

Dementia Beyond Drugs

Changing the Culture of Care

by G. Allen Power, M.D.

Q: What is culture change and why is it necessary?

A: The culture change movement began as a means to transform nursing homes from sterile institutions into more life-affirming homes for our elders. The institutional approach to care sees elders primarily for their diseases and deficits, rather than as whole people.

Accordingly, it creates an environment that places *tasks* before *relationships*, perpetuates helplessness, and corrodes meaning for those who live there. This approach has made home- and community-based care institutional as well.

Well-intentioned changes to dementia programs fall short because of the overriding negative effects of this care environment. It is only through transformation to a new system of care that we can make significant headway in reversing the damaging effects of institutionalized living.

Q: The title of this book refers to two concepts, dementia medication and culture change. How are they related?

A: Behavioral distress in dementia is largely a function of the care environment, which creates unmet needs and erodes well-being. We see the behavioral distress as the problem, rather than a symptom of these larger issues, and so we respond with sedating medications to reduce the *behaviors*.

Culture change challenges us to look deeper for the unmet needs, and to create opportunities for well-being as a means to relieve distress.

Q: What are some of the key differences between the institutional and the experiential models of care?

A: The institutional model focuses on disability and decline; it fails to recognize the strengths and abilities retained even in advanced stages

of the illness. As such, it sees behavioral distress as neuropathology and tries to “control” it through medication use. It doesn’t recognize the critical influence of the care environment on the individual’s well-being.

The experiential model views people with dementia in a more holistic manner. I ask the reader to consider dementia primarily as “a shift in the way a person experiences the world.” Rather than trying to “normalize” the person’s perspective, we recognize his own unique point of view and find ways to change the care environment to create a world in which he can continue to succeed.

Think of it as being similar to the way we build ramps to enable people in wheelchairs to continue to be successful in accessing the world around them. We don’t ask them to walk; instead we shape the environment around their needs.

Q: How has our society’s view of aging created the institutional model of care and what can we do to change it?

A: Society views aging as decline because we are overly preoccupied with what adults can and cannot “do.” We fail to recognize that elderhood is a separate developmental stage, in which the assimilation of experience and perspective into *wisdom* replaces the busy workday world of younger adults.

As a result of our skewed perspective, we have created institutions that merely try to mitigate decline by medicalizing the aging process and creating a stifling environment that we label “protective.” We do not see the rich tapestry that elders continue to weave, despite illness or frailty. By seeing elders with “new eyes,” we can begin to celebrate and cultivate their gifts rather than simply disempower, isolate, and overmedicate them.

Q: How can we provide care that is more “humanistic” and “enlightened”?

A: There are many examples, as I apply the framework of my model to a variety of care scenarios. But a central humanistic tenet follows Tom Kitwood’s charge that we acknowledge the *personhood* of each individual and their capacity for growth and engagement through all stages of life, and all stages of dementia.

Here’s an example of how we can be more enlightened: When people in the nursing home “wander,” we used to restrain them, but now we use wander alerts, create circular pathways, use signs on doors and better lighting to create a safer place. We think we have become more enlightened. We haven’t.

I encourage care partners to replace the term “wandering” (suggesting purposeless activity) with “searching,” and then ask, “What are they searching for?” Often it’s some connection, some relationship, something that has personal meaning in an environment that offers none. So by providing the stop signs, circular paths, fenced-in courtyards and alarmed doors, we have merely created a safe place for the person to be lost and searching for the rest of their lives. We’ve missed the larger need.

Q: The common view is that it’s best for people to age at home instead of in a care facility. You argue that a person with dementia receiving care at home experiences some of the same difficulties as those receiving care under the institutional model. Explain.

A: Family members and community-based care professionals have been taught the same “declinist” view of dementia that our biomedical model perpetuates in nursing homes. Home-based care also relies primarily upon informal family care partners who lack the resources to create an environment that meets the changing needs of the person with dementia. As a result, the home becomes an inflexible, disempowering environment where sedating medications are prescribed by family

doctors as heavily as what is seen in nursing homes.

Q: How can a family caregiver embrace the experiential model of care?

A: My book offers new perspectives for viewing people who live with dementia, showing their potential to continue to be actively engaged in their care and with the world around them. It provides extensive advice for all care partners on how to communicate with and understand the needs of people in distress. It teaches empowerment within safe parameters and explains ways to restore meaning to the many activities of daily life.

Q: For many care providers, changing from the institutional model of care to the experiential model can seem overwhelming and even impossible. What can they do to begin the transformation?

A: The book gives many tips that can be applied immediately to enrich the lives of those who live with dementia. For the deeper operational aspects of transformation, there is a section that explains the basic steps to de-institutionalizing care environments. There is also a resource list of organizations that can provide further detailed guidance, such as the Eden Alternative and the Pioneer Network.

Q: Can we really provide drug-free dementia care? How?

A: Organizations who seriously undertake this model of care will see immediate reductions in their use of medication. However, because a deeper transformation is a slow, organic process, much work must be done before all sedating medication can conceivably be eliminated. There are, however, organizations that have moved far down this path, where psychotropic medications have become the rare exception rather than the rule.

We’ve had a similar learning curve with eliminating physical restraints in nursing homes. I personally have not ordered a

physical restraint in over a decade. I believe that, through this transformational process, antipsychotic drugs can become the “restraints of the 21st century.”

Q: In what ways would you like to challenge your readers to change how they provide care?

A: This book challenges some of the most fundamental “truths” we have all been taught about dementia. The first major challenge is to re-frame our view of aging, and then our view of dementia.

These chapters are chock-full of paradigm shifts and challenges, from debunking most “hallucinations and delusions of dementia” to advocating the elimination of dementia-specific living environments as a civil rights issue.

Q: If you could send out one message to your reader, what would it be?

A: There is hope for those who live with dementia. It is in our hands to provide a life worth living or to prevent it, depending on whether we are willing to take on the hard work of transformation.

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