our training because we show people how to completely operationalize our philosophies and culture through an evidence based model.

KM: We tend the process. Person centered culture is fluid. We must keep modifying and adapting the process.

JG: Please describe some of your research.

TA: We are engaged in translational research. We have conducted two studies. One of them was in 2009. We completed another study more recently where we worked with three large nursing homes in New York. The Comfort Matters palliative care implementation was at worst cost neutral; at best it created cost savings. There is no reason for an organization not to have an effective palliative care program. Our model uses very little or no antipsychotic medications and removes medications and exams that are no longer useful, such as prostate medications and mammograms.

IH: Additionally, we calculated that we saved thirty thousand dollars per patient per year by eliminating nutritional supplements that are no longer useful to the resident.

JG: Why do you think other memory care providers are not using the Comfort Matters model?

TA: The memory care industry is on the verge of changing the way care is delivered to everyone. This is new. When I presented at the Institute of Medicine and interacted with many people from around the country, I learned that there is a general philosophy about person directed living that most agree upon. The issue is how to operationalize the philosophy on a deeply cultural and sustainable level. We have been successful in translating the philosophy down to the finest details. It is embedded in every system and every employee. We have been training other organizations to do the same and have seen wonderful outcomes. Success does not come over night. We work for two years with our clients so that when we move on, person directed comfort is steeped in every aspect of their culture and operations.

JG: What other consistent outcomes have you witnessed with the implementation of Comfort Matters on this campus?

KM: Comfort Matters creates lower rates of incontinence and more toileting, minimal antipsychotic usage, no restraints, few alarms, no sundowning, an increased usage of pain medications (we use Tylenol), decreased hospitalizations, increased family and staff satisfaction, decreased staff turnover, and weight gain due to liberalized diets.

JG: Are people alarmed that you are not making the residents eat three balanced meals per day?

TA: The effectiveness of liberating the diet is not only our finding. The American Academy of Nutrition and Dietetics supports that position. They support eating whatever makes you happy whenever you wish.

JG: Is that a new position for the American Academy of Nutrition and Dietetics?

TA: No, they have been promoting liberalized diets since 2005. Their position was updated in 2012. That is what I show doctors when they prescribe an eighty year old Lipitor and put them on a cardiac diet.

JG: Has your research or experience shown which person would live the longest: the person who takes Lipitor and is on a cardiac diet or the person with no medications who eats whatever and whenever they want?

TA: Generally the person who eats what they want lives longer and in that time has a better quality of life.

JG: Are there safety issues of people wanting to eat at all hours?

TA: Most of the residents need ambulatory assistance. If a resident regularly likes to have a midnight snack, they will not be up walking around and in the kitchen alone. Staff understands that addressing this habit is part of their responsibility.

JG: Will the staff prepare a meal late at night?

KM: Yes. We have meals in the freezer that can be microwaved. We see too much polypharmacy with our new residents. It takes us a while to start cutting back on the medications. Our medication average is four per person per day forever. That includes pain medication.

JG: Is that lower than the national average?

IH: It is much lower. The national average of medications taken by someone age sixty five to seventy nine is twenty. For those eighty and older that average is twenty two.

TA: I had the opportunity to speak to the Institute of Medicine a couple of years ago. We told them about our medication rate. They were amazed. It seems like an obvious quality of life choice to us. When a person has a terminal condition and you give them many medications, they often cannot eat because they are full of medications. They also may not feel well because of the strength of the medications on their frail frame. It makes sense to start reducing the medications. We talk with families about Aricept and Namenda. The resident might have been taking medications for nine years and they might not be working much anymore, if at all. Now they are just creating expensive urine and uncomfortable stomachs. Liberalizing the diet often contributes to weight gain because the residents feel better and eat more.

JG: Are families hesitant to reduce the medications?

TA: Someone has to be brave and suggest medication reduction to the family and explain why. Families are usually ready and willing to lower medications.

KM: We want the right drug in the right dosage for the right person for the right reason. Some people need medication, but you must investigate all medication usage. There is an experimental nature to how we view everything. We are continually examining what works and what does not. When we take a medication away, we watch closely for any positive or negative effects. We see positive affects almost always. We carefully document and observe. The documentation helps us with the inspectors, as do our favorable health outcomes. Inspectors need to be certain that we are making choices that are safer and have better outcomes for our residents.

JG: Do you need more staff to make these medication changes?

KM: It is the opposite. Residents who are on fewer medications generally eat better, are happier, and are more stable. Their digestion works better too, which can make for better toileting. Another reason our residents do not need as much medication is because we let them live as they wish to the highest degree possible. We have one nurse for the thirty eight people at Vermillion Cliffs. We need fewer staff because we use fewer medications and treatments, resulting in fewer calls to the doctors and fewer incident reports. We have four or five nursing assistants on days and evenings, depending on our situation. For example, if we have a new resident who is having trouble adjusting, we have more staff. As I mentioned earlier, ours is a fluid model based on the needs of the residents.

If you let people sleep as long as they like, they are far happier when we help them up out of bed. We need fewer staff when the resident is not angry that we woke them up and are forcing them out of bed. It is the same for eating, showering, and all other activities.

TA: We also use our entire staff to keep an eye on the residents. Our housekeepers are engaged. There is much more appeal to a housekeeping position when they are a part of the caring environment. They are welcome to speak up for a resident. The rest of the staff appreciates the feedback and validates their concern and involvement. Our housekeepers are a valued part of the team and they know it.

IH: I love the story that Karen tells about one of our housekeepers.

KM: I was a nurse on the floor. One of the housekeepers asked, “Would you come and check on Mrs. M?” I asked, “Why?” She responded, “I do not want to tell you because you will think it is silly, but would you just check on her to make sure is she alright?” I conducted an assessment but nothing seemed amiss. I asked the housekeeper, “Please tell me what is different?” Her response was, “Mrs. M is not singing this morning.” I answered, “Thank your for your feedback. We will watch her closely.” The next day, Mrs. M spiked a temperature due to a urinary tract infection. The housekeeper, who listened to the resident singing each day, detected the early sign of discomfort. She knew the resident well. Importantly, the housekeeper knew that it was her place to voice her concern and that we would respond accordingly. We train many other managers around the United States. You would be surprised how few organizations include and understand the importance of feedback and connection between the housekeeper and all other staff.

TA: They often remain an untapped resource.

IH: Our culture makes it easier to recruit people to work here. Our culture is also a marketing tool to attract residents. Because of our reputation, families want their family members to live here.

JG: Do you maintain the same staff at the same residences?

TA: Yes. There is a big push nationally for consistent staff assignments.

KM: The staff tells us what a big difference it makes. With consistent staff assignments, the families get to know the care partners and the other staff. This enables the families to be more involved and connected to the care. Organizations, including Beatitudes, who use consistent staff assignments, have seen the number of family complaints drop or end all together.

TA: We had had approximately one hundred data points in our research. We were not just determining whether is it cost effective for staffing. We measured hospitalization and emergency department visits.

We had positive changes in all areas because an empowered team works toward a common goal. There is a higher goal than just receiving a paycheck. Most people who work in healthcare are service minded. They do not stay in the industry if they are not. It is not about a job. We want to make a difference. We create the

culture for the staff to experience making a difference and being a part of a culture that is positive and life affirming.

KM: Our team also vets the products that we use. For example, we tried a different, thinner brief, but found that the cost savings were not what we had expected because we had to use more of them. Management can bring ideas, but the expertise and experience of the care team is more heavily weighted in decision making.

JG: How did you vet the briefs?

TA: I am proud to say every staff member participated in that process. We did have to tell a few family members that we looked a little extra padded because we were wearing briefs so we would understand the experience better. The families were quite impressed. I actually had a couple families offer to try them and report their experience, so I directed them to Walgreens where they could buy their own supply. Even though we were not all perfectly comfortable, the trial was well worth our time.

KM: We try many new ideas. We had residents in Adirondack chairs at one point. We had beanbag chairs another time. We used the Merry Walkers. We have learned to vet any product or system.

TA: When I began working at Beatitudes, we had many residents who were experiencing weight loss. Rather than accept weight loss as standard, we decided to carefully watch how people were eating. We learned that people were not eating or drinking their supplements. One day I collected a sample of every supplement the residents were taking and lined them all up. The staff tasted one or two supplements. That experience achieved full staff buy in to stop feeding our elders with unnecessary, bad tasting supplements that likely were making them feel full or nauseous or both.

KM: We challenge everything, but not all at once. We choose one subject at a time and then challenge the beliefs around the issue. We also examined bed rails. You may have noticed that we do not use bed rails. In one situation, we had a certified nursing assistant who was sure that one particular resident could move herself and insisted that we keep the bed rails. We stood watch outside the room for hours. She never moved, so we got rid of the bed rails.

JG: How did you determine your policy around restrictions other than bed rails?

TA: Our policy around restrictions is person directed.

KM: The policy is informed by the reaction of our residents.

IH: Our policies are based in knowing the person intimately. We also interview the family to learn what the resident was like before moving in, what kind of music they enjoy, and other personal preferences.

JG: Do you have locked doors in your memory care residences?

TA: We have secured doors, but what we use to secure the elevator is a red rope that implies that very important people live here. Buzzers, bells, and alarms are not consistent with comfort for people who have trouble thinking.

JG: Does the rope work?

KM: Yes. It has been very effective.

TA: The rope is also considerably cheaper than most other options that would create upset and distress.

KM: Our staff is highly engaged with the residents so wandering off is not an issue for us.

TA: When we renovate, we will not have an elevator to contend with. The residents will always feel as though they are part of the community, and should not feel compelled to leave. For now, our care model must overcome bad design. There was no consideration of person directed dementia housing when the residence was built fifty years ago.

KM: In order to remove alarms and other restraints, all of the staff of the Beatitudes Campus must be included and updated. When we ran into problems with our elevators, we brought people in from the other departments. Anyone who gets off the elevator needs to know to wait until the elevator door closes and to not let a resident on. We want to ensure that employees do not unknowingly bring people downstairs. We examined all of the systems and detailed our policies in writing. The Comfort Matters culture is organization wide and involves each employee.

JG: How do you balance the less restrictive atmosphere of your dementia residences with the regulations?

TA: We understand that regulators come to their work just like we do—not knowing everything there is to know, and having to learn. We never know whether or not they have had the opportunity to learn. Occasionally we have to convince the regulators. We seize the opportunity to educate regulators about what is important for the people we are serving because we are the experts. We can speak for the residents, and we need to speak for them. It would be unethical to fail to speak for them when we know what they need.

KM: The new guidelines for dementia are focused on person directed care and keeping people comfortable. An organization must put into place the policies and practices that support comfort and person directed care. All employees need dementia specific training. This creates the opportunity to dialogue and explain to inspectors and regulators why our care process is safer. It also enables our residents to experience the best quality of life possible. Our inspectors in Arizona are open to learning. They have spent a lot of time talking with staff. In the past, most regulatory concerns were brought to the director of nursing and the administrator. Today, regulators come in and speak to the housekeeper, the diet aide, and the nursing assistant. When an organization creates a team that has been empowered to do what they know needs to be done for the residents, the inspectors do not have to go to the higher level administration. The regulators see quality and comfort embedded in every fiber of the care. Our care team knows each person individually and can anticipate what gives comfort and happiness. Our care culture is embedded in every person who interacts with the residents, which is almost everyone who works at Beatitudes Campus.

IH: Our culture is designed to empower the housekeepers, and all other members of the support system, to be able to make decisions along the way.

TA: When we began our work, we did not have as much of the confidence that we are showing you now. We have witnessed outcomes of our evidenced based care model over many years. I have had a couple of advisory calls with the Centers for Medicare and Medicaid Services. They solicit our feedback to learn the best organizational practices for people in assisted living. Dementia does not know licensure. Our campus serves people at all levels of physical and cognitive ability. Some live in their own homes and others in skilled nursing, memory care, or assisted living. We are building strategies that support people where they are rather than strategies that add an extra layer of potential distress. In the early stages of or our culture transformation we ran into the “you cannot do that” response regularly. Change is generally met with resistance and fear. I suspect

that is still the case in some organizations. We started to ask ourselves whether commonly held beliefs were fact or folklore. Beliefs such as: “you cannot have people eat whenever they want because the regulations will not let you” or “you have to have a nurse watch them as they eat even though the environment does not support good nutrition and a comfortable experience when they are with a group of people.” Are these ideas fact or folklore? We learned that those and many others are folklore.

JG: How did you learn that these commonly held beliefs are folklore?

TA: We began this exploration in our early stages of culture change. We spoke regularly with the Health Department. I would ask, “Is this really a regulation? Could you direct me to the F-Tag?” F-Tags are guidelines for federal and state regulations. Sometimes the actual guideline can be different than what its interpretation has become over time. I researched many F-Tags.

KM: The organizations that we are training around the United States have done the same. They have built relationships with their regulators so that they can ask these kinds of questions and complete the groundwork ahead of time. The guides that are available are very well laid out. We learned to love the regulations.

We shared the guides with all of the departments so that we have the same information. When the guide for the dementia specific care was designed, we shared it with our director of nursing. She then met with her staff and they evaluated their processes. They made sure they were operationalizing person directed dementia care in every aspect of the residents’ lives. We have learned to work within the framework of the regulations.

TA: We make our regulatory adherence transparent. We do not organize according to what we think might go wrong. We organize our system to meet the requirements of what is being asked in the regulations. That is the reason we commit to understanding both the letter and the spirit of the restrictions.

Occasionally the process is not perfectly smooth. We have had said, “You are telling me this, but we do not agree and here is why. I will bring you the F-Tag and the scientific literature that supports this position.” We have all of the research and F-Tags on hand for these conversations. We are prepared to have the research and other information that will allow the regulators to see things our way. Often, all we ever had to say was, “I have literature that supports our position. Would you like to see it?”

KM: Many surveyors have held other jobs previously. One is not required to attend school to be a surveyor. They understand the letter and are becoming better about the spirit of the regulations. Ten to fifteen years ago, surveyors were visiting and I was sitting and crocheting with a couple of ladies in the dementia living neighborhood. One resident was untangling as fast as I could crochet. We were sitting and talking about the arthritis in our fingers. Another staff member was reading the paper to someone. Another was sitting in the common area and another was styling someone's hair. There were approximately five different activities happening. The surveyor asked, "Where is your activity?"

IH: They were looking for group activity.

TA: They said, "That is not what we are expecting to see." We explained that everyone was involved in an activity and it was fine. Person directed activities are those that the resident feels like doing, not some class type structured activity that we impose upon them.

IH: We recently met our resident Terry Lee and Mr. Shubundi from our dementia living residence out on the putting green. That is an activity. Regulators had to be told that activities can be broken up into small groups. Terry Lee and Mr. Shubundi walked across the campus to the putting green and interacted with other residents and with all of us in the process. Then they practiced their golf. I do not know that you would see that situation in many other life course living communities.

TA: Terry Lee was formerly an executive for Marriott and likes to inspect for problems. She will comment, "That needs to be painted. Why is that not being taken care of? You know that plant needs watering." This behavior is ingrained in her nature.

KM: When we bring guests to the Vermillion Cliffs, she wants to make sure we are taking care of them to her standards.

TA: She will let us know if she thinks that we have not done what we should. We have a culture where she is free to be her supervisor self.

That is just it. Even those living with dementia are individual people. Most of our residents come in with sixty five or more years of life behind them. We honor that life and the person they are because of their life experience. We must have a

culture that allows people to be themselves. That is the heart of person directed living.

JG: Do you have any intergenerational activities?

TA: We partner with several of the schools in the area. One is Washington High School, which is just down the street. They bring the students here for service projects. We designate a student of the month. We also honor the Washington High School students with a big banquet at the end of the year where we award scholarships.

JG: Are the residents involved in those events?

TA: Our residents decide who wins. They also donate the scholarship funds. We have many retired teachers who live here. Our campus is based in purposeful living. On our campus, there are over ninety seven clubs and meetings that were started by residents and are resident run.

IH: Every Wednesday night we have a Hootenanny on campus. Igor Glenn organizes the Hootenanny. He is a musician who was formerly with the New Christy Minstrels. The New Christy Minstrels were a group of twelve to fifteen people that produced many popular songs. He still travels all over the world. Every Wednesday, people come from all over the community with their instruments to participate in the Hootenanny.

TA: They are professional musicians.

IH: Some of them live on the Beatitudes Campus and others are from outside the campus. Some of them decided to live here because of the Hootenanny.

TA: We also have an active resident run group, Seniors for a Sustainable Future, who have lobbied in Washington, DC. We have residents who have spent their lives making contributions to the broader community, which is why many of our groups are civic minded.

JG: Being a faith based organization, are the Beatitudes residents diverse in lifestyle and religion?

TA: Did you see our sign our front that says, “Open to business for everyone”? We were the first organization in Arizona that was publically open and affirming to people of all lifestyles. We are very proud of that. We believe that everyone has

a place at the table. We had a number of residents who wanted to more fully connect with the lesbian, gay, bisexual, and transgender community. They contacted the people who operate P Flag, which is a support group that supports the lesbian, gay, bisexual, and transgender community and their friends and families. Today, they meet on campus weekly. We recently screened the movie Gen Silent on the campus. Our lesbian, gay, bisexual, and transgender support group has approximately one hundred fifty members.

IH: We hold many activities for the community, including AARP, Alzheimer's groups, and other support groups. The Beatitudes residents are welcome to attend all the community activities.

JG: Please describe your home based services.

KM: We provide a variety of home health services through our Beatitudes at Home and Beatitudes Home Health programs. Our caregivers offer support to our campus residents and to those in their homes in the local community.

TA: We are a life plan community without walls.

JG: How have you eliminated sundowning[2] in your dementia residences?

TA: People who have trouble thinking have specific needs. They need to be able to sleep when they are tired. They need to eat what they want and when they want. They need to receive assistance with activities of daily living in a way that is meaningful and appropriate to them—not convenient for us but for them. They need to be engaged in ways that are meaningful and that celebrate who they are as people. Their environment should exist to support them. Someone who cannot think well generally cannot tolerate a lot of noise and commotion. They cannot make sense of it. They think, "I am uncomfortable and afraid and do not know what to do." Loud, unpredictable, institutional type culture is noxious to those with thinking problems. If we help people sleep when they are tired and wake when they are refreshed, they are often their best self. We have to anticipate their needs and know each individual well enough that we know when they are hungry or thirsty. If their stomach is aching because they are hungry, they are not going

[2] Sundowning is characterized as agitation, irritability, or confusion that often begins or worsens in the later afternoon.

to be able to tell us. If we are mindful in managing these aspects, the likelihood that someone will sundown is substantially reduced.

Reducing sundowning also is achieved with medication management or reduction. For example, nine hours after someone receives an antipsychotic, anxiolytic or Ativan, that person experiences what is referred to as a hangover effect. They feel like they had too much to drink. When practitioners give a medication to someone that makes them feel bad nine hours later, this sets up the conditions that create the anxiety and unhappiness that lead to sundowning. When a person has difficulty thinking and feels sick or hung over most of time, they are prone to sundowning.

IH: Tena just explained the engagement part of the Comfort Matters culture. If an older resident with dementia begins fixating on picking their children up from school, we find ways to calm them that do not involve drugging them. Another phrase I enjoy hearing Tena say often is, “We like to give their brain a better offer.”

TA: We have been engaged in many behavioral consultations in Phoenix and all over the country. We have found that boredom is almost always a factor in sundowning. Many people still do not understand that the start button is broken for those with dementia.

JG: Do they need to be engaged?

TA: They do not want to just be sitting there, but they are unable to move to the next step. Their brain will not allow them. Someone has to be the kick starter. When we make their brain a better offer, we are offering them something of value; something other than frustration and boredom. They cannot verbalize it but they are thinking, “Thank you. I was just waiting for you to help me out.” If we can anticipate the need for a start, we can prevent a resident from becoming frustrated. Frustration is how they communicate that they need a kick start if we have missed the cues. At such times, we give them a start, not a pill. This is a non pharmacological measure that is much more effective most of the time.

IH: A kick start will differ from person to person. Someone might want a chocolate bar or an ice cream sandwich. Someone might want to get up and walk around. Someone else might want to knit and feel the texture of the yarn in her fingers.

TA: Another resident may just want to spend time with you because they see you as family or as a friend.

JG: Is preventing the agitation in essence what enables you to stop using the antipsychotic medications?

KM: Everyone, including us, has the potential for sundowning. People living with dementia do not have the same tolerance for boredom and agitation. We are mindful of tolerance.

TA: A person with memory issues cannot reason. They are not able to say to themselves, "Oh it is alright. I just need to sit here a few minutes and they will bring me something to eat. Then this pain in my belly will go away. I can wait. It is not a big deal. Let me distract myself by looking at this magazine."

JG: Someone living with dementia does not have tolerance for delayed gratification?

TA: Right. When they have needs, they need them met immediately. When the care team deeply knows the residents, they do not wait until a resident is agitated. The care team identifies the need and prevents the delaying of gratification.

JG: What are your thoughts on preventing falls?

KM: Meeting the needs of a person is the most important and effective way to prevent falls.

TA: Exactly. Why do you pop up out of a chair? You are hungry or bored or need to use the toilet.

When the care team notices that someone is "rejecting care," there are two options. The provider can contact the doctor and be given a prescription to calm the resident or understand the reason for the agitation and address the need. Here, if a resident is "resisting care," we determine the cause. We might suspect that their arthritis is more painful today because it is humid. We would change the dosage of their Tylenol and observe. We do not need to call the doctor to make the resident comfortable.

KM: Calling the doctor is a last resort.

TA: Yes. Absolutely.

JG: How do you walk the line between dignity and risk?

TA: You saw two of our later stage memory residents practicing their golf on your way in. Would you have known they have memory challenges if we had not told you?

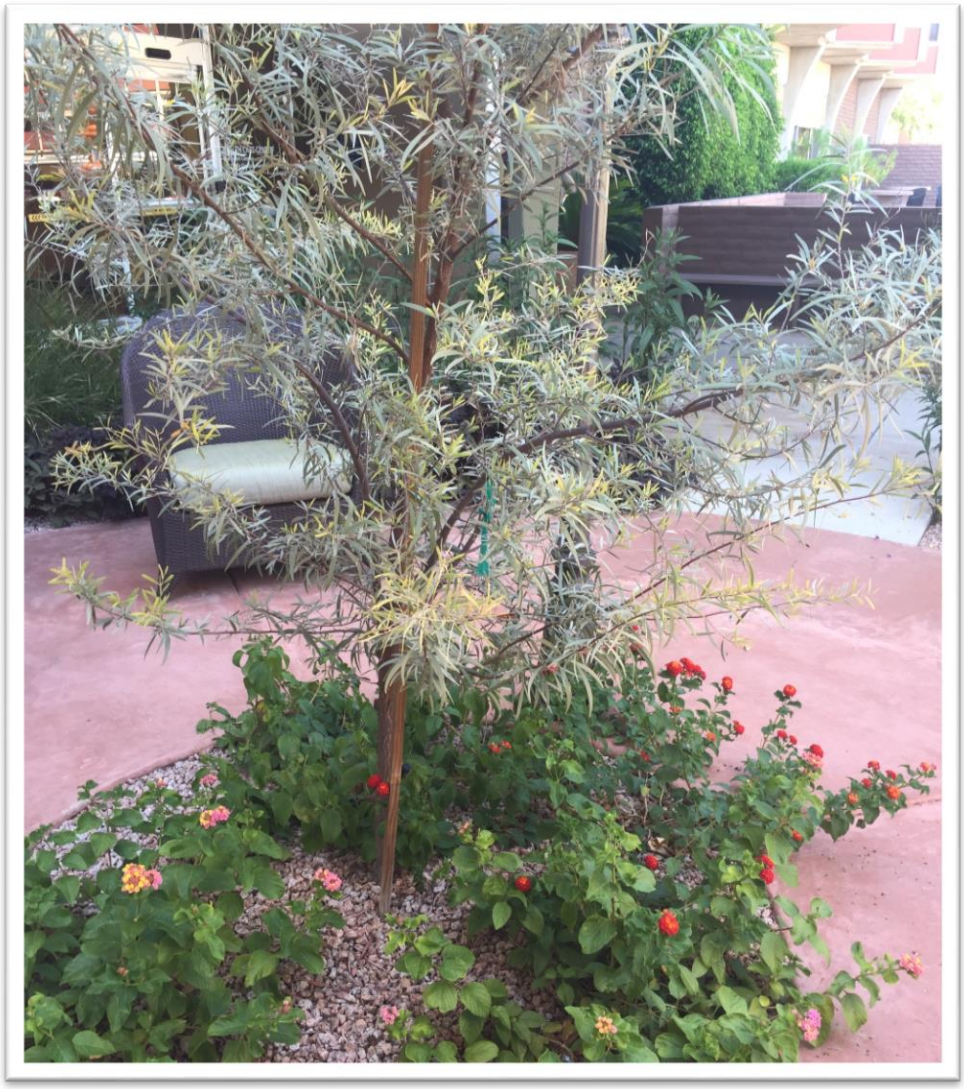
JG: No. You are not concerned that they might fall over the ball or trip during the walk over to the putting green?

KM: They have support from the activities person who accompanied them.

TA: Think about it—humans fall. It is the threat of litigious activity that blocks organizations from enabling a person to experience freedom and quality of life. We consult with the decision makers. We tell the family that an activity is vital to their parent's experience in life, because this is what their parents have always done. When the family agrees, we share the responsibility for that risk.

JG: Do you also find that you are educating the families?

TA: Most people do not understand the progression of dementia. We continue to educate and inform the families with an ongoing dialogue. Karen mentioned partnering with the families. We see the families as our partners. That is essential. If we do not partner with the families then they will never understand the best choices for their parents. Often, this is their first experience with dementia. We have experience with thousands of people living with dementia. We are there to guide them throughout the time their parent is living with us.



Dementia friendly walking path.

KM: This is informed consent.

TA: Yes, at its highest calling.

JG: Which of your staff are trained in Comfort Matters?

KM: Every employee is trained in the Comfort Matters culture. We host an orientation for all of our new employees about Comfort Matters, what is expected of the employee on campus, and how employees should approach the residents. After orientation, employees attend either a two hour or eight hour monthly training. All employees working specifically in the memory neighborhood, the

department managers, and supervisors attend the monthly eight hour training. We continually educate and invest in our human capital.

JG: Even grounds staff is trained in Comfort Matters?

KM: Absolutely. Each of our four hundred and twenty five employees are engaged in continual training.

KM: I am the Comfort Matters nurse educator for the campus. We are conducting Comfort Matters training around the country, but we have maintained a strong dedication to our employees on this campus. Tena and I teach the eight hour training.

JG: Please describe the Comfort Matters training program that you are providing throughout the United States.

IH: When we began to teach the Comfort Matters model, Tena taught other organizations on a train the trainer model.

TA: It was not as easy for people to make the necessary changes with education alone, then being sent off on their own. There was no one to guide them through the operational steps.

IH: We give a two hundred and fifty page education manual to every organization that is involved with our Comfort Matters training. You might say, "This is proprietary material. Why would you share it freely?" But the knowledge alone is not enough. To operationalize the knowledge and model, an organization needs hands on support over a long period of time. The training is always evolving.

IH: Presently, we have fourteen client organizations that are participating in our Comfort Matters training. We have coaching calls with them every week or every other week, depending on how long they have been in training.

IH: Our newest client is the Actors Home in New Jersey.

JG: Are you teaching them how to implement your dementia living model?

IH: Yes. They are a Comfort Matters provider now.

JG: Are you training the housekeepers too?

TA: Yes. We have manuals specific to each position, including housekeepers.

IH: When we begin with a new consultation, we spend a week with them at their organization.

TA: We spend a considerable amount of time preparing before that first week. We talk with the management to determine how we can support them through the process, because change is difficult. Karen and I or Karen and Linda Travis and I will learn the priorities of the management and draft the agenda for week one. We customize the plan according to the individual needs of the organization. Generally, we spend the first day getting to know the care team and make observations in their neighborhood. We teach to the strengths of each team member and identify opportunities for change to make comfort more available to the residents. On the first day, we will look for signs that a resident may be in pain. Pain is under recognized and undertreated for those living with dementia.

JG: Is that because they cannot verbalize the fact that they are in pain?

TA: Yes.

JG: How does one recognize that someone living with dementia is in pain?

TA: There are reliable tools available. They just need to be used as part of the model of care. Positioning is another issue, as is boredom. We examine all the factors that could make someone uncomfortable and determine how that discomfort is communicated, or better yet, prevented. We begin to build relationships with the staff as the training progresses. Eventually the care team will start to find their way with our education, support, and guidance. We do not go in as dictators. We will be working with them for two years. We offer two separate eight hour education sessions during the next two days. We guide the care partners in directions. We may ask, “Did anyone notice that Mr. J was in pain?”

KM: We will solicit their observations.

IH: Tena and Karen establish the baseline or benchmark the first week and construct a plan from that point.

TA: Change happens in many ways. It is important for us to get a good baseline on the first day. Then we conduct two one day eight hour education sessions. Our

education is multi modal in that there is didactic education, video, discussion, case studies, and exercises.

This model is evidence based. The workforce across the country that we are training is made up of people from many different cultural backgrounds. The multi modal approach allows for the greatest understanding. We, at Beatitudes, hail from twenty seven different countries, and speak over ninety percent of the languages of the world.

We spend the first two days meeting the staff where they are. We continue to build our relationships with them so they understand that we are not adversarial. We present them with information that they likely never knew. We may also be verifying and vetting things that they already knew to be good care but that the system did not support.

KM: Many of the staff we train is happy to have us. We are telling our story. They are telling their story. Even in the education we are making those bonds.

TA: On the first evening, we may bring an example from the day so the staff can examine it. We really use their strengths and their opportunities in framing the education. We think that process is unique. We believe that is the best opportunity for learners that we can give them. At the end of the day on Thursday, after we have done the education, we have a learning circle. Accountability and involvement are vital to success. We go around the circle and ask everyone what they have learned. That is a moment of realization for them. We ask what each person learned that will influence them to revise one process the next day. We teach, the participants have realizations, and they make the changes.

KM: They tell their peers, bosses, and everyone else in the room that they are planning to make specific changes.

TA: There is beautiful symmetry to it. We provide teaching and a safe enough environment for people to realize that possibly they have not been providing the best care and help them pave a path to do so. We have some people who break down and say, “I had it all wrong and now I understand.” The staff describes the process as rewarding. People working with the elderly generally want to create the best possible lives for them. We help them attain that wish.

KM: At one of our organizations, we had a maintenance man stop to thank us. He was happy to become part of the team.

TA: On Thursday, after we have done the education and sharing circle, we send the staff off to apply all of their learning and realizations.

KM: We work together with them in the application.

TA: The staff is often excited to try new methods. Sometimes they will tell us, "That person is suffering so much. I cannot believe I had not noticed the signs before. Now I know I can fix it. I have the tools. I know they hurt. I know that they are rejecting care because they have arthritic pain." Those moments are exciting for us all. We work as a team to create comfort. It is rewarding for the staff to have calm, comfortable residents.

KM: We work with many departments, including the activity department and the social department, to help them become part of the transformation.

JG: Do you see recurring themes from organization to organization?

KM: We see similar themes in every group. We expect to see issues regarding the treatment of pain. We also usually have team dynamics to address.

TA: Our model is being continually validated when we witness the transformations.

JG: Themes you have mentioned are pain, sundowning, and team dynamics. Are there other themes that you commonly address in your training?

KM: Positioning.

JG: Does positioning mean how you sit someone?

KM: Positioning refers to how people are sitting, what they are sitting in, how long they are sitting, and how liberalized their routines are.

KM: The Comfort Matters concept is based in how the team orchestrates what to do and when to do it. The staff is often stuck in a routine designed to accomplish their responsibilities. We pry that process open with them and examine how much of the plan is based around the needs of the residents. Sometimes the processes and schedules are too rigid. One example is requiring everyone to be in the dining room from noon until one. Residents have to move whether they are

done or not because the dining people have to start cleaning up. This creates an elevated stress level with residents reacting to caregivers and housekeepers rushing the process of eating, which should be pleasurable and relaxing.

TA: Or the overhead pager is going off.

KM: Noise is often another theme. If they have overhead pagers or other alarms, it is an issue that we will deal with. From the beginning of working with a new client, we immediately start seeing patterns. Some organizations have worked on diets and supplements before we arrive. Some organizations use far too many antipsychotics and anxiolytics. The usage varies from state to state.

TA: We check the statistics before we go so we have a sense of what we will be facing. We look at their Centers for Medicare and Medicaid Services filings also. On the last day of the first intensive week, we sit down with members of the team and create a strategic plan for moving forward. We ask them where they believe they have opportunities to enhance comfort. We help them with the list. We also help to prioritize the list. Next, we help them to establish structures for communication. Good communication is vital.

JG: Are you referring to communication to the resident from the care partner?

TA: All communication is important, including communication with us because we have coaching calls. In the early process, we have a weekly thirty minute coaching call.

IH: Before Tena and Karen leave on Friday, the weekly coaching calls are scheduled.

JG: In this two year process, what happens after the first week other than the coaching calls?

TA: This is where we differ from some of the other more prescriptive programs. The culture of each organization is unique to them, including who they serve and where they are located. We help them recognize what direction they should move and we help them get there. Our process is not prescriptive in any way. We do not have a rigid timeline.

JG: What do you discuss in the weekly call?

TA: We gently and kindly guide our clients. Earlier this week I was on a call with a fairly new organization. They were evaluating dining for comfort. I began by asking them about the process. We learned that management and housekeeping had embraced the model but that the nursing and food service teams had not. I asked why they were not adopting the new model. They responded, “Some of them are reluctant to change.” Culture change will not happen in a divided team. Our contract is for two years, so we have time to work this early issue out.

KM: Sustainability is at the forefront of our minds when we work with the clients who are implementing Comfort Matters. If they fail in sustaining the Comfort Matters model, we have failed. From the first day of our training, we begin impressing the need for continuing education for every member of the care team. Organizations must make continuing education a part of their policy. We give them all the materials they need. We expect that each member on their team will complete the core competencies. Some organizations begin with the memory neighborhood and then bring it outward in layers to the other staff. However, if they have a housekeeper and a relief housekeeper or anyone else who is in the memory neighborhood, they too must have their competencies completed. They can provide the continuing education in their weekly team meeting or in other creative ways. One group hosts Comfort Fairs that they have periodically scheduled in addition to their education.

We adapt our teaching to the competencies of the care team and the individual needs and issues of the organization. All of the staff must be engaged. When we return, we will be able to see it. They also must be able to explain the process of implementation to us. We leave them with the educational materials and nurture their transition on the coach calls. We have one group that has been working with Comfort Matters for approximately four months. They are doing very well with their transition. I told them that in about another three weeks, our calls would become bimonthly rather than weekly. They were not happy because they have become reliant on our weekly calls as an accountability of sorts.

JG: Are the coaching calls mostly you advising?

KM: We say very little during the coaching calls. We listen as they work through a process.

TA: We facilitate the process, which is about them and not about us. Most people want to doing a good job and are committed to working out the kinks. Comfort Matters does two things. It helps change staff practice through competency

building—we build competency toward dementia appropriate care—and it also helps organizations change their systems of operations. Both aspects are necessary.

JG: Could you give an example of system change?

TA: When we address dining systems, an organization might be serving fifty people in their dementia neighborhood. The common thought is that you are feeding fifty people. That is wrong. You are feeding one person, and you may have to do that fifty different ways. How do you create flexibility in your systems so that fifty people can all eat differently? They eat different foods, at different times, in different locations, and in different amounts.

KM: The kitchen here at Beatitudes expects a variety of food orders at a variety of times. The food supervisor is part of the training, so it begins to make sense to them why the system is being changed. The supervisor must create a system that supports the staff in supporting the resident.

JG: What communication, other than the weekly or bimonthly calls, do you have with your clients?

IH: Our clients provide us with monthly data. They maintain a chart that shows the use of a tool called PAINAD, which is measured against rejection of care. We want to see the use of PAINAD increase—because they are monitoring people in pain—and the rejection of care decrease. All of that is measured.

JG: What pain medications do you usually use?

IH: Tylenol.

JG: How do you convince the management of organizations that they will realize a return on investment for the cost and time of the Comfort Matters implementation?

IH: We do not ever guarantee results. Comfort Matters implementation has been cost neutral for the organizations we have trained. Our consultant calculated that Comfort Matters implementation resulted in a thousand dollar increase in value per resident per month. We charge our training clients sixty dollars per resident per month for two years.

JG: After you have completed the first week of training and the weekly and bimonthly calls, how do you continue to evaluate and train the organizations that you work with?

IH: Six months into the training, one of our educators returns to their campus to evaluate and fine tune policies and procedures based on the individual needs of the organization. After approximately a year, we return to conduct an accreditation survey. This is an essential aspect of the training program. Two educators return to measure the ability of the organization to demonstrate that they have embedded Comfort Matters into their practices. The educators ask questions and observe. Once the provider is accredited, we give them a plaque stating that they are a Comfort Matters provider. Accreditation lasts for one year. They also get camera ready art that they can put on their website stating that they are an accredited Comfort Matters provider. We also provide a press release that they can customize to their needs. Six months after accreditation, we return to determine their needs. We continue coaching calls every other week until we reach the two year mark. We have been consulting in Comfort Matters for a year and a half. We have two organizations that have completed their accreditation. They have both asked for pricing to continue with us beyond two years. They are already seeing the value of the program.

TA: We have clients who are dedicated to person directed care, but do not look good in their Centers for Medicaid and Medicare records. They want to fix the problems but honestly do not know how to do so. Last week I was at an organization and one of the certified nursing assistants ran up to me and said, “I just want to talk to you. I just want to thank you.” And I said, “What are you thanking me for?” She replied, “Because you gave me tools. I am so happy. We can care for the residents in the way we have always wanted and hoped. It has made all the difference.”

JG: Do they ever come up with innovative methods of implementation that you had not thought of?

TA: They do. That is one of the amazing outcomes. When that happens, we connect one organization to another.

KM: We might link a dietician in one organization who has wonderful ideas with another dietitian across the country. They can exchange best practices.

TA: One organization that just started in June made a bulletin board to post their successes. In their weekly team meetings they highlight all of the successes of the week. This reinforces that change is possible. I often receive permission to share their stories with other organizations.

KM: Some organizations have invited us to present with them. They want to share their story and to gain the recognition of their peers for their accreditation and culture change success. It is meaningful to have a group of organizations that are touting their success at sustaining Comfort Matters. This shows that it is possible.

TA: We love when people from the organizations we are training stand up and tell their story. They become experts themselves over time. We recently returned from the Pioneer Network where Karen, our colleagues from New York, and I did a three and a half hour seminar. Then Comfort Champions came up and talked about their specific experiences. Brought the house down.

KM: When people learn that more organizations are successfully practicing Comfort Matters and experiencing positive outcomes, they might think it is possible for them. It is easy for an organization to think it is not possible because they have more challenging residents or they cannot afford the implementation. We all struggle to enable the best possible lives for our residents and we all have the potential to shift to person directed care.

JG: Do your clients measure any outcomes of the implementation?

TA: We measure emergency department visits and hospitalizations. We have been implementing and researching Comfort Matters here for eighteen years, but we have been teaching others for twelve. Comfort Matters is a culmination of what we have learned from all of our experiences. From the beginning we decided to measure outcomes of cost and quality of life of each person. Those of us who have worked in care service understand that if we are not focusing on the person when evaluating outcomes, we have missed the point. For example, what is the quality of life of a person who is drugged and dazed and sitting in a wheelchair alone all day? That person would never fall or become agitated, but they would have no quality of life or comfort in living. Data measure is important in evaluation and affirmation of the program. Facts are useful with our board and our grantors.

JG: Have the organizations that you are training witnessed decreased staff turnover?

KM: Yes, we have experienced lower turnover rates of the line staff.

TA: We are not conducting traditional translational research with all of the organizations we train because that would add another layer of staff. We have conducted research with three organizations in the New York City area: the New Jewish Home, the Isabel Geriatric Center, and Cobble Hill Life Care. From this research, we collaborated with CaringKind to produce the Palliative Care for People with Dementia Guidelines.

JG: What do you charge for the two year Comfort Matters consultation?

IH: We charge ten thousand dollars to start that first week. Then we charge sixty dollars per resident bed at a minimum of twenty five beds. Once they become accredited, our fee drops to fifty dollars per resident bed and we continue on with coaching calls and all the other support. We do not charge them for extra calls or additional support requests. After two years, organizations have the opportunity to sign a renewal contract.

JG: Do you stay in a hotel for the first week site visit?

IH: We may stay in a hotel or on their campus with the residents.

TA: Which is always so much fun.

IH: We would rather stay with the residents if we can.

JG: Is the Comfort Matters model more expensive to maintain than the older and more industrialized models?

IH: That is important. The organizations that we have trained have realized better health outcomes and cost savings. They have also found that the savings have made the implementation cost neutral. With no margin, there is no mission.

TA: I would like to show you a short video. Less than two hundred people have seen this. This is one of our residents, Joanne.

[Audio from video]

JOANNE (J): . . . and some people have lost hope. Can I help with the hope bit?

CAREGIVER (C): What?

J: Can I help with the hope bit?

C: You give hope every time you smile, Joanne.

[End video]

TA: Joanne helps with hope all the time. That is what this work is. It is hopeful work. It is being able to do something that serves people in a more profound way. It is hopeful for us. It is hopeful for them. It is hopeful for their families.

JG: Thank you for sharing the video and thank you for this interesting discussion.

KM: Thank you.

IH: Thank you for coming to Phoenix.

TA: Thank you for your interest in Beatitudes Campus and Comfort Matters.

END