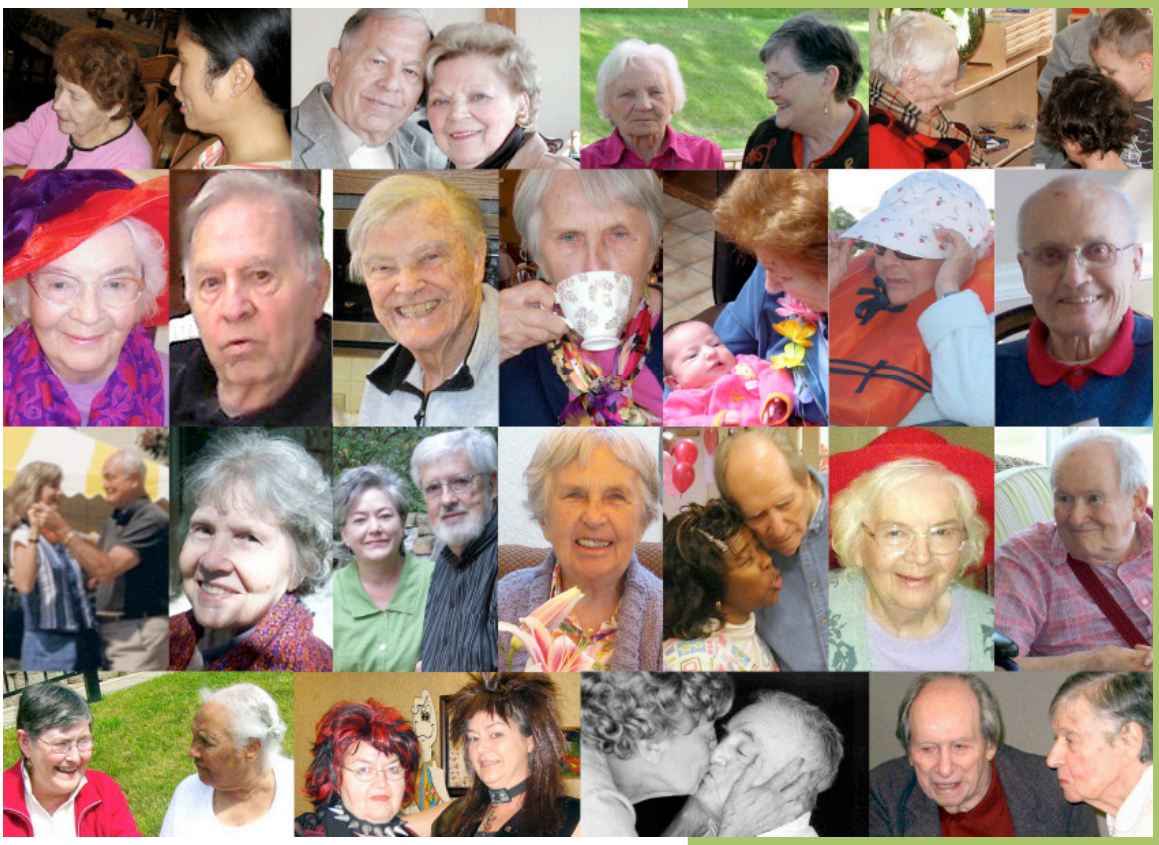
# Dementia Care: The Quality Chasm



Dementia Initiative

January 2013

# Overview

This white paper constitutes a group consensus effort begun in January 2012. The information contained in the paper was developed from a number of sources including an extensive literature search conducted specifically for this project (see Appendix 1 for details), a draft conceptual framework paper to initiate discussion about person-centered dementia care, pre-meeting email exchanges among the *Dementia Initiative* participants (see Appendix 2 for a list of participants), a consensus meeting held in Washington, DC on June 29, 2012, initial draft of a white paper prepared by UCLA researcher, Dr. Lené Levy-Storms, and extensive contributions and comments from the *Dementia Initiative* participants. The final version of the white paper was prepared by the writing/editing team led by Karen Love and Jackie Pinkowitz.

Dr. Levy-Storms systematically analyzed the participant email exchanges qualitatively to identify rich, direct quotes. These quotes are interspersed throughout the white paper to add the voice and insights represented by the diversity of the Dementia Initiative participants.

Most importantly, two people living with dementia have included their thoughts and perspectives to this paper. We are most thankful and appreciative to Steve Hume and Richard Taylor for their contributions. We also thank a handful of powerful thought contributors — Virginia Bell, Dawn Brooker, David Edvardsson, Tom Kitwood, Vivian Tellis-Nayak, and William Thomas — giants in the field of person-centeredness whose work paved the way for us to advance information and understanding about this important topic.

**ACKNOWLEDGEMENT**

We gratefully acknowledge the Archstone Foundation, Samueli Institute, American Health Care Association (AHCA), National Center for Assisted Living (NCAL), Silverado Senior Living, and Trinity Senior Living Communities for their funding support.

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# Glossary

**Behavioral expression** — Term preferred by the *Dementia Initiative* experts rather than "behavioral problem." Included are behaviors such as agitation, anxiety, aggression, and screaming. It is important to understand the root cause of behaviors as they are often expressions of unmet needs, such as pain, hunger, thirst, boredom, loneliness, or an underlying medical condition that the person with dementia is challenged to communicate to a care partner or to address him or herself.

**Care partners** — People actively engaged in providing care and/or support such as family members and others known through a personal relationship and formal caregivers.

**Dementia** — Refers to symptoms typically characterized by a loss of cognitive ability, impairment in memory, and brain changes in areas such as language, reasoning, and judgment severe enough to interfere with everyday functioning.

**Dementia care stakeholders** — People living with dementia, family members, care partners, service providers, healthcare practitioners, policy-makers, researchers, consumer advocates, funders, academicians, and regulators among others.

**Holistic** — Refers to a bio-psycho-social-spiritual orientation to healthcare and well-being.

**Personalized approach** — Term preferred by the *Dementia Initiative* experts rather than "non-pharmacologic" as the latter has a medical model of care connotation instead of a holistic one.

**Personalized practices** — This term defines specific person-centered practices. These practices are individualized and are intended to support the personhood and authenticity of each person who is living with dementia.

**Person-centered core values and philosophy** — The Dementia Initiative participants believe there is a moral and ethical responsibility to support persons living with dementia as holistic, existential beings. Every person has his/her own meaning of life and authenticity (personality, spirit and character) that supersedes any physical condition. This forms the foundation for person-centered dementia care.

**Person-centered operational practices** — This term refers to the broad processes that anchor and operationalize person-centered dementia care.

**Person-centered** — Has its roots in humanistic psychology and the seminal work of Carl Rogers and Abraham Maslow based on the understanding that people are multi-dimensional beings and the psychosocial context of health and well-being is as important as the physical/medical aspects.

**Personhood** — "Standing or status that is bestowed upon one human by others in the context of relationship and social being. Personhood implies recognition, respect and trust." (Kitwood, 1997, p.8)

**Structural Elements** — The eight structural elements constitute the "frame" or building blocks for person-centered dementia care.

# Executive Summary

The seminal 2001 Institute of Medicine's (IOM) report titled "Crossing the Quality Chasm" called for a redesign of the nation's healthcare system, and described healthcare in America as impersonal and fragmented. The IOM report stated that a critical element needed in the redesign was a shift to a person-centered approach moving away from the traditional clinician/disease-centered approach. The title of this white paper, "Dementia Care Quality Chasm," was purposefully selected as a nod to the IOM's red flag warning about our nation's impersonal and fragmented healthcare systems and practices. Overall, dementia care in this country is impersonal and fragmented, and this paper is a call to action to change to what is considered the gold standard — a person-centered approach. Given the already staggering financial and caregiving demands of dementia, the U.S. is facing significant, if not crippling, societal challenges if effective person-centered systems and practices are not implemented soon to address and better manage the care, services, and supports for people living with dementia and their care partners.

The overall state of dementia care in the U.S. catalyzed the organization of a grassroots initiative of a diverse group of national dementia care experts representing the practice, policy, and research sectors to come together and discuss dementia care in general and the overuse of antipsychotics to manage behaviors expressed by persons living with dementia in particular. This effort is known as the *Dementia Initiative*. As discussions among the diverse group of dementia care experts got underway in the Spring of 2011, it became quickly evident that focusing on one dysfunctional aspect of dementia care, in this case the overuse of antipsychotics, was not possible without backing up and addressing the root cause of the dysfunction.

The current bio-medical approach to healthcare focuses almost exclusively on the *physical* condition of a person. Health and well-being, however, are contingent upon one's *psycho-social-spiritual* dimensions. The separation or disregard of these interconnected dimensions created the impersonal and fragmented healthcare culture. The effective, person-centered systems and practices emerged from humanistic psychology and the seminal work of Carl Rogers and Abraham Maslow. Optimal health and well-being are supported through the person-centered holistic integration of the bio-psycho-social-spiritual dimensions.

The holistic orientation of person-centered practices encompasses all aspects of health and well-being. The *Dementia Initiative* participants only focused on the holistic framework of what is needed to support *person-centered dementia care*. Understanding and responding to behavioral expressions by people who have dementia is addressed in the paper after the whole person-centered dementia care framework is described so that this information is presented in context.

There is no better time for our nation to "cross the quality chasm" for dementia care as the current National Alzheimer's Project Act (NAPA) and other national dementia initiatives provide timely pathways to improve systems and practices of care. Evolving to the use of person-centered dementia care practices includes all stakeholders — individuals living with dementia, their family members and other care partners, healthcare practitioners, long-term care service and support providers, consumer advocates, policy-makers, researchers, funders, regulators, academicians, and scholars among others. Everyone needs to advance to using person-centered practices if they are not already doing so. The *Dementia Initiative* experts present this consensus white paper that includes recommendations as the first step to evolving dementia care systems and practices in this country to person-centered ones.

# "Dementia Care: The Quality Chasm"

## SECTION 1. PERSON-CENTERED DEMENTIA CARE

### INTRODUCTION — Formation of the *Dementia Initiative*

A number of nationally significant events occurred during 2011 and 2012 regarding Alzheimer's disease and other types of dementia (described collectively hereafter as dementia): President Obama signed into law the National Alzheimer's Project Act (NAPA); the Inspector General's Office (OIG) of the U.S. Department of Health and Human Services (HHS) issued a report noting an overutilization of antipsychotic medications for nursing home residents with dementia; the Senate Aging Committee held a 2011 hearing that heightened awareness that relevant information was needed on approaches and strategies to use as an alternative to automatically giving antipsychotic medications for what are perceived as behavioral challenges; the Centers for Medicare and Medicaid Services (CMS) launched an educational initiative to improve behavioral health and reduce the use of antipsychotic medications in nursing homes residents; and HHS collected comments and developed a national plan (NAPA) to address Alzheimer's disease (http://www.hhs.gov/news/press/2012pres/05/20120515a.html).

Many dementia care experts across the country are concerned about the current orientation and direction of the national plan specifically and the quality of dementia care generally. Of concern in NAPA: (1) the language in the plan is focused too narrowly on Alzheimer's disease and not more globally on dementia; (2) there is too great a focus on the "cure" and too little on the "care" for people currently living with dementia; and (3) the plan is silent on what is considered the gold standard, person-centered practices.

Of specific concern about the quality of dementia care across the country is the lack of adoption and use of practices that have been demonstrated to provide the most humanistic and positively oriented approach to care, services, and supports — person-centered practices. All too often, people living with dementia are treated almost as if they are defective humans whose needs revolve only around their activities of daily living (e.g., dressing, bathing, toileting, grooming, eating). They are viewed as not having preferences or interests to experience fun and social

connections. In 2005–2006, the Alzheimer's Association convened a national campaign, the "Campaign for Quality Residential Care," to form consensus practice recommendations to optimize well-being for people who have dementia based upon a holistic, person-centered framework (Tilly & Reed, 2006). Printed copies of the recommendations were widely distributed both through the Alzheimer's Association efforts and those of the multitude of national organizations that were part of the consensus process. Despite developing multiple training tools and resources to operationalize and implement the practice recommendations, a limitation of this Campaign was its inability to raise sufficient awareness to overcome structural barriers in the field, and achieve the desired reach, penetration, and impact of the concepts and recommended approaches.

These factors catalyzed the organization of a lay effort to convene a gathering of a diverse group of national dementia care experts representing the practice, policy, and research sectors to discuss and form consensus on strategies and practices for recommended dementia care. Known as the *Dementia Initiative*, this effort was led by leaders at CCAL-Advancing Person-Centered Living. The Leadership Team also included representatives from the practice, policy, and research sectors — English Rose Suites; the Mayo Clinic's Alzheimer's Disease and Research Center; Samueli Institute; the Senate Special Committee on Aging; and UCLA's Luskin School of Public Affairs. (See Appendix 2 for a list of the sixty-plus *Dementia Initiative* participants.)

This white paper is intended for a wide and diverse audience of readers since dementia care impacts a broad spectrum of stakeholders: people living with dementia, family members, care partners, service providers, healthcare practitioners, policy-makers, researchers, consumer advocates, funders, academicians, and regulators, among others. All too often information is written and disseminated for individual audiences and not shared among all those impacted by the topic. This limitation impedes the collective understanding of issues and solutions to address them. The white paper is written to all the stakeholders so that this important topic and societal challenge can be collectively addressed and person-centered solutions advanced and widely disseminated.

## BACKGROUND — Information About Dementia

The term "dementia" refers to symptoms typically characterized by a loss of cognitive and intellectual ability, impairment in memory, and brain changes affecting areas such as language, reasoning, and judgment severe enough to interfere with everyday functioning. Dementia can be caused by many conditions, the most common of which is Alzheimer's disease. Other common forms include vascular dementia, Lewy body dementia, and frontotemporal dementia. Alzheimer's disease accounts for 60 to 80 percent of dementia (Alzheimer's Association, 2012).

Today, 5.4 million Americans are living with Alzheimer's disease in the United States — 5.2 million aged 65 and over, and 200,000 under the age of 65. By 2050, up to 16 million will have the disease. Currently, one in every 8 Americans age 65 and older has Alzheimer's, and nearly half of people age 85 and older have the disease. Providing services and supports for people with Alzheimer's and other dementias was estimated to cost the United States about $200 billion in 2012 alone; $140 billion of which is paid by Medicare and Medicaid. In 2011, 15.2 million family and friends provided 17.4 billion hours of unpaid care to those with dementias — valued at $210.5 billion (Alzheimer's Association, 2012).

Alzheimer's disease is the sixth leading cause of death in the United States and the only cause of death among the top ten that cannot be prevented or cured. Dementia is the leading cause for placing someone in a long-term care setting such as an assisted living facility or a nursing home. The prevalence of Alzheimer's is expected to increase three-fold over the next 35 years (Alzheimer's Association, 2012). Given the already staggering financial and caregiving demands of dementia, the country is facing significant if not crippling societal challenges if effective ways are not identified and implemented soon to address and better manage the care, services and supports for people living with dementia and their care partners.

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— Dementia Initiative Participants

## ORIGINS OF PERSON-CENTEREDNESS

It's helpful first to understand the context of healthcare and how person-centeredness evolved before delving into person-centered dementia care. In the United States, healthcare systems and processes were designed around efficiency and standardization to enable a clinician-centered and disease-centered approach to the delivery of healthcare. Efficiency and standardization was an effective model for the industrial age that needed to mass-produce materials and equipment. However, it turned out not to be an effective design for healthcare. The seminal 2001 Institute on Medicine's (IOM) report titled "Crossing the Quality Chasm" called for a redesign of the nation's healthcare system and described healthcare in America as impersonal and fragmented. The IOM report stated that a critical element needed in the redesign was a shift to a person-centered approach moving away from the traditional clinician/disease-centered one. In the decade following the IOM report, however, little national progress had been made to shift to making person-centeredness the standard of healthcare and long-term services and supports (LTSS). The Affordable Care Act (ACA) of 2010 helps to reinforce the need for change by requiring that services funded by the Centers for Medicare and Medicaid Services be provided in a person-centered manner.

**The 2001 IOM report stated that a critical element needed in the redesign of the nation's healthcare system was a shift to a person-centered approach moving away from the traditional clinician/disease-centered one.**

Discussion about the origins of person-centeredness would be incomplete without addressing a significant factor that led to the need to develop an alternate approach to healthcare and long-term services and supports in the first place. The current bio-medical approach to healthcare focuses almost exclusively on the *physical* condition of a person. Health and well-being, however, are contingent upon more than the physical condition and also includes the psycho-social-spiritual dimensions. The separation or disregard of interconnected components of healthcare created the impersonal and fragmented healthcare culture.

Imagine you are sitting in a theater for a concert listening to a well-known symphonic orchestra with outstanding string, woodwind, brass, and percussion sections led by a skillful conductor. However, your seating is uncomfortable and the theater is freezing. While you may highly rate the musical performance, the overall concert experience would not rate highly, since basic

comfort is part of the concert experience. The two dimensions are interconnected. Similarly, the psycho-social-spiritual dimensions of health and well-being must be taken into consideration along with the bio-medical dimensions of health and well-being when considering how to deliver quality care. Increasingly, research shows that "how" care is delivered can be critically important to overall success — as important in many ways as "what" care is provided. While birthing and hospice practices have changed over the past several decades to integrate a holistic, person-centered approach (i.e., the comfort and well-being of the person are important aspects as is the clinical care aspect), most of the rest of the spectrum of healthcare in general has not.

The person-centered approach to healthcare emerged from humanistic psychology and the seminal work of Carl Rogers and Abraham Maslow. Humanism is based on the understanding that people are multi-dimensional beings, and the psychosocial context of health and well-being is as important as the physical/medical aspects. Optimal health and well-being are supported through a holistic integration of the bio-psycho-social-spiritual dimensions. Holistic person-centered practices move beyond the current bio-medical approach. A growing body of empirical evidence indicates that person-centered practices are more pleasant to experience, help to optimize health and well-being outcomes, and result in higher satisfaction.

> *"The healthcare experience … is based on every interaction a patient and/or their family have on the care journey and is ultimately measured by the very perceptions those individuals have of their experience."*
>
> Jason A. Wolf, PhD, Executive Director, The Beryl Institute

Depending on the constituency, numerous terms for person-centeredness are used such as patient-centered, resident-centered, person-directed, and relationship-centered. The most commonly used term is person-centered and as such has been adopted for use in this white paper. While much has been written about person-centeredness, there is little consensus among all the diverse stakeholders about what specific values and practices are involved and how they become operationalized. This white paper presents a holistic (bio-psycho-social-spiritual) theoretical and contextual framework for person-centered dementia care.

**This white paper presents a holistic (bio-psycho-social-spiritual) theoretical and contextual framework for person-centered dementia care.**

## The "CONTEXTUAL FRAMEWORK" for Person-Centered Dementia Care

"*Within all of us resides the need to be whole*." Oliver Sacks, MD

Tom Kitwood's work at the University of Bradford in England was most influential (Kitwood, 1997) in applying person-centered values to dementia care. His person-centered model of dementia care focused on enhancing the "personhood" of individuals who have dementia through respectful, close relationships. While there have always been some family members and care providers who intuitively recognize the importance of supporting the personhood of the individual who had dementia, Kitwood's work and research gave voice and credence to the need to realign care and supports. The prevailing mode was to view people who have dementia solely in terms of their condition (dementia) and its symptoms. Once labeled as having dementia, they are often perceived as less than whole. With this mistaken perspective, attention to their life history, interests and preferences, wants and needs, and what they find purposeful and meaningful in daily life is diminished if not ignored.

Qualitative studies have found that the way in which people with dementia are viewed by society in general and healthcare and service providers in particular influence the very nature of their care (Edvardsson et al, 2008). If people believe that a diagnosis of dementia means that the personhood of an individual is diminished or lost, the context of care and services can get reduced to providing only for basic physical needs and supports rather than attention to the personhood needs of the whole individual.

The dementia-centered illness context unfortunately prevails in healthcare and long-term care services and supports not only in our country but worldwide. Coupled with a clinician-centered, biomedicine, payment-for-service culture, supporting and fostering the personhood and individuality of persons with dementia becomes lost in the mix. While this ethos may have silently become the norm, it is imperative for a moral and ethical society to realign its standards and practices to a humanistic culture.

"*Humanizing dementia care is a human rights issue*." (Kim McRae, family caregiver)

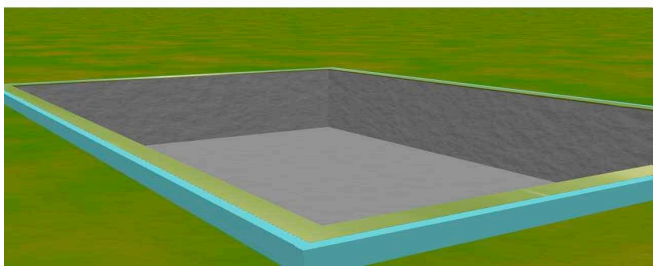
White and colleagues (2008) demonstrated that person-centeredness is a multidimensional construct. There are numerous components that have to come together to yield person-centered outcomes. The Center for Excellence in Assisted Living (2010) organized a multidimensional framework through consensus with 11 national organizations including the Pioneer Network, CCAL–Advancing Person-Centered Living, and the National Center for Assisted Living, among eight others.

**The multidimensional framework for person-centered dementia care —**

- Core Values and Philosophy — forms the "foundation" of person-centeredness
- Structural Elements — eight elements provide the "frame" — (1) Relationships & Community (belonging), (2) Owner/Operator/Board Governance, (3) Leadership, (4) Care Partners/Workforce, (5) Services, (6) Meaningful Life and Engagement, (7) Environment, and (8) Accountability
- Operational Practices — each structural element has discrete practices that anchor them to achieve person-centered outcomes
- Personalized Practices — individualized practices to support the well-being for each person who has dementia

A house analogy is used below to illustrate and describe the multidimensional conceptual framework for person-centeredness.

*A.* The ***core values and philosophy*** serve as the "foundation" of the house. A strong foundation is critically important, as it needs to support the whole house. Similarly, the *core values and philosophy* support the whole framework of person-centeredness. *Core values and philosophy* include meaningful relationships, knowing the individual as a unique person, focusing on their strengths and capabilities, and entering the world of the person with dementia.



B. The person-centered ***structural elements*** constitute the "frame" or building blocks of the house. The frame provides the structure for the whole house (roof, exterior walls, windows, doors, and sub-flooring). In the same way, the eight *structural elements* provide the frame for person-centeredness. A house would not be functional without a roof or exterior walls just as person-centeredness cannot be achieved without each of the structural elements in place. In person-centeredness for example, if leadership does not understand and/or support person-centeredness, only minimal aspects of person-centeredness can be achieved.

C. House components such as plumbing, electricity, water, heating, insulation, appliances, light fixtures, and interior walls serve to make the house functional. The ***operational practices*** are equivalent in that they make the person-centered structural elements functional. For example, an operational practice for Relationships & Community is to ensure that staff and other care partners have time to build and maintain a relationship with the person who has dementia.

D. The finishing and decorative aspects of the house correspond to ***personalized practices***. The type of flooring (e.g., carpet, tile, wood), the color of the walls, the furniture selected, the furnishings and other decorative items all serve to transform the house into one's personal space and home. Similarly for person-centeredness, individualization is important. For instance, listening to music is only pleasurable if it is the type of music someone enjoys. One person may like country music while another person may prefer gospel music. A person who does not care for country music will not find listening to it pleasurable.

All components are equally necessary but follow an order. A house cannot be furnished until the foundation is laid, the framing completed, and mechanical systems and interior finishing done. Similarly, individualized practices are not effective without first having laid the person-centered foundation of the core values and philosophy, structural elements, and operational practices. Information about responding to behaviors expressed by people who have dementia is equivalent in the house analogy to the "furniture." Discussion about this aspect of dementia care needs to be preceded by information about the whole context of person-centeredness first. The following sections describe each component (e.g., core values & philosophy, structural elements, operational practices, and personalized practices) of the conceptual framework for person-centered dementia care.

## The CORE VALUES & PHILOSOPHY for Person-Centered Dementia Care

*Core values and philosophy* are valuable because they communicate a set of beliefs. For person-centered dementia care, an extensive review of peer-reviewed and gray (non peer-reviewed or catalogued) literature was undertaken to inform and shape the formation of the *core values and philosophy*. The following represents some of the most notable that have been posited for person-centeredness:

- Kitwood (1997) — positive interactions are key to supporting the personhood of persons with dementia by facilitating deep and mutually empathetic relationships between people.
- Adams & Clarke (1999) — partnerships in care that allow for direct involvement in decision-making by persons with dementia, families and formal service providers that focus on: reciprocity, mutual sharing and collaborative relationships between all partners in dementia care throughout the progress of the disease.
- Epp (2003) — the key elements include a focus on: treating the person, not diseases or disabilities; understanding that individuals have unique histories and preferences; eliminating dehumanizing practices; maintaining dignity and autonomy; and recognizing the centrality of relationships.
- McCormack (2003) — fundamental principles: all individuals have dignity, autonomy, worth, and a set of unique moral principles, view, histories, and desires.
- Eden Alternative, Nancy Fox, et. al. (2005) — seven primary domains for well-being (the path to a life worth living, the ultimate outcome of a human life): identity; growth; autonomy; security; connectedness; meaning; and joy.
- Brooker (2007) — four major elements: a value base that asserts the absolute value of all human lives regardless of age or cognitive ability; an individualized approach recognizing uniqueness; understanding the world from the perspective of the individual living with dementia; and providing a social environment that supports psychological needs [VIPS].

- Edvardsson, Fetherstonhaugh, & Nay (2010) — core components as defined by people with dementia, family members, and staff in residential care: promote a continuation of self and normality; know the person; welcome family; provide meaningful activities; be in a personalized environment; and experience flexible routines and continuity of care partners.
- Byrne, Frazee, Sims-Gould, & Martin-Matthews (2012) — focus on the person, preservation of autonomy, and interactions characterized by recognition, validation. collaboration, and negotiation.

The *Dementia Initiative* experts believe there is a moral and ethical societal responsibility to support persons living with dementia as holistic, existential beings. Based upon their collective experiences and expertise and guided by such notable frameworks as listed above.

**The following are the consensus *core values and philosophy* for person-centered dementia care:**

1. Every person has his/her own meaning of life, authenticity (personality, spirit and character), history, interests, personal preferences, and needs to continue to experience life at all stages of dementia. The person is not their dementia illness; rather the condition is only one aspect of their current status.
2. Focus on the strengths of the person living with dementia rather than on what abilities and capabilities have been diminished or lost.
3. "Enter the world" of the person living with dementia to best understand, communicate with, and interpret the meaning of his/her behavioral expressions from their perspective.

## The "STRUCTURAL ELEMENTS" for Person-Centered Dementia Care

The core values and philosophy provide the foundation. Eight structural elements provide the "frame" or building blocks needed to support person-centered dementia care. The structural elements are universal to all long-term service and support settings (e.g., home care, adult day care, assisted living, hospice, nursing homes). Not all of the structural elements apply, however, to providing care at home as family members are not operating within an organizational structure. For service and support settings, the structural elements are interdependent and interconnected to one another meaning that desired person-centered outcomes cannot be achieved or sustained by only implementing some of them. For example, if an entity's owner, operator, or board of directors (*Governance structural element*) do not fully commit to and support person-centered dementia care, only incremental success can be achieved by leadership and other staff. Person-centered outcomes will not be able to be sustained because they are not rooted and inculcated into the entity's operational culture.

For those caring for a person with dementia at home, the Governance and Leadership elements are not applicable. It is important for them to have a coordinated system in which all care partners share the common values of person-centered dementia care, understand their roles in caring for the person who has dementia, and openly communicate with each other.

**The structural elements needed to support person-centered dementia care are:**

1. Relationships and Community (belonging)
2. Governance
3. Leadership
4. Care Partners/Workforce
5. Services
6. Meaningful Life and Engagement
7. Environment
8. Accountability

1. **Relationships & Community** — Relationships and belonging (community) are basic human needs. Without them, interactions are impersonal. Their importance, value and benefit elevate them to first place. For individuals living with dementia, relationships and belonging are especially important and add familiarity, comfort, meaning, and context to daily living.

2. **Governance —** As the ultimate decision-makers, the owner/operator/board are essential to establishing, implementing, and sustaining the operational culture within their organization. Without their active involvement and commitment, person-centered dementia care cannot be created or sustained.

3. **Leadership —** Leadership refers to the head of an organization and executive and managerial staff positions. These individuals are the key communicators and supporters to ensure that person-centered operational practices are implemented, achieved, and sustained. Staff empowerment and decentralized decision-making are key leadership practices that support person-centered outcomes and higher staff retention.

4. **Care Partners/Workforce –** A distinction is made for this structural element because staff caring for persons with dementia in adult day care, home care, assisted living, and nursing homes have some different operational considerations than do family members caring for someone at home. Both types of caregivers need to be oriented and trained in person-centeredness and dementia care competencies. For staff, a person-centered dementia care organizational culture values and recognizes their importance. Staff are not viewed as simply people being paid to accomplish tasks, but rather as integral to the success of the entity in general and for individualized person-centered dementia care in particular. Care partners and workforce practices are based on personal interactions and relationships.

5. **Services —** Person-centered services refers to the actual provision of care and support based upon individual preferences, values, lifestyle choices, and needs to support his/her unique rhythms of daily living. "*Service is compassion made visible*." — Karen Love

6. **Meaningful Life & Engagement —** Experiencing a meaningful life affirms an individual's sense of self, purpose, and self-esteem. Having meaningful things to do adds purpose and enjoyment in daily life and fosters emotional health and a sense of connection with others. Since people have different needs for solitude and socialization, what is purposeful and meaningful for each individual is unique to them.

7. **Environment —** Person-centered environments are multifaceted and need to incorporate the physical and social-emotional dimensions. The attention to and integration of effective design, indoor and outdoor space, colors, light, sound, furniture, and furnishings blend to create a warm, comfortable, orienting, safe place to be.

8. **Accountability —** This term refers to the practice of ensuring that desired outcomes are actually being achieved. It is important to periodically check to determine whether effective person-centered outcomes are, in fact, happening. Accountability means having some means to regularly evaluate performance (culture, operations, processes, systems) and if practices are achieving desired person-centered outcomes. Such evaluative data can be collected through internal and external means, including resident, family, and staff satisfaction surveys.

The structural elements are the "building blocks" of person-centeredness. For organizations, there is an order to implementing the structural elements. Commitment to the person-centered *core values and philosophy* by the Governance of an entity is needed first. Next, the *structural elements* of Relationships and Community, Governance and Leadership are addressed. Once these three structural elements are firmly anchored, the remaining ones are addressed (Care Partners/Workforce, Services, Meaningful Life and Engagement, Environment, and Accountability).

While the *structural elements* are inextricably linked to one another, the *individualized practices* that support them are flexible. Indeed, each organization is meant to implement processes that reflect their own culture, circumstances, creative ideas, and insights from residents, staff, and family members.

## The OPERATIONAL PRACTICES for Person-Centered Dementia Care

The person-centered *core values and philosophy* and the *structural elements* need to be appropriately operationalized in order to create and sustain desired outcomes. Operational practices define the broad processes needed to support person-centered dementia care *core values and philosophy* and the *structural elements*. The *personalized practices* described in the next section define the specific practices needed. This white paper is not intended to provide the full operational processes and strategies to implement person-centered dementia care. The purpose is to present a theoretical and conceptual framework for person-centered dementia care, so only a general description is included.

### Core Values and Philosophy

The core values and philosophy communicate the foundational set of beliefs for the entire person-centered dementia care conceptual framework. The person-centered *operational practice* for this first element is ensuring that the *core values and philosophy* are practiced. Because they are so significant, they are repeated below:

1. Every person has his/her own meaning of life, authenticity (personality, spirit and character), history, interests, personal preferences, and needs to continue to experience life at all stages of dementia. The person is not their dementia illness; rather the condition is only one aspect of their current status.
2. Focus on the strengths of the person living with dementia rather than on what abilities and capabilities have been diminished or lost.
3. "Enter the world" of the person living with dementia to best understand, communicate with, and interpret the meaning of his/her behaviors from their perspective.

### Relationships & Community

Having and maintaining a meaningful relationship with someone who has dementia is an essential component of his/her well-being at all stages of the illness. Positive and successful relationships are based upon five features (Maxwell, 2002): respect, shared experiences, trust, reciprocity (looking out for one another), and mutual enjoyment. Each person is unique, so the ways in which relationships are nurtured and maintained will vary. Time is the essential operational ingredient to form and sustain relationships. People need time together in order to build trust, share experiences, and enjoy things with each other. For care partners at home

who may already feel overwhelmed with caregiving responsibilities, the idea of carving yet more time to do something else may seem unrealistic. In reality, the small amount of time actually needed to nurture and maintain relationships helps to ease the emotional care burden and can provide a sense of purpose. An *operational practice* to support relationships in the work environment is a culture that ensures staff have time to spend with residents/clients in order to form, nurture, and maintain relationships.

Community refers to belonging and fitting into a group. The group could be a family unit, participants in an adult day center, and residents of a nursing home or assisted living to name a few examples. The bonds of relationships help form the basis for belonging.

### Governance

This structural element only pertains to organizations providing services and supports and not for family care partners. Governance includes the owner, operator, or board of directors of an organization. They are the highest decision-making authority and as such are ultimately responsible for the operational culture, ethos, and values of an organization. The governing body needs to be fully supportive of a person-centered care culture, involved with its effective implementation, and routinely ensuring that desired outcomes are being achieved. The governing body cannot simply delegate this responsibility to the leadership because then they don't have knowledge or understanding about what is involved in order to develop and fund policies and programs to support it. Active involvement by the governing body is a key *operational practice* for person-centered dementia care.

### Leadership

The Leadership element only pertains to organizations providing services and support and not for family care partners. Effective leadership is essential to supporting a person-centered operational culture within an organization. Much has been written in management and leadership literature about effective leadership models (Blanchard et al, 2009; Chait et al, 2005; Collins, 2001; Greenleaf, 1991). An *operational practice* for this element is a collaborative leadership model emphasizes relationships over tasks. The traditional hierarchical model of long-term care doesn't build a community culture centered on people and relationships that is needed to support person-centeredness.

### Care Partners/Workforce

Care partners are people actively engaged in providing care and/or support for people who have dementia. Care partners can include family members, friends, and paid staff. A crucial *operational practice* for all care partners regardless of the setting is having comprehensive information and training in person-centered dementia care to build knowledge and skills. For those working at the organizational level, a key *operational practice* is to have the appropriate number of staff at all shifts seven days a week in order to be able to provide person-centered dementia care.

### Services

Services refer to actual provision of care and support based upon individual preferences, culture, values, lifestyle choices, and needs to support his/her unique rhythms of daily living. The provision of services that optimize physical, social, emotional, spiritual, and intellectual well-being for a person who has dementia is the *operational practice*.

### Meaningful Life & Engagement

Meaningful and engaging things to do throughout the day are essential to support health and well-being. These rhythms of daily life not only provide purpose and structure to the day, but the meaningful activities help to support life roles and functions that are important to preserving value, self-esteem, and confidence, as well as to identify and create a sense of belonging. The *operational practice* is ensuring that meaningful life & engagement is effectively supported.

### Environment

The physical and social environment in all care settings (e.g., home, assisted living, adult day care, nursing homes) can have a significant impact on the overall well-being and quality of life for people who have dementia. The goal of positive environments is to enable them to achieve maximum functioning, comfort, functionality, safety, and well-being. They can experience a reduced stress threshold to environmental and sensory stimulation. For instance, noise and light levels and other forms of sensory stimulation can cause unintended negative outcomes. The *operational practice* for this element is having an effective physical and social environment.

### Accountability

This last structural element is important to test whether or not the other structural elements are actually achieving desired outcomes. The *operational practice* for Accountability is ensuring that all of the person-centered dementia care practices and processes are, in fact, producing intended outcomes.

## The PERSONALIZED PRACTICES for Person-Centered Dementia Care

"*Music can lift us out of depression or move us to tears — it is a remedy, a tonic, orange juice for the ear. But for many of my neurological patients, music is even more — it can provide access, when no medication can, to movement, to speech, to life. For them, music is not a luxury, but a necessity*."

— Oliver Sacks, MD, Professor of Neurology/New York University School of Medicine

*Personalized practices* within the person-centered dementia care conceptual framework refer to interacting with people who have dementia in ways that honor and support his/her individual personhood. *Personalized practices* recognize that people are multi-faceted, unique beings. As described earlier in the "Origins of Person-Centeredness" section, overlooking and/or separating the psycho-social-spiritual dimensions from the medical dimension leads to impersonal and fragmented care. *Personalized practices* recognize and support the whole person. Individualized practices are the specific ways of supporting the personhood of each person who has dementia.

### Behavioral Expressions

Behaviors expressed by persons living with dementia is arguably one of the most challenging aspects of care. Ninety percent of people with dementia experience some form of behavioral disturbance during the course of the illness (Alzheimer's Association, 2004). Behavioral expressions are covered here because how to best understand and manage them are addressed by using *personalized practices*. The topic is currently an area of heightened national concern because of the overutilization of antipsychotic medications (Inspector General, 2011). Because of the significant negative consequences associated with the overutilization of antipsychotics, behaviors associated with dementia are discussed in detail below while other aspects of dementia care are not.

The term "behavioral problem" is frequently used to describe any non-normative behavior persons with dementia may exhibit. This term can have paternalistic connotations and generally assumes a negative orientation to these behaviors. Although behaviors might be considered non-normative to an observer, they might be reasonable reactions of the person with dementia in particular situations. These behaviors are often expressions of unmet needs, such as pain,

hunger, thirst, boredom, loneliness, or an underlying medical condition that the person with dementia is challenged to communicate to a care partner or to address him or herself. Behavioral expressions are a form of communication. In person-centered dementia care, one of the *core values* is to view things from the perspective of the person with dementia, which aids in uncovering the cause of the behavior being expressed.

The term preferred by the *Dementia Initiative* experts instead of "behavioral problem" which has a negative context is *behavioral expression*. Behavioral expressions by persons with dementia can occur at any stage. Most people with dementia experience some form of behavioral disturbance during the course of the illness. The reasons for behavioral expressions are complex and vary by individual. For example, agitation may arise from becoming overstimulated, environmental factors such as noise and not recognizing where they are, needing to rest, pain, and unmet psychosocial needs among other causes (Kolanowski & Litaker, 2006; Volicer & Hurley, 2003). The determination of when a behavior rises to the level of a "problem" is subjective and typically depends on the tolerability of the care partner and the context in which the behavior occurs.

The term preferred by the *Dementia Initiative* experts is **"behavioral expression."**

> "*One of the blind spots people have is seeing the distress as the problem rather than as a symptom of a larger need, so they treat the distress and never get to the heart of the matter.*"
>
> — Dr. G. Allen Power, author of "Dementia Beyond Drugs"

The overutilization of antipsychotics and other medications (e.g., benzodiazepines, anticonvulsant/mood stabilizers) to manage what are perceived as troublesome behaviors remains a first-line response to symptoms of distress and agitation. For a six-month review period, the Office of the Inspector General found that, for more than 1 in 5 claims (or 317,971 of the 1.4 million Medicare claims), atypical antipsychotic drugs were administered in ways that did not meet CMS standards for drug regimens in nursing homes (Inspector General, 2011).

A recent article in *The New England Journal of Medicine*, "Relapse Risk after Discontinuation of Risperidone in Alzheimer's Disease," is of concern to the *Dementia Initiative* experts. The article describes a double-blind randomized control study of people with Alzheimer's disease who exhibited psychosis or agitation and had been placed on risperidone to manage the symptoms. The symptoms were found to return after discontinuation of the risperidone treatment leading clinicians (the target audience of the *Journal*) to believe that the treatment should not be discontinued. However, as with all studies, one must not generalize results beyond the study population. In this case, the authors selected individuals with dementia who had psychosis and had reduced psychosis following use of resperidone. The vast majority of individuals with dementia taking antipsychotics are not receiving them for psychoses. Numerous randomized control withdrawal trials have shown that it is extremely safe (and often beneficial) to stop atypical antipsychotics among individuals with dementia. Another problem with the study's interpretation of the results is the failure to identify the root cause of the behavioral expressions, thus inappropriately continuing the notion that antipsychotics are generally the desired course of treatment. As discussed, many of the behavioral expressions among individuals with dementia are normal reactions to a situation or are labeled as psychoses when they are often not. The use of a sedating medication such as resperidone will "treat the behavior" (e.g. the symptom) but not the underlying cause for the behavior. Thus, withdrawing a medication without addressing the underlying cause will, of course, result in the return of the behavioral expression.

The custom to medicate is not surprising, given the clinician-centric, bio-medical, payment-for-service healthcare culture. Using medications as treatment is efficient and expedient and has become our society's expectation and norm. The alternative to treating behavioral symptoms with medications is to determine the root cause of the behavior and then address the cause, such as pain, boredom, illness, or loneliness, with the appropriate person-centered strategies. Although perceived as a more time and labor intensive process initially, once the root cause is identified the solution is often relatively simple and saves time in the long run. A *personalized approach* yields far better results from a humanistic context, carries less medical risk for the person with dementia, and promotes well-being.

While the term "non-pharmacologic" is the term most widely used to describe methods to respond to behavioral expressions other than the use of medications, the term underscores a bio-medical orientation rather than a holistic one.
The *Dementia Initiative* experts recommend using the term "personalized approach" instead of non-pharmacologic to emphasize individualized focus rather than generic status quo practices.

The *Dementia Initiative* experts recommend using the term **personalized approach** instead of "non-pharmacologic" to emphasize the need for an individual focus and not generic status quo practices.

It should be noted that *personalized practices* are not what the medical community refers to as an "intervention." The *Dementia Initiative* experts view the term "intervention" as medically oriented and describes an action to respond to a medical symptom. For instance, administering an antipsychotic medication is considered an "intervention."

### Personalized Practices

*"I know this is a bit heretical coming from someone with a research background, but an over-reliance on research data and its categorized strength as meaningful evidence further medicalizes what is essentially a discussion about the way people live their life. If someone is agitated and expressing their agitation through behavior, it is not always a medical need. A music lover may be upset at being deprived of the music they love; a food lover may be upset at being unable to enjoy the foods that they love; a person may simply be thirsty. You could medicalize these and develop clinical interventions to address these needs, but I personally do not need to rely on the evidence developed in an 'RCT' to inform me that people find music soothing, food enjoyable, and water refreshing."*

— Peter Reed, PhD, CEO/Pioneer Network

The following *personalized practices* are derived from multiple sources including the research literature, gray literature, and the professional experiences of the *Dementia Initiative* experts. The diversity of sources of these practices indicates a fundamental value of knowledge about practices that may be generated in the research (evidence-based) as well as those developed in the practice arena. It is the view of the *Dementia Initiative* experts that both have strengths and weaknesses, and neither is inherently superior to the other. The listed *personalized practices* are not intended to represent a full compendium of all possible practices but rather a fairly robust representation of options.

**Samples of *personalized practices* are categorized below within the domains of the structural elements.**

| RELATIONSHIPS & COMMUNITY |
| --- |
| ***Communication & Relationship-Building*** — Interpersonal relationships are at the core of human wellbeing. Dementia may include symptoms such as difficulty with word finding and remembering names and details of recent experience that interfere with communication and with maintaining and building relationships. Combined with relocation to a new care environment or changes in care providers and others, this can lead to frustration for a person with dementia and disruption to the development and maintenance of these needed relationships. For caregivers and others interacting with people who have these difficulties, patience, openness and authenticity in each interaction will foster trust and help build relationships and community. |
| ***Family and Friends*** — Family and friends provide the social supports all humans need. This may be particularly true for people with dementia who seek a sense of history and selfhood through interactions with people who know them well. However, changes in the person with dementia can be confusing and upsetting to their family and friends and may be disruptive to these relationships. Staff reacting to their frustration may intervene in more or less helpful ways. In general, helping family and friends acknowledge the changes and offering them tools for engaging with the person as he or she is today will enhance wellbeing for both the person with dementia and with the family and friends on whom they increasingly rely. |

## GOVERNANCE

***Owners/Board Members' Commitment and Experiential Involvement*** — Each governing body member needs to experience firsthand a person-centered operational culture and use the experience to help them develop policies and funds necessary to support person-centered outcomes in their organization. For example, members can visit an organization that has already implemented a person-centered dementia care operational culture and learn from their transformative process.

***Person-Centered Dementia Care Knowledge and Skills Development*** — Commitment by the governing body to pay for the infrastructure needed to fully train and build person-centered dementia care knowledge and skills for all staff members.

## LEADERSHIP

***Modeling and Coaching Effective Person-Centered Dementia Care Practices*** — Leaders foster an authentic learning environment through ensuring an effective training system, and providing informal coaching and modeling of effective practices.

***Nurturing Meaningful Relationships*** — Leaders create and sustain genuine meaningful relationships and communication with residents and family members, encouraging their insights and feedback as partners in care and caring.

## CARE PARTNERS/WORKFORCE

***Investment in Practices that Sustain a Stable Workforce*** — Staff stability is needed to maintain a person-centered operational culture. When staff turnover is high, there are cascading negative outcomes including time existing staff have to commit to continually orienting new staff members. Some turnover is inevitable, but high levels are indicative of operational and management problems retaining staff.

***Consistent Staffing Assignments*** — Having the same staff members consistently provide care and support for a resident/client helps to build relationships and personal knowledge about how to best provide the care and support.

| MEANINGFUL LIFE & ENGAGEMENT |
| --- |
| ***Activity Materials*** — Items should be adult in nature. Items that look like children's toys may be recognized as childish to the person living with dementia, and can encourage care partners to view a person living with dementia as less than a mature adult. |
| ***Art*** — Many persons living with dementia have a lifetime of experiences being creative and making creative things such as paintings, sculpture, music, photography, etc. Others may not have been especially talented in any of the arts, but enjoyed making art projects and creating music. For persons living with dementia with considerable communication challenges, the symbolic and emotional language of the arts provides a way to express themselves without frustration, have meaning, and connect with others (belonging). Providing opportunities for them to express creative and artistic interests can help increase their feelings of self-identity, worth, purpose, and self-confidence. For some, the familiar actions of making art can be a calming and relaxing experience. |
| ***Children*** — Spending time with children of various ages (preschool to high school age) can be meaningful if these social interactions were previously part of something they enjoyed. These social interactions with children can be stimulating and interesting and provide emotional benefits. |
| ***Music*** — Music that is perceived as familiar and pleasant by the listener has been found to override confusing stimuli by providing a comforting auditory environment that can decrease distress, evoke positive feelings, and create a sense of meaningful connection with others. Listening to music the person prefers can create pleasant and positive feelings including relaxation. The use of music can also help refocus a person's living with dementia attention on a pleasant emotional state. Music can be used to introduce a sense of familiarity into a new environment or to maximize familiarity in an existing environment. |
| ***Pets*** — Pets provide the opportunity to have close physical contact with warm bodies that can provide comfort and pleasure and something to talk to, watch, caress and hug. Pets can provide meaning, a sense of wonder, and alleviate loneliness and boredom. Stroking a pet can have a calming effect and offer something interesting to do. Pets are non-judgmental beings that can support well-being. |
| ***Social Interaction*** — Everyday social interactions, including brief positive interactions with casual acquaintances and caregivers, fosters a sense of well-being. Laughing, singing, or simply being with others can exert a calming or energizing influence. Knowing that one is part of a social community larger than oneself can provide a reassuring context when a person is feeling particularly lost or upset. Social interactions may also be too stimulating at times and the best caregivers are aware of times that being alone is what is needed for a person to recoup his or her sense of self. |

## MEANINGFUL LIFE & ENGAGEMENT (continued)

***Solitude*** — Some people have enjoyed lifelong activities they do by themselves such as reading or listening to music. A person's engagement style does not necessarily change if they have dementia. Trying to get them to participate in activities with others may only serve to frustrate and upset them. It is important to be sensitive and mindful of a person's living with dementia lifelong engagement style when considering how best to engage them.

***Spiritual, Religious, and End-of-Life Practices*** — Many people need to feel a connection to something beyond their own person. This can be through spiritual/religious practices, or by connecting to a larger community. Spirituality is more diverse than religion as it is not restricted to any specific religious beliefs, institutions, or practices. It generally includes a belief in a greater being beyond the human experience. For many people, religious and/or spiritual memories and rituals [e.g., music, sounds, smells (incense), visuals (statues, icons)] bring a sense of great comfort.

***Touch (Tactile)*** — Beneficial touch can take many forms including massage, therapeutic touch, and Reiki. The terms refer to different techniques used to induce relaxation and feelings of calm. Caring touch transmits connection and compassion.

## SERVICES

***Bathing*** — Care partners learn the preferences of the persons living with dementia in terms of morning/evening bathing and other facets that may help make the experience more comfortable such as warm towels. Knowing what each individual prefers helps to make bathing a comforting, private, and pleasant experience.

***Dressing*** — People have preferred dress styles (for example, a woman who never wears slacks). Care partners support and assist the person as appropriate, encouraging them to be as independent as possible. Using a warm vocal tone and unhurried movements will help keep the experience calm and positive.

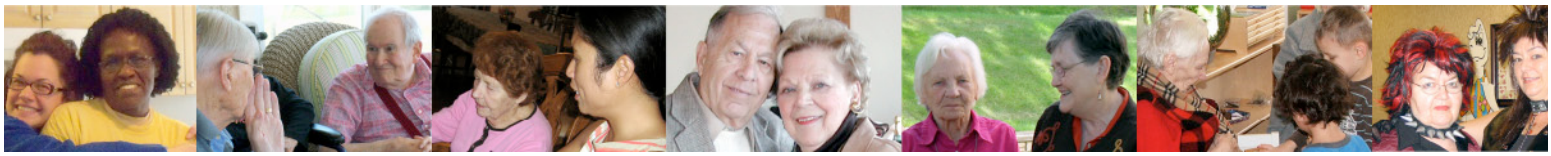
***Grooming*** — Most people enjoy the feeling of looking their best. Men may need support to shave, and a woman may need a reminder to put on her lipstick if this is customary for her. Encouraging them to brush their own hair is an excellent way for them to get upper-arm range of motion exercise.

***Movement, Exercise, and Function Practices*** — Movement should be encouraged throughout the stages of dementia. It can be used to maintain and enhance motor functions. In mild to moderate stages, it is possible to target balance, mobility, strength, and stamina. Care partners can help to move limbs to manage stiffness and atrophy. There is evidence that some cognitive function may be improved by physical activity. Physical exercise may assist with neurogenesis (neuron growth) and angiogenesis (blood vessel growth) in the brain.

| ENVIRONMENT |
| --- |
| ***Comforting and Therapeutic Smells (Olfactory)*** **—** In dementia, the sensory and visual parts of the brain are some of the most preserved. By stimulating the senses, there is an opportunity to tap into remaining abilities in order to create an increased awareness of self and the surrounding environment. Pleasant smells in the physical environment can be calming or comforting. It is important to learn about the person's likes, dislikes, and preferences, and to ask if there are any known allergies or sensitivities to scents, oils, etc. |
| ***Light*** — Exposure to light has been shown to increase total nocturnal sleep time, decrease daytime napping, reduce behavioral outburst, and increase stability of rest-activity rhythms. |
| ***Lighting and Coloration*** — Because of related visual deficits, older adults generally require between 2–3 times the amount of light as younger individuals. Persons living with dementia can face particular visual deficits such as difficulty distinguishing color, depth perception, and sensitivity to contrast because of diminished cognitive ability to decode information. Being exposed to sufficient light is associated with an increase in serotonin (a neurotransmitter chemical produced in the brain) that can boost mood. Avoid bright sunlight, slanted sunlight through windows, or poorly positioned lighting, which can cause glare, especially if it reflects off highly polished floors and table tops, and glossy walls. |
| ***Noise/Sound*** — Environmental noise and sound can create stress for persons living with dementia. Background noise from phones, machines (e.g., dishwasher, washing machine/ dryer, microwave), traffic, lawn mowing, television and radio can cause auditory over-stimulation resulting in agitation. Noise can disturb rest, relaxation and sleep. It is easy to become immune to hearing unwanted sounds, so it is important to be mindful of ambient sounds in the environment. |
| ***Outdoors/Nature*** **—** Being outdoors and experiencing nature can provide pleasurable things to do (e.g., gardening, watching birds, sitting on a beach, walking). Besides the physical exercise benefit, for some the outdoors helps them feel a spiritual connection. Exposure to natural sunlight also helps to regulate a body's circadian rhythm and sleep/wake cycles. |
| ***Sensory*** — Sensory stimulation can enhance a person's living with dementia sense of comfort and well-being through visual, auditory, olfactory, gustatory, and/or tactile stimulation. Sensory practices have been shown to decrease persons' living with dementia restlessness and agitation. Sensory practices can enhance quality of life for both the person living with dementia and his/her care partner.<br>"*I want all my senses engaged*." — Maya Angelou |

## ACCOUNTABILITY

***Sustaining Quality Person-Centered Dementia Care*** — Sustainability requires a commitment to ongoing quality assurance that includes regular assessment and evaluation of operations to determine if desired outcomes are being achieved. Operational performance data need to be regularly collected and analyzed and findings utilized to determine whether operational and organizational processes are achieving desired results.



# DEMENTIA CARE: THE QUALITY CHASM

## SECTION 2. ISSUES & RECOMMENDATIONS TO ADDRESS BARRIERS & CHALLENGES TO PERSON-CENTERED DEMENTIA CARE

### Healthcare providers and practitioners

**Issue:** The current orientation of healthcare providers and practitioners to viewing a person living with dementia as "a disease-condition" overlooks the totality of their multi-faceted personhood. This flawed orientation not only influences but often negatively impacts healthcare providers' and practitioners' attitudes toward and interactions with (or lack thereof) the person, and limits options for treatments in humanistic ways that engage and enhance meaningful living.

**Recommendation:** *The Dementia Initiative* participants, working in collaboration with public and private entities (organizations that are members of the Leadership Council of Aging Organizations and NAPA leadership among others), should establish a nationwide multi-stage campaign across research, policy, and practice sectors to advance knowledge and understanding of person-centered dementia care practices, including a training and skills development program for the adoption, implementation, and sustainability for long-term usage of this consensus dementia care framework.

In addition, establish a Dementia Advisory Group, including people living with dementia to develop a plan for appropriate prescribing guidelines for the use of antipsychotic medications for people who have dementia.

## Acute and Post-Acute Care

**Issue:** The hospitalization and rehabilitation of people who have dementia can often exacerbate their distress and negatively affect their functional abilities. The unfamiliar environment, routine, and people, combined with the stress of whatever illness has caused their hospitalization, frequently causes the emergence or exacerbation of behavioral expressions. The behaviors are often treated by administering mood-altering medications. This practice can result in cascading negative effects, such as falls, when the person gets discharged to their home or a residential care setting while still on the medication.

**Recommendation:** Include in the above referenced educational campaign, information that can help to reduce unnecessary hospitalizations and use of off-label antipsychotics.

(1) Hospitalizations for persons with dementia are associated with numerous negative outcomes and should be prevented when possible. There is a general lack of awareness that in many cases infections and co-morbidities can be effectively treated on-site or in out-patient or long-term care facilities, and result in fewer negative outcomes.

(2) A pro-active approach to anticipating common infections (e.g., UTIs and pneumonia) and exacerbations of co-morbidities (e.g., musculo-skeletal, cardiac, pulmonary, digestive) in persons with dementia can facilitate early detection and successful treatment delivered where the person resides.

(3) Hospitalizations for persons with dementia decrease when proxy decision-makers better understand the clinical course of dementia, its common complications, and advanced directives. Studies reveal educated proxy decision-makers were much less likely to choose aggressive, burdensome, and costly interventions in the last months of life when information about specific details pertaining to healthcare decisions (resuscitation, hospitalizations, antibiotics, and feeding tubes), along with realistic outcomes were discussed.

## Adoption of Person-Centered Dementia Care Values and Practices

**Issue:** A strong theoretical and conceptual framework, values and practices exist for person-centered dementia care as was detailed earlier in the paper. However, this information is not widely known by dementia care stakeholders and, as a result, not widely accepted or used leading to fragmentation and a continuation of the medical-model status quo.

**Recommendation:**

(1) Work with NAPA to have the consensus person-centered dementia care framework and practices included in its recommendations and plans; and

(2) Use the above-referenced national education campaign to advance adoption, implementation, and long-term usage of this consensus dementia care framework.

## Measurement Tools

**Issue:** There are a number of tools for measurement of person-centered care in various settings. A few of the tools are dementia specific. A common limitation is the need for them to be used and validated beyond the development period. Also, the conceptual underpinnings of the tools are generally not explained in detail, making comparability difficult. The tools that currently exist need further testing for validity, reliability, and applicability (Edvardsson et al., 2009).

**Recommendation:** The *Dementia Initiative* participants should identify appropriate research partners and funders to further develop and validate person-centered dementia care measurement tools.

## Person-Centered Dementia Care Outcomes

**Issue:** There is a general concept that people will know the desired person-centered dementia care outcomes when they see them. There is a lack of any well-developed, consensus agreement upon desired outcomes for person-centered dementia care.

**Recommendation:** As part of the national educational campaign identified in the first item, the materials developed should identify desired person-centered dementia care outcomes as defined by consensus agreement.

## Research Mindset and Methodologies

**Issue:** The prevailing mindset among researchers, funders, academicians, and policymakers among others is that randomized control trials are the only gold standard for research and developing evidence-based practices and that quantitative research methodologies are superior to other methodologies. Further, research in dementia care generally focused on studying the "symptoms" of a condition rather than the flip side — what fosters well-being. These issues have greatly hampered dementia care and the ability to make progress in improving standards of dementia care. Just as each individual thrives best when practices are individualized to suit their preferences, interests, and needs, a research study best informs when the design and research method is suited to the hypotheses and research questions. Many research questions in the psycho-social-spiritual realm are not suited for the randomized controlled trial. Research studies fail and/or lack face validity when subjected to the wrong design and methodology.

**Recommendations:**

(1) Form consensus about what the different "gold standard" methodologies are for addressing dementia care research questions based on bio-psycho-social-spiritual dimensions;

(2) Form consensus about what constitutes "evidence-based" information for person-centered dementia care;

(3) As part of the educational campaign referenced previously, educate funders and researchers about the barriers and problems caused by the conventional mindset and approaches to dementia care research, and the need to "culture change" the prevailing mindset; and

(4) Identify and work with appropriate researchers and funders to create a flow of effectively designed research projects to provide the evidence base for person-centered dementia care practices.

Borrowing from items identified by David Edvardsson in previously published works, the following is a list of areas that need further person-centered care research:

1. Identify appropriate, valid, and reliable qualitative and quantitative measurement tools for person-centered dementia care.

2. Identify and assess desired person-centered dementia care outcomes.
3. Study and assess the effects of well-described person-centered practices.
4. Study and assess the effects of different models that operationalize person-centered dementia care practices.
5. Investigate whether person-centered practices have measurable and significant effects on the health and well-being of persons with dementia.
6. Study the cost-benefit analysis of person-centered dementia care.
7. Conduct interdisciplinary studies in which person-centered practices are integrated into mainstream research and clinical trials.
8. Identify and assess what training education and skills are needed to prepare and support care partners (e.g., family members, healthcare practitioners, long-term service and support providers).

## Resources

**Issue:** There are few well developed resource materials on person-centered dementia care. There is no master list of the well-developed resource materials already available. A master list should include materials that have been curated (reviewed by a group of experts and deemed to meet a desired level of acceptance).

**Recommendations:**

(1) Establish a Dementia Advisory Group of people living with dementia to best inform and shape the *Dementia Initiative* work.

(2) Prepare a white paper on how to implement and operationalize person-centered dementia care practices that has consensus agreement by the *Dementia Initiative* experts.

(3) Identify appropriate person-centered dementia care training resources and materials and affordable ways to access them.

(4) Create an open-source process and network to broaden the input into the national *Dementia Initiative* effort.

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## APPENDIX 1 — Literature Search Description

Literature searches were done in four databases using the search terms: "dementia" AND "intervention" NOT "drug therapy." Retrieved articles were briefly reviewed for relevance. In the end, there were 332 articles deemed relevant. Lin Chen (a research assistant from UCLA) extracted the following from each article: author, year, setting, participants, study design, results, and notes. In addition, each article was ranked in terms of the strength of its evidence using criteria from the Administration on Community Living (formerly Administration on Aging) (http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Title_IIID/index.aspx). For example, the highest rank would be from an experimental or quasi-experimental, published in a peer-review journal study that has been translated at a community site and is available to the public. Finally, each article was categorized into a group based on predetermined categories of non-pharmacological practices (psychosocial therapy, behavioral stimulation, blended therapy, etc.). These categories derive from a combination of experience in dementia care as well as the groupings observed in the literature. (See Appendix A for details on this review.) All confirmed participants for a June 29, 2012, meeting in Washington, DC, received a copy of the concept piece including the results of the literature review of non-pharmacological practices.

## APPENDIX 2 — List of *Dementia Initiative* Experts

Names in **blue** signify the Dementia Initiative Leadership Team.

| PRACTICE | |
|---|---|
| **Jayne Clairmont**<br>Owner & CEO | English Rose Suites<br>jclairmont@englishrosesuites.com |
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| **Daniel Kuhn, LCSW**<br>Author, dementia care expert | Rainbow Hospice and Palliative Care<br>dkuhn@rainbowhospice.org |
| **Kathy Laurenhue, MA**<br>CEO | Wiser Now, Inc.<br>laurenhue@msn.com |
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| RESEARCH (continued) | |
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| EX-OFFICIO | |
|---|---|
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## APPENDIX 3 — Person-Centered Dementia Care Literature Search

Accessible by going on-line to www.ccal.org