

Long-Term Care for the Future

Just What Is Real Anyway?

Peter J. Whitehouse

Aging represents both a demographic challenge and an opportunity to reinvent the story of humanity in a new way. As a geriatric neurologist involved in the clinical care of persons with dementia and in prevention and public health, a cognitive neuroscientist studying both dementia and wisdom, and an ecologically oriented bioethicist concerned about a sustainable future for our species and others, I see aging and care as important issues in themselves. However, they also have a role to play in leveraging culture change, not only in long-term care but also in society at large. Much-needed genuine hope for the future can come in many forms, but we must be vigilant about detecting unreal false hope (like biomedical models of curing age-related conditions such as dementia), instead building up real true hope, for example by adjusting our expectations about inevitable material and scientific progress based on unlimited resources.

We need to think long term and with care about caring, across the life course, through time, and around the globe. Hence, the focus of this *Care Home Stories* book has significant implications for the broader challenges that humanity faces in today's world. Examining the challenges, changes, and continuities of care home stories in the narrowest context of people's experiences in places identified as providing enduring care, like nursing homes and assisted living, is an important enterprise in its own right. However, as in every field of human endeavor, it is critical to examine the widest context for the evolving changes in any narrow domain of human activity by examining the patterns in culture and nature in which those changes are embedded. With the current intense global connectedness of the world of ideas and the world of nations and communities, it is all the more critical to look at problems and potential solutions from a big picture perspective, that is to say as systems thinkers and not as narrow specialists. This broader shift characterizes the evolution of my own thinking from being a neuroscientist studying brain nuclei and pharmaceutical interventions to being a change agent in relation to the flourishing of human and other life.

Our future survival depends on our ability to see intergenerative connections between modes of thought and action, between professions and disciplines, and between communities of diverse composition. *Intergenerative* is a word we coined (see below) to signify going between sources of cultural generativity (like intergenerational and interdisciplinary or even transdisciplinary) to create innovations in thinking and valuing. We are in a world where we must reflect deeply on our experiences and imagine more connected and healthier societies. Trusting and sustainable relationships are key to the intellectual and value explorations and reflections. This reimagining of aging and care is the subject of this chapter that describes relationships with two personal mentors and three related experiences in long-term care.

MY LONG-TERM MENTORS: SID KATZ AND JOE FOLEY

My long-term care home experiences began with two mentors, Drs. Sid Katz and Joe Foley. The lessons I learned from these two wise elders colored not only my professional career engaging with nursing homes and assisted living but also my sense of who I am as a human being, especially now as an emerging elder. Relationships, particularly those between people of different generations and different life experiences, are key to human flourishing as individuals and as communities – a theme to which I will return later.

Sid Katz was a distinguished geriatrician – a member of the National Academy of Medicine. He developed the Katz ADL scale, which is still a widely used instrument to assess the functional capabilities of older people in the community and in long-term care. He was the first author of the Institute of Medicine (now the National Academy of Medicine) report that transformed the way we think about assessing and changing nursing homes. The report, entitled “Improving the Quality of Care in Nursing Homes,” led to fundamental changes in the structure, process, and outcomes of care and reimbursement of nursing homes. It also motivated the development of the Uniform Minimum Data Set (UMDS), which nursing homes were required to collect in order to measure quality of care. I actually worked on the Cognitive RAP (Resident Assessment Protocol) that is part of the UMDS. Dementia is a common condition in long-term care, and my practice caring for people with cognitive impairment motivated in part my interest in long-term care and working with Sid.

Sid chose his words carefully, because clarity of communication was critical to how he shared his theoretical ideas. He was Jewish, a fact that emphasized his rabbinical nature: he was a true teacher, one who sought out young people to mentor. We wrote a paper together (Whitehouse et al.) on the relationship between wisdom and quality of life, a concept that continued to be a dominant

theme in my own scholarship and engagement in life. One key lesson I learned from Sid was when he told me how he imagined the changes that might occur in nursing homes based on his work, but that they would not occur until long after his own death. This sense of long-term thinking past one's own personal mortality stuck with me. It also influenced my thinking that you are not socially dead even after you have ceased to breathe, in the sense that your story goes on beyond personal mortality. The idea of legacy became key as I thought about my own career and the lives of my older patients. Legacy was a name and a concept that I used in many of my later long-term care intergenerational projects, as described below.

Joe Foley was almost the polar opposite: a neurologist with an Irish sense of humor and concern for the particular. He was actively Catholic but culturally irreverent. He was a storyteller and would share his past adventures in Boston Catholic schools and in his neurology residency with some of the early neurological greats at Harvard. He was a model for committed patient care and for not putting up with nonsense. He once told me that I should say little about nursing homes until I had actually lived in one. He thought that the UMDS caused too much paperwork and took nursing assistants and nurses away from patient care. Joe's stories were all about the past – his past mentors and students. So if Sid oriented me to the future, Joe taught me the value of understanding your roots. To exaggerate a bit, Sid was a man of future ideas, Joe of past stories.

Both of them transformed my thinking. My early career had been successful as a neuroscientist describing brain changes in patients with Alzheimer's. I was a leader in developing drugs to treat people with dementia. However, both Sid and Joe allowed me to see the bigger picture. As the power of pharmaceutical and genetics models and economics corrupted the biomedical field, I became concerned that false hope based on promises of pharmaceutical fixes were seducing us. One phrase I came to dislike was "care today; cure tomorrow": it implied that we just needed to invest enough biological research dollars to eradicate the problem of Alzheimer's, and hence care would become outdated. By that time, it was clear that our understanding of dementia was confused and that Alzheimer's was composed of a diverse set of processes intimately related to aging that drugs would not effectively address. Hence, care today *and* care tomorrow are critically important. Besides, I came to realize that if we improved the care of people with dementia, we would improve the quality of life for all of us. Caring for persons with dementia opens opportunities for individual and community growth.

FIRST LESSON: THE FLOOD

My first story in long-term care begins when I finally took Joe's long-offered advice and lived in assisted living in Toronto between 2011 and 2013. As part of my fieldwork as a strategic advisor in innovation to the CEO of one of the University of Toronto's hospitals, I was a part-time resident in The Terraces, an independent/assisted-living facility that is part of Baycrest Health Sciences. The Terraces was a lesson in the reality of the future of long-term care in many ways, but one stands out for me. During my stay, a powerful storm flooded the transformer in the basement, forcing the evacuation of the residents to various locations depending on their level of frailty. I was prepared because I had just returned from a camping vacation, so I had my headlamp to walk the darkened halls and appropriate clothing and food to weather the storm. The inability to repair the transformer and restore power quickly necessitated an evacuation in which I provided some assistance. Some whose families could accommodate them went home, some who were too sick went to the hospital, and the majority went to the nearby Holiday Inn, a place that I was quite familiar with based on previous visits.

In our Baycrest case, the event ended up being a community-building success as a result of great staff and organizational response, but that is not likely always to be the outcome. These kinds of severe weather events will increase in the future because of climate change. How can we learn from disasters in order to be better prepared the next time? In both Hurricane Katrina and superstorm Sandy, many of the most vulnerable were elders. Decisions about whether to evacuate nursing homes or to allow residents to ride out the storm in place were difficult. Mass evacuations are stressful and expensive. Understandably, circumstances became overwhelming, and in some instances elders clearly died in long-term care (with perhaps some being helped to die through physician-assisted euthanasia).

SECOND LESSON: THE UNREALITY SHOWS

During my career, I visited many long-term care units around the world, especially in Japan and Europe. I was involved in studying SCUs (Special Care Units) for people with dementia. Many tried to help people with dementia feel at home by allowing them to bring personal furniture and mementos when they moved in. One locale took this attitude to such an extreme that I felt a bit uncomfortable – an unreal reality. That place, Hogeweyk, a nursing home in the Netherlands, achieved international media attention by being called Dementiaville. It started a movement called Dementia Villages.

Rather ironically, I visited Hogeweyk with Vicki de Klerk, a leader of the international Validation Therapy movement. Validation asks us to try to see the world through the eyes – that is, the past life and current experiences, of the elder with dementia. The facility creates an environment that is designed to mask the dementia by pretending that the residents are in an earlier time and place, complete with a non-functional bus stop perhaps to fool the residents into thinking they are free to leave. Units were designed to match various forms of Dutch social life (one even mimicked Indonesia for those who immigrated to the Netherlands from the former colony). The community is invited in to shop, go to the theater, and eat at their restaurant.

The project has been compared to the 1998 movie *The Truman Show*, a satirical comedy featuring Jim Carrey playing an adult who had been raised since birth by a corporation and who lived in a simulated television game-show village. This was an early form of reality television. During our visit to Hogeweyk, both Vicki and I were slightly put off, not so much by the several hundred Euro fee for a short interview, but by our guide's apparent lack of interest in our work or our views. Staff seemed to be in a world of their own making and focused on their business model.

The Glenner Centers in San Diego is developing a superficially similar but essentially different project called Town Square. Their planned reconstruction of a San Diego urban environment within a large warehouse involves a place to visit, not live. The sets include a grocery store, a drugstore, clothing shops, an auto shop, museums, schools, and other places one might find in a town square. The project involves creating activities for persons with dementia as well as their caregivers and other family members (and perhaps others). Unlike Hogeweyk, this program seems more playful, where being back in time is a form of storytelling and play rather than fostering an actual false belief of being in an earlier historical period. The opportunity to be intergenerational exists. Play amongst children and elders is something that comes naturally and should be encouraged. Such an environment can foster relationship building and mutual learning.

Town Square links to broader efforts to make communities more dementia-friendly around the world. Most of these efforts focus on helping people with dementia navigate their own “real” community and assist community members to better understand the effects of cognitive loss on their fellow citizens. This process of adapting communities seems more real to me than pretending an entire residential ward exists in the 1950s. The learning that can come from visits to such a living museum can foster flexible thinking; playful reminiscence seems better than serious fakery.

THIRD LESSON: INTERGENERATIVITY

Whatever you think of reality, today it seems at times to be quite unreal. The United States and other political environments seem full of Orwellian 1984 language games to the point that we now have alternative facts and fake news. The world is changing rapidly and is full of wicked problems, amazing opportunities, and complex challenges that seem difficult to fathom and act upon. Climate change and income inequity would rise to the top for me as problems. We seem to be missing the courage and wisdom to address our current ecological, economic, and social realities. We are becoming more of a danger to our own species and others as we enter the Anthropocene – a geologic age dominated by human activity. Yet maybe we can find the wisdom to foster values and take actions to address these challenges. Never has a hopeful vision for the future been more important to the human species. Reimagining both “aging” and “care” can be a part of this process, with enormous short- and long-term implications for our species. My experiences in long-term care have contributed to my shift in focus from medical to social interventions.

My last and latest experience with a long-term care institution offers a positive vision of the future. It is intergenerational in nature, creating opportunities for children, youth, adults, and elders to interact. It involved two innovative partners, a long-term care facility and a public community school. Judson Smart Living is a long-term care complex closest to the original intergenerational school founded by my wife, others, and me in 2000. My wife, a developmental psychologist, wanted to start a school to serve the needs of disadvantaged children who were not getting a good education in the Cleveland Metropolitan School District. As a geriatric neurologist I felt we needed to create spaces in society for elders in general, and especially those with dementia, to continue to contribute to community.

We both believed that learning was most powerful with a focus on holistic experiences and social construction. We believed that relationships and reading were critical to empowering students to get a good start in life, particularly those born in disadvantaged social and economic situations. We now have three intergenerational schools that have been nationally and internationally recognized for their contributions to the education of children and the brain health of elders. For example, in 2012 we were awarded the Eisner Prize for lifetime achievement in intergenerational advocacy. The pedagogy of our schools involves creating opportunities for children of elementary-school age and adults and elders to form mostly one-on-one relationships and share stories. Reading mentoring involves pairs of different ages that read books to each other or share stories from their lives.

The “Legacy of the Clark Freeway Fighters” was one such co-constructed narrative project. The children in our school interviewed elders who in the

1960s had saved the local nature center in Shaker Heights, which our children often visit, from a corrupt politician who wished to place a highway through it. We published a book of stories and photographs capturing the spirit of their activism in hopes of perpetuating such spirited citizenship in the minds and hearts of our children (Harris and Whitehouse). We published the story as an article in the *Journal of the American Geriatrics Society* entitled “Occupy Nature: Passing Activism across Generations” (George et al.). We also won an award from the Environmental Protection Agency for capturing the pedagogical experiences that we shared with elders in the nature center.

Some of the elders who came to the nature center with us were from the community, but most were from Judson Smart Living. The school bus and the senior transport bus would arrive at the same time, and the naturalist teachers prepared lessons about the importance of understanding our watersheds and other environmental features and community. Essentially the seniors served as mentors for the children, as in our signature reading mentoring program, for example. However, as I learned from Joe and Sid, mentoring can be reciprocal, as youngsters taught elders about computers, for example.

Upon the fifteenth anniversary of our first intergenerational school, we created “The Intergenerativity Project.” With Richard Geer and Qinghong Wei from Community Performance International, we collected stories from many people in the school, including students, staff, teachers, parents, volunteers, and board members. The stories captured the spirit of the school and formed the foundation of a community play called *Moments and Memories* that was performed both at Judson Smart Living and in the school. The title of the project comes from a word we invented to capture the importance of relationships in innovation. Generativity is a word associated with opportunities created by aging and other human activities to bring forth experiences, stories, and potential wisdom gained by an individual. Intergenerativity means bringing sources of creativity together to create something new. We say it is innovation through integration, or “going between to go beyond” (Katz and Whitehouse).

This collaboration between an innovative school and a long-term care partner led to knowledge and wisdom as well as love and compassion. The important message of the story is that long-term care facilities are a part of community, just as schools are. Children and elders are the most vulnerable in our society, yet they represent our past and our future. So too can the power of intergenerational learning and stories enrich our understanding of the possible. Those who control the present – adults – would do well to listen to the full range of human experience and imagination in our efforts to avoid the failure of repeating unsuccessful attempts at addressing contemporary challenges. If we are to create resilient communities that can survive and thrive in response to the social, economic, and ecological challenges we face, it is important that caring for the long term emerge as a fundamental attribute not only of health

institutions and educational programs but also of the entire community. Just as I remember Sid and Joe as mentors, I remember that collective wisdom begins in individual relationships and shared stories.

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