4

Person-Centered Long-Term Care

The number of older adults in the world in need of long-term care is expected to reach 277 million by 2050.[1] In 2014, approximately nine million people in the US received long-term care services from adult day-care programs, home health agencies, hospice organizations, nursing homes, and senior living communities.[2] As of July 2014, there were 15,600 long-term care residences that were home to 1.4 million people.[3] The number of people needing long-term care will continue to grow as the aging population increases and people live longer with more chronic conditions and cognitive and functional limitations. From 2000 to 2050, the number of people in need of long-term care is projected to more than double from 13 to 27 million.[4]

Person-Centered Long-Term Care

Long-term care organizations are moving away from a traditional model of care to what is referred to as person-centered or person-directed care. Thomas Kitwood, a psychologist from the United Kingdom, spearheaded this movement approximately 20 years ago.[5] The traditional long-term

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care model takes a more standardized, institutional, medical approach with top-down decision making inherent in a vertical organizational culture. Person-centered care uses an interpersonal approach that is steeped in the philosophies of dignity, comfort, well-being, and respect. Person-centered is a shift from a culture where the provider and staff dictate when people will sleep, eat, and shower, what they will eat, and what they will do for activities to honoring the individual rhythms and preferences of the patient. In a person-centered culture, the staff acts as a single team that shares responsibilities and accountability. The staff is empowered to be part of the system design and care planning and to form meaningful connected relationships with the residents.

> Throughout a culture change, hierarchy begins to flatten and decision making moves closer and closer to the elders and their care teams—no matter where the elders live. (Christopher Perna)

The person and the family are in the center of the person-directed care organizational structure and are part of every decision regarding their care and daily routine. This enables and encourages elders to communicate what is most important to them in their life and in their death and what should be prioritized to meet those wishes. Some of our interviewees, such as the leadership of Beatitudes Campus, would describe meeting the psychological, physical, and spiritual needs of their residents as providing comfort. Others, like Christopher Perna, Dr. Allen Power, and Rebecca Priest, who embrace the Eden Alternative philosophies, may refer to the same as enabling well-being. The person-centered paradigm shift has been described as the provider moving away from thinking, “What is the matter?” to “What matters to our patients?”[6] A person-centered model of care is not limited to the long-term care, memory care, or assisted living settings. Formal and informal caregivers of a person living at home and staff of adult daycare centers can adopt person-centered philosophies and practices.

The built environment can support person-directed care. The small home setting promotes a nurturing environment where 10–20 residents live. The Green House Project,[7] founded by Jude and Bill Thomas,[8] led the small home movement in the US. Components of a small

home that contribute to well-being or comfort include private bedrooms, beds that are not hospital beds and do not have side rails, gentle lighting, large communal living spaces, no alarms, plants, and often animals. Life and living are central to the homes with the great room, the kitchen, and the dining room in the center of the house. The homes have the same care team each day and the team shares responsibilities much in the way family members would. The business case for the small home person-centered model is convincing. The Green House Project model realizes better financial outcomes than traditional models of long-term care. Green House providers have witnessed 7 percent higher occupancy rates, 24 percent private pay occupancy, equal or less in capital costs, and equal staffing costs.[9] We will describe other financial benefits of person-centered long-term care throughout the chapter.

Researchers at the LeadingAge Center for Applied Research are conducting an ongoing study of culture change in the long-term care setting.[10] They have found that a fully implemented person-centered culture change resulted in residents experiencing improved perceptions of their quality of life. Other outcomes included reductions in:

- Depressive symptoms;
- Antipsychotic drug use;
- Pressure ulcers;
- Incontinence episodes;
- Catheter use; and
- Urinary tract infections.

Our interviewees have realized similar outcomes. In the subsequent interview summaries you will find reoccurring themes of the person-centered care design and operation. Some of the themes are the patient and family as an integral part of the decision-making care team, individualized daily life for the patients, smaller home-like settings, behavior as communication for those living with dementia, continued education and adaptation, and staff that does not rotate.

> Dr. Thomas began to envision a culture of care where people can thrive, not just survive. (Christopher Perna)

Christopher Perna, The Eden Alternative®

Christopher Perna is the former President and CEO of the Eden Alternative. Jude Thomas and Harvard-trained geriatrician Dr. William Thomas founded the Eden Alternative in 1990 as a response to nursing homes that were too harsh and medical. They set out to reimagine long-term care in a home-like setting with plants, animals, and a team of caring professionals who behave, in many ways, like family. They identified three main issues or plagues facing those living in long-term care: the plagues of loneliness, helplines, and boredom. Inspiration to address the three plagues led to the ten founding principles of the Eden Alternative. In 2004, Jude and Bill Thomas convened a task force of culture change experts and established the seven Domains of Wellbeing. Those domains are identity, growth, autonomy, security, connectedness, meaning, and joy.

> It is not about being politically correct—it is about shifting how your brain perceives things. (Christopher Perna)

Words Make Worlds

An important aspect of the Eden Alternative culture is the use of words. They believe that words make worlds and choose to use words that are respectful and that speak to a person's abilities rather than disabilities. Some examples include:

- Someone is living with dementia or memory challenges rather than suffering with Alzheimer's.
- The clinical team is referred to as care partners—some even remove the word care from that term.
- Person-centered care is often referred to as person-directed care.
- Patients are referred to as residents.
- Facilities are referred to as homes, residences, or communities.
- Older individuals are referred to as Elders—always with a capital E.

Training and Outcomes of Eden Alternative Adoption

The Eden Alternative trains care professionals to operationalize the patient-centered culture for home, assisted living, skilled nursing, and long-term care residences. They offer a variety of trainings, consulting services, and educational programs including webinars. Providers can become part of the Eden Alternative Registry by completing training that generally takes 12–18 months. During this process, providers are coached and guided in culture change specific to their organization.

Signature Healthcare[11] is a recognized Eden Alternative provider. In 2012 they began to implement culture change and operationalize the Eden Alternative philosophies and principles. Today the Signature Hometown[12] arm has 60 residences for older adults that are located in rural communities of six states. Forty of those residences are on the Eden Alternative registry. Signature Healthcare conducted a five-year retrospective review study to measure the impact of their culture transformation.[13] The researchers studied the homes that are on the Eden Alternative registry and used those that are not yet on the registry as control comparisons. The researchers found that homes on the Eden Alternative Registry saw improvements in operational and quality outcomes.

Operational outcomes:

- Higher occupancy rates;
- More monthly admissions to their homes;
- Much higher earnings before interest, tax, depreciation, and amortization;
- Better Center for Medicare and Medicaid Five-Star Quality Ratings[14];
- Lower rate of nurse turnover; and
- Lower number of worker's compensation claims.

Health outcomes:

- Lower incidence of depressive symptoms;
- Elimination of all incidences of pressure ulcers;
- Substantially lower number of daily medications taken;

- Lowered use of antipsychotic medications;
- Substantially fewer hospital readmissions;
- Fewer residences needing assistance with the activities of daily living;
- Great reduction in the number of falls; and
- Much less weight loss for residents.

Eden Alternative International Regional Coordinators are active in Australia, Austria, Canada, Denmark, the Faroe Islands, Finland, Germany, Iceland, the Netherlands, New Zealand, Norway, South Africa, Sweden, Switzerland, and the United Kingdom. The coordinators are trained and licensed as ambassadors to bring the Eden Alternative training and principles to providers around the world.[15]

Rebecca Priest, St. John's

Rebecca Priest is the former Administrator of Skilled Nursing at St. John's Home. Rochester, New York-based St. John's is a full-spectrum senior service provider with four home- and village-like campuses.

In 2001, with the guidance of Eden Alternative training, Rebecca and her team embarked on the implementation of the Eden Alternative philosophies into their organizational culture. Rebecca, the administrator of skilled nursing, had the full support of the board and the president and CEO Charlie Runyon—support that Rebecca claims was crucial to their success.

> We have a built environment with cues to remind the residents that they are in their house. It is not an institutional space that belongs to a medical team. It is the home of the Elders.

Small Homes

Two of St. John's campuses are dedicated to long-term care and are on the Eden Alternative Registry. Both have a small home setting and care culture. The St. John's Home is especially interesting because the

structure of the residence is a tall institutional style building. The floors are H shaped with long narrow hallways like a hospital. The building is not how one would envision small homes. Rebecca Priest and her team have creatively renovated and redesigned the floors into small homes that are centered not around the nursing station, but around the living room and dining room of the residents. This is a physical example of placing the Elders in the center of the organizational structure and prioritizing their needs for social connection and a warm home-like environment. The residents bring their own furniture for their rooms and are encouraged to decorate the shared spaces with some of their sentimental items.

St. John's Penfield campus consists of two Green House properties that are home to ten Elders each. These homes are indistinguishable from the others in the residential neighborhood (Fig. 4.1). The homes have the physical characteristics of the Green House design including a large great room, kitchen, and dining room that are central to the structure. At the time of my visit, the Green Houses had a pet dog and a large garden space that connected the two homes (Fig. 4.2). In her Ted Talk, Rebecca explained that the new model of person-centered care in the small home setting and community has changed the concept of long-term care and opened the door for others to follow suit.[16]

The built environment is useful in sending cues that feel like home, but the culture of the care team is the most important aspect of the Eden Alternative philosophies. One vital component of that culture is a care team that does not rotate (dedicated staff assignment) and knows the individual preferences and needs of the residents. This is beneficial from a quality-of-life perspective because the Elders know the people who are caring for them on a daily basis. The care partners who are helping the Elders, with intimate personal care are not strangers. We will delve into this subject in more depth a little further into this chapter.

> We support an operational structure that allows for innovation and quality assurance from the staff, without blanket policies from the administration.

Fig. 4.1 Green House at Penfield

Fig. 4.2 Penfield Green House Great Room

Care Team Empowerment

The St. John's care partners are an integral part of the design and execution of all of their duties. This empowerment gives them ownership in the process. When care partners behave as a team and share responsibilities and accountability equally, the quality of care is better. The comparison example of a siloed care team Rebecca gave was one which a resident who had pneumonia or a bad cold had finished eating. After the meal, the care partner would not leave the clean-up for the housekeeping staff. He or she would immediately wipe the area with disinfectant because the resident was ill. If the clean-up was left until the housekeeping staff arrived for their rounds, there would be more chance of contaminating the other residents. The care team is trained in versatility and can meet all the needs of the elders. If one care partner neglects an overflowing wastebasket, another will either bring it to the attention of the care team member or change the basket him or herself. This is much like the way siblings would take care of their older family member. This model has resulted in better safety and cleanliness at St. John's.

When an organization uses this type of team-based culture, they need fewer full-time employees, which creates consistency and deeper connectedness to the residents. It also lowers overhead cost. The staff to resident ratio in the small home person-centered model is 1:4 as compared to the average of traditional skilled nursing facilities in the Rochester region, which is 1:6. At first glance, one might conclude that fewer staff would indicate less time to spend directly with the residents. The outcomes, however, are in stark contrast with that conclusion. St. John's caregivers provide 45 percent more direct hours per patient daily than the average of regional traditional skilled nursing facilities. The increased caregiver attention has resulted in 80 percent fewer resident falls as compared to the traditional skilled nursing model.

Staff Satisfaction

As experienced by Signature Healthcare, after the Eden Alternative principles were operationalized at St. John's, their caregiver turnover rate plunged. Rebecca attributes this lower turnover rate to the fact that the care partners enjoy their jobs more because they are an empowered part

of the team and they establish rewarding relationships with the Elders. Call-ins are when a staff member calls in sick or is otherwise unable to go to work. St. John's receives 75 percent fewer staff call-ins than the regional average of skilled nursing facilities that do not embrace the Eden Alternative principles and the small home model. This is beneficial for consistency and stability with the residents and is financially advantageous because there is less need to train new staff.

> Shifting from uniforms to regular attire is one of the stepping stones for culture change.

Uniforms

To promote a less clinical environment Rebecca encourages the care partners to wear casual professional attire in lieu of scrubs or other uniforms. Research has shown that when Elders see people in uniforms, they act sicker and more dependent.[17,18,19,20] Rebecca and her team witnessed their residents behaving more independently when the care team began wearing professional attire. The residents were more likely to try to move out to the garden or go into the kitchen for a snack on their own.

> Mr. H is now seen as a man living with dementia rather than a stranger continually strolling around.

Those with Dementia Live in Community

Most people living in long-term care have dementia.[21] Rebecca estimates that 87 percent of the residents of St. John's long-term care homes have some stage of dementia. It requires refined organizational processes to create a person-directed care environment to meet their needs. The residents of St. John's who have dementia live *in community*, meaning they are not segregated onto a different floor or building. Rebecca maintains that this is possible because the care partners

know the residents individually and can interpret their behaviors. Often those with dementia cannot express their needs accurately with words and will do so through behavior. Many clinicians will react to this behavior with antipsychotic medications and label them as resisting care. A person-centered caregiver would recognize the behavior as an unmet need.

While I was visiting St. John's, I had the pleasure of meeting Mr. H, a resident in the later stages of dementia. I learned that when Mr. H first began living at St. John's, he and the other residents faced some challenges in how they related to each other. The care team wanted to understand Mr. H's needs so they decided to find out more about him. They met with him and his family and compiled a binder about him that is on display and available to the care partners and the other residents. They learned Mr. H was an avid traveler and a marathon runner and concluded that might be why he likes to walk around most of the time. They also made the binder about Mr. H's life so they could have appreciation for his accomplishments and see him through the lens of his abilities rather than his difficulties (Fig. 4.3).

Another behavior of Mr. H caught the eye of the care team. When Mr. H would approach his fellow residents, he would often touch their hair or their arm. People did not know how to react to this somewhat intrusive habit. After further examination, St. John's dementia specialist decided that his unmet need was that of touch and human connection. Today, whenever the care team greats Mr. H, they offer him a hug, which is uplifting for the care partners and Mr. H. This is one example of the level of person-centered dedication that is required to meet the needs of someone who is living with dementia. This type of intervention has resulted in St. John's seeing a 100 percent decline in adverse elder-to-elder interactions and behaviors.

The residents of St. John's Home have a lot of spaces that foster meaningful connection and autonomy. The multi-storied building has an ice cream shop, a library, comfortable lobbies with fireplaces, a nursery school, and a courtyard. The only locked doors are those that lead outside to the parking lot and streets.

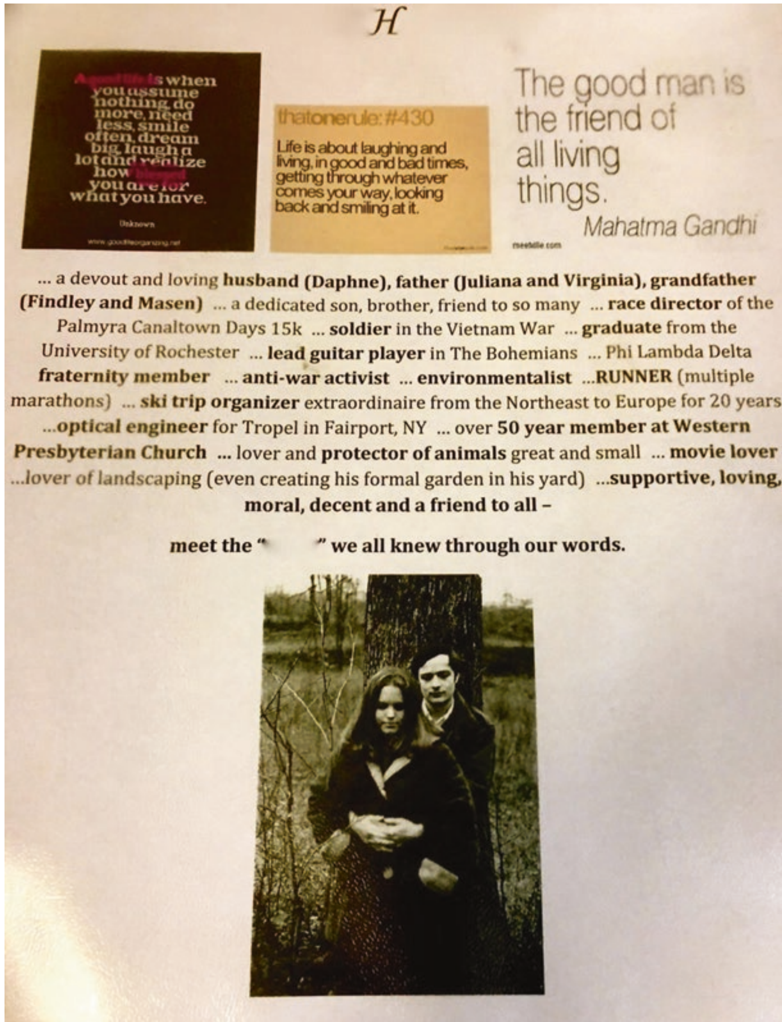

Fig. 4.3 Mr. H's binder

Enabling People to Die in Their Home

The disparity between the number of people who prefer to die at home and the number who actually do die at home is of great interest to providers of person-centered care. Despite the fact that 80 percent of

Americans would prefer to die at home, only 20 percent do.[22] The desire to die at home is not unique to the US and neither is the inability of the healthcare system to make it possible.[23] We will cover this subject in more detail in the forthcoming interview summaries of Diane E. Meier and Kristofer Smith. Saint John's is able to provide better end-of-life care than traditional skilled nursing centers because they have a system that is capable of honoring the wishes of the residents. They also involve residents and their families in the care plan including the advance care directive.[24] In St. John's, 70 percent of the care residents die in their home and 30 percent die in the hospital. These outcomes can be compared to the regional averages of traditional skilled nursing facilities that are not using the small home model. In these facilities, 80 percent of the residents die in the hospital and 20 percent die in the care home.

Stakeholder Satisfaction

The average satisfaction rate for traditional skilled nursing residences in the Rochester region is 74 percent. St. John's has achieved a 100 percent satisfaction rate from residents and their families. They attribute this to their small home care culture based in the Eden Alternative philosophies (Fig. 4.4).

> Policies that are good for dementia are almost always good for everyone. Good dementia care is good elder care and vice versa.

Antipsychotic Medications

The Centers for Medicare and Medicaid Services and care providers around the world are concerned with the high rate of antipsychotic usage.[25,26] All of the people who first move into St. John's Green House residences and most of those entering St. John's Home are on some form of antipsychotic medication. St. John's welcomes those who have had difficulty adjusting to other long-term care homes. Rebecca and her team use person-centered interventions to meet the needs of the residents rather than medicate their behavior. Mr. H is a perfect example.

Fig. 4.4 St. John's to traditional skilled nursing regional comparison

St. John's also has no alarms except for exceptional circumstances, no glaring lights, no beeping machinery, no blaring televisions, and no overhead or intercom system, because they contribute to a disruptive environment for all of the residents and more so to those who are living with dementia. Because new residents are moving in regularly and some may have mental health issues, the rates of antipsychotic usage are rarely zero. Today St. John's has accomplished a great reduction in the number of residents taking antipsychotic medications. They have a 15 percent rate of antipsychotic usage in both of their

care homes: 10 percent in St. John's Home where 450 elders reside and 5 percent in the Green Houses where a total of 20 people reside. Dr. Allen Power is an Eden Alternative trained geriatrician who was formerly with St. John's. Today he travels the world championing person-directed care and advocating against the use of antipsychotic medications for those with dementia.

> People with dementia are frequently denied their human rights in both the community and care homes. In addition, people with dementia are not always involved in decision-making processes and their wishes and preferences for care are often not respected.[27] (World Health Organization)

> Dementia doesn't rob someone of their dignity, it's our reaction to them that does. (Teepa Snow[28])

Dr. Allen Power, Geriatrician, Advocate, and Author

Allen Power is an internist and geriatrician. He was recently named Schlegel Chair in Aging and Dementia Innovation at the Schlegel University of Waterloo Research Institute for Aging in Waterloo, Canada. He is an Eden Alternative associate and designed an Eden Alternative course[29] specifically for dementia care that is based on his book entitled *Dementia Beyond Drugs*.[30] Allen also authored *Dementia Beyond Disease*,[31] a book that is based in the Eden Alternative's seven Domains of Wellbeing. In his books and presentations, Allen shares case studies of successful person-directed care for those living with cognitive challenges that resemble the model we have described at St. John's and those we will cover in the next interview with the Beatitudes Campus leadership. We have chosen to highlight three of the themes that are central to Allen's mission: surplus safety and restraints, non-segregated living for those with dementia, and dedicated staff assignments.

> I define security as supporting both emotional and psychological security. Many restraints have the opposite effect.

Surplus Safety and Restraints

Allen believes that surplus safety leads to the adoption of policies and procedures that are designed through the litigious lens of the worst-case scenario. Safety surplus thinking usually results in the use of physical and or chemical restraints. Restraints are defined as medication or devices that restrain movement. Some commonly used restraints include antipsychotic medications, alarms, locked doors, bedrails, low chairs that people cannot rise from, and Velcro belts.

According to Allen, approximately 15 percent of Americans who have received the diagnosis of dementia and are living in nursing homes are taking antipsychotic medications, representing approximately 180,000 to 200,000 people. It should be noted that the Centers for Medicare and Medicaid Services include individuals without dementia in their calculations of antipsychotic usage in nursing homes. This dilutes the rate to 15.1 percent. If we only looked at people in nursing homes who have a diagnosis of dementia, the rate would be closer to 25 percent. In his book, *Dementia Beyond Drugs*, Allen writes that, in the US, four out of five people, or 4,000,000 people, with dementia are living at home or in a retirement community. Based on a study by the US Department of Health and Human Services, 14 percent of that cohort is taking antipsychotics, representing over 500,000 people. He highlights this number to raise awareness that the overuse of antipsychotic medications is not limited to nursing homes.

> The only risk-free environment for humans is a coffin. (Bill Thomas, Cofounder of the Eden Alternative and the Green House Project)

Providers must balance quality of life against risk, and they must involve the entire care team, the management, the resident, and the family in the decision because individual priorities will vary. In his interview, Allen gave an example that explains the risk versus quality-of-life balance that Heather Luth, the Dementia Program Coordinator at Schlegel Villages in Canada, experienced.[32] Heather had a resident who was constantly at the door wanting to leave. They tried several person-centered interventions

to divert this activity, but none worked. The gentleman was under stress every day. Heather did not want to make a staff-centered solution and drug his stress away, but wanted to meet whatever need he was expressing. He told the staff he wanted to get outside in the fresh air and meet people. Eventually Heather and her team took a big gulp and, with the consent of his family, gave him the key code to the door. Today the resident regularly greets visitors and opens the door for them or just sits outside watching life happen. It is easy to pathologize the needs and desires of a person with cognitive limitations as a behavioral psychotic symptom of dementia. Most, if not all, people would be frustrated being locked inside day and night. Like most people with or without a brain disorder, the resident just wanted to be able to go outside. He has continued this routine for the past four years. In those years, he left the campus and took the bus three times. Fortunately he was safe and people brought him back. With the new technology of today, if the resident left campus more often, they might consider using a non-invasive GPS tracking device. Allen points out that the trade-off in this situation is the risk of three days of leaving campus versus safety of four years of being stressed by the door and being medicated with dangerous drugs.

> 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.

In Chap. 6 of *Dementia Beyond Disease*, Allen outlines a seven-step framework that can function as a guide for organizations that are considering unlocking memory care units and desegregating those living with dementia. They include:

1. Hold a discussion of the desired activity and explore its meaning for the person and his/her understanding of the upside and downside risks involved;
2. Explore the person's values and tolerance for risk. Not everyone views risk/reward the same way, so this must be individualized to have any impact;

3. Look for the conditions and resources needed to help empower the person to succeed;
4. Explore a continuum of empowerment, adjusting the parameters to balance autonomy and safety;
5. Make collaborative decisions;
6. Monitor outcomes and adjust the plan as needed;
7. Keep other stakeholders informed of the process.

In his blog series *Hidden Restraint*,[33] Allen describes unlocking doors as a challenge much like the challenges providers faced when they began to untie people from more severe restraints in the 1990s. These changes take a complete operational redesign to remove the structural, relational, and operational factors that contribute to residents wanting to leave. That redesign is neither quick nor easy, but it is possible. At its best, it will include a home-like setting and a care culture that fulfills the Eden Alternative's seven Domains of Wellbeing including identity, connectedness, security, autonomy, meaning, growth, and joy. In blog three Allen gives two compelling case studies of providers who chose to unlock the doors of their memory care areas.[34] We urge you to read them for inspiration.

> Antipsychotics can double the risk of death and triple the risk of stroke in people with dementia, heavily sedate them, and accelerate cognitive decline. (Jeremy Wright, Chairman of the All-Party Parliamentary Group on Dementia, United Kingdom.[35])

Restraints do not provide security and peace of mind to the resident who is being restrained. The sobering irony of chemical and physical restraints is that they have been proven to not increase safety and, in many cases, to put the person at greater risk.[36,37,38,39] According to Allen, restraints have proven to increase the risk of serious injuries, emotional distress, bedsores, incontinence, and muscle wasting. The research findings about restraints led government insurers and providers to reduce the use of physical restraints and antipsychotic medications. Hopefully this trend will continue as more and more providers seek person-centered, less invasive interventions to meet the needs of their clients.

> In many ways, we are reinforcing the stigmas and fears by locking up people whose brains have changed. People with dementia deserve for us to see them for who they are beyond their limitations.

Philosophy of Segregation

Allen does not think that people with dementia should be segregated from society and their communities, including care communities. He believes that segregating people reinforces the negative stereotypes of dementia held by clinicians and the public that those with cognitive challenges are no longer equal. Allen addresses this issue often in his publications and speaking engagements. He feels strongly that it is an issue of human rights and is confident in his beliefs because he has seen many examples of providers that do not segregate and by doing so have greatly improved the well-being of the residents.

> The best providers to those living with dementia understand that is about preserving people's humanity as much as possible.

Dedicated Staff Assignments

Another factor that contributes to well-being is connected relationships that are formed when staff does not rotate. Maintaining a dedicated staff assignment is a vital component of person-centered care. It is a reoccurring theme in this chapter because it is so important. A dedicated staff is one that does not rotate; care partners work with the same individuals each day. A resident does not have the invasive experience of having new unknown individuals helping them with private and intimate activities.

When a person living in a long-term care residence exhibits combative or aggressive behavior, the care team knows the person well enough to understand that they are in pain, are hungry, or are agitated. The care team is also so acutely familiar with the daily habits, tendencies, and preferences of the residents that they can often anticipate needs and meet those needs before the resident becomes agitated. Because they are with

the same residents every day, care partners might know whether a resident likes to sleep in late, would like ice cream, wants to sing, move around, or to smoke a cigarette. If the care partner needs to take the person to a balcony or out to the courtyard to smoke, they will do so. In our interview, Allen shared the story of Arcare's transition to dedicated staff assignments and the surprising outcomes they realized as a result.

> It takes a community—A relationship-centered approach to celebrating and supporting old age. (Daniella Greenwood)

Daniella Greenwood is the Dementia Strategy and Innovation Manager at Arcare Aged Care in Australia.[40] Arcare has 27 residential care communities in Victoria and Queensland. From 2012 to 2013, Arcare surveyed their staff and their residents and family members to determine what components of care were the most important to them. The research shows four categories of importance. One was identified as connections. Many comments that were written in mentioned the importance of continuous relationships. The survey findings about the importance of connected relationships led Arcare to transform their culture by implementing a dedicated staff assignment model throughout their organization. Three aspects of the model are:

- Employees work a minimum of three shifts per week;
- Every employee including the care team and the catering team work with exactly the same small group of residents every time they come to work;
- Residents and their families are continually encouraged to provide feedback to their care team.

Much to their delight, not only did the culture change increase staff, family, and resident satisfaction, it yielded commanding health and financial benefits. The transformation had early promising results; one community of 38 residents found that within only six weeks, the staff was able to spend more time with the elders without sacrificing their task completion.

Outcomes for staff included:

- 19.8 percent increase in job satisfaction for the care team not including nurses;
- 30 percent increase and job satisfaction for the nurses.

Financial outcomes by reducing operating cost included:

- 50.2 percent reduction in staff turnover;
- 27.5 reduction in sick leave;
- Average decrease in day and evening care partners of 28 per month.
  - In one area the staff needed decreased by 46 percent, from 48 to 26.

Family satisfaction outcomes were:

- 45 percent increase in family satisfaction;
- 100 percent decrease in formal complaints by family members.

The health outcomes for residents of one early adopting community included:

- 69 percent decrease in chest infections;
- 90 percent decrease in pressure sores;
- 25 percent reduction in skin tears;
- 12.9 percent reduction in falls;
- 6 pound average weight gain;
- 51.6 percent reduction in psychotropic medication use.

Arcare continually audits their communities to ensure that they are promoting meaningful connections for their staff, the elders, and the families. They have been recognized for the level of care they provide, and Danielle is a sought-after lecturer throughout the world.

> Housekeepers often remain an untapped source of care and safety. (Tena Alonzo, Beatitudes Campus)

Another glowing example of a provider that uses a dedicated staff is Beatitudes Campus. All of the staff from grounds people to physicians are

trained in person-centered care. One story that registered nurse Karen Mitchell tells that spotlights the importance of the training is about a housekeeper. One day when Karen was working as a nurse, the housekeeper asked her to check on a patient. Karen conducted a basic assessment but did not find anything of concern. She pressed the housekeeper to tell her what was worrying her. The response was, Mrs. M. is not singing this morning. She sings every morning. Because of this feedback Karen kept a close eye on Mrs. M. who developed a temperature the next day due to a urinary tract infection. The housekeeper knew the resident and her habits so well that she was able to recognize the early signs of discomfort.

Tena M. Alonzo, Karen Mitchell, and Ivan Hilton, Beatitudes Campus

Tena Alonzo is the Director of Education and Research and the Director of the Comfort Matters™ program at Beatitudes Campus.[41] Karen Mitchell is an Educator of Comfort Matters™.[42] Ivan Hilton is the Director of Business Development for Comfort Matters™.

Phoenix, Arizona-based Beatitudes Campus is a life plan community (sometimes referred to as a continuing care retirement community) with 700 residents. The long-term care residences of Beatitudes Campus are brilliant examples of fully person-centered care and have similar characteristics and outcomes to those that we have outlined earlier in this chapter. We wish to highlight two specific areas of excellence of the care team at Beatitudes Campus; the elimination of sundowning in their memory care and their Comfort Matters™ research and training.

Sundowning

Sundowning or sundowning syndrome is the tendency for someone living with dementia to become agitated, confused, or hyperactive in the late afternoon or early evening. Some attribute this behavior to the sleep

disturbances that are often experienced with those living with dementia. Some people, like Allen Power and the staff of Beatitudes Campus, are convinced that sundowning is caused by a care culture imposed by the provider that is not in sync with the changing rhythms and cognition of residents with dementia. Beatitudes Campus has eliminated all cases of sundowning in their memory care communities. They have done this by employing a high degree of person-centered care.

> People living with dementia do not have the same tolerance for boredom and agitation. We are mindful of tolerance. (Karen Mitchell)

Many people with dementia do not have the capacity to rationalize their way out of bad moods or to delay gratification. If a resident who likes to sleep late has the housecleaning staff banging around while cleaning the room early in the morning, that resident, would become grumpy. They also may become tired and agitated in the later afternoon or early evening. This would be the case for any other person, with or without dementia, who is not a morning person. If a resident of Beatitudes Campus memory care is not a morning person, no one wakes that resident until the resident wants to rise. The staff knows the rhythms of each resident and adapts to those rhythms, rather than making a person with cognitive difficulties adapt to the preferences or convenience of the care team. This places the well-being of the resident in the center of the care plan and execution. There is no shower or other schedule imposed on the residents by the Beatitudes care team. It takes a fluid and adaptive care team that does not rotate to individualize the day according to rhythms and preferences of each resident.

When frail people are on many medications, it can make them feel ill and not want to eat. Without a healthy amount of nutrition, a person could become agitated in the latter part of the day. Residents in the memory care communities at Beatitudes Campus take far fewer medications than the national average. This contributes to a healthier appetite and weight gain. Another contributing factor to mitigate wasting is liberalized diets. The care team of Beatitudes Campus encourages residents to eat whatever and whenever they like. If a resident

wants to eat a chocolate bar at midnight, they are given a chocolate bar. The care team prepares meals around the clock in the kitchen located in the residence. On my visit, I noticed an easily accessible ice cream freezer that was stocked with a variety of ice cream bars and sandwiches. Another freezer held a selection of cookie dough. Whenever a resident wants to bake and eat warm cookies, they do so with a care partner. When a person is allowed to eat when they feel like eating and what they want to eat, they are less likely to become agitated and experience sundowning.

> When a person feels sick or tired most of the time, they are prone to sundowning. (Tena Alonzo)

Antipsychotic medications slow a person down, which accounts for some of the sundowning that is pervasive in many long-term care homes globally. Like the person-centered care models we have already profiled, Beatitudes Campus uses little or no antipsychotic, anxiolytic, or sedative medications. Some residents arrive already taking such medications, which accounts for the fact Beatitudes Campus cannot claim zero percent usage at all times. Eventually the new residents acclimate to the care culture and have no need of those types of medications.

Another crucial aspect of person-centered care is identifying pain. Often people who are living with dementia are not able to communicate that they are in pain. Their communication can come in many forms, including agitation, confusion, and moving around. If these behaviors occur in the late afternoon or early evening, they are labeled as sundowning. The Beatitudes Campus program, Comfort Matters™, was designed as a palliative care model for organizations that provide care for those living with dementia. The care setting can be in any location. A featured component of Comfort Matters™ is training the care team to identify pain. A staff that does not rotate and that is trained in pain identification will likely know a patient well enough that they can spot any sign of pain and administer Tylenol before the agitation and sundowning begins.

Comfort Matters™

In 2005, the management and care team of Beatitudes Campus began to research and transform the way they cared for and interacted with individuals with dementia who live in their 700-person campus and in a private home. Beatitudes has two residences that are dedicated solely to those with dementia. The average age of the other approximate 660 independent living residents is 85. Tena and Karen estimate that approximately 65 percent of that population has some stage of memory issues. Their research led them to build an organizational care model based in comfort and well-being named Comfort Matters™. The purpose of palliative care is to provide support and comfort by relieving pain and the stresses of illness for someone living with a long-term or chronic condition. In 2012 the Alzheimer's Association New York City Chapter (now named CaringKind) collaborated with Beatitudes Campus to study palliative care through the lens of dementia. Eventually they began a project, which is still in process that consists of the Beatitudes Campus team providing 30 months of training and staff coaching, while the Comfort Matters™ model is implemented in three New York area nursing homes.[43] The implementation is being measured for many health and satisfaction outcomes. The results to date are promising. In 2010 LeadingAge awarded Comfort Matters™ with the Excellence in Research and Education. In 2013 LeadingAge honored Comfort Matters™ with the Public Trust Award.

Tena and Karen, along with the Comfort Matters™ team, built an interdisciplinary evidence-based educational program to help caregivers and care providers implement Comfort Matters™. The Comfort Matters™ training team coaches providers for the period of two years as they navigate through the course material and undertake organizational culture change. In 2016, the Horizon House in Seattle, WA, became the first Comfort Matters™ Accredited Organization.[44] In the past 16 months, 12 care providers have begun their journey of implementation and accreditation by Comfort Matters™. Tena and Karen

and the Comfort Matters™ team have hosted numerous delegations of long-term care providers from Europe and Asia. It is our hope that Comfort Matters™ will become the standard of care for all people living with dementia.

Barriers to Person-Centered Care

Culture change in an established organization or health system is always a challenge. To become person-centered, the institutional process must be broken down to a fluid relationship between management and the care team. Processes have to be flexible to meet the individual needs of each resident.

Culture change must be adopted throughout an entire organization with buy-in from senior management and the board. This process is lengthy and without continual reinforcement may not be successful because it can be tempting to slide back to the old ways of doing things.

A not so obvious challenge lies in combating the stigma of dementia and of older individuals that can act as a cultural plague. When the care team treats the residents with parental control that is based around the believe that cognitive challenges or frailty make a person less whole, rather than respecting them for who they are and honoring the lives they have led, the care will not be person-centered. Their policies and procedures will not be built around the well-being of the residents.

On first thought, providers might think that adopting a new culture would be more costly. As demonstrated by Signature Health, St. John's, Arcare, Beatitudes Campus, the Green House Project, and other providers that we did not include in this chapter, person-centered long-term care presents the opportunity to have better outcomes at a lower price and the need for fewer care staff. It is our hope that these examples will inspire a greater adoption of person-centered long-term care and eventually become an expected standard of care both in the US and internationally.

Providing access to palliative care and bringing care to the home that enables older adults to age in place, direct their own care plan, and experience their final days in the place of their own choosing is one of the

highest form of person-centered care. In the next chapter, we write about the growth and gap of palliative care around the world and describe models of home-based care that improve access and increase well-being while substantially reducing care costs.

The full interviews referenced in this chapter can be found at this link: www.accessh.org/agingwell.

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