

Living with Dementia: Changing the Status Quo



2016



DEDICATION

This white paper is dedicated to all the amazing people living with dementia who are speaking out and teaching the world about living with dementia.

ACKNOWLEDGEMENTS

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TABLE OF CONTENTS

Executive Summary	4
Introduction	6
What Fuels Misperceptions, Stigma and Stereotype	9
The Traditional Medical Culture	11
Person-Centered Approaches	14
Well-Being	18
Words Matter	22
Transitioning to a Bio-Psycho-Social-Spiritual Culture	25
Conclusion and Recommendations	28
References	33
Appendix I — White Paper Contributor	38
Appendix II — DAA’s Person-Centered Dementia Values & Principles	40

EXECUTIVE SUMMARY

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*“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that.*

*It is to enable well-being.” ~ Atul Gawande (2014, p. 259)*

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Dr. Gawande’s statement is an important “shot over the bow” about the inadequacy of conventional medicine to enable well-being. The oft-cited Preamble to the Constitution of the World Health Organization defines well-being as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. This white paper examines the impact that the traditional medical model of care has upon the well-being of people living with dementia as well as the societal factors that contribute to undermining their well-being. This paper represents the collective perspectives of diverse stakeholders including individuals living with dementia who are the utmost experts of the lived experience. The consensus opinions expressed in the paper are meant as a wake-up call about the significant and serious societal issues impeding the well-being of people living with dementia and their ability to live as well as possible with a chronic condition.

Traditional medicine is responsible for significant and life-altering advances in the management of many illnesses, and the valued work of healthcare professionals is deeply appreciated. Current medical models, however, often fail people and families affected by dementia. Once diagnosed with dementia, peoples’ feelings, actions, and expressions can become reduced to symptoms within a problematized field of possibility. There tends to be a process of dehumanization that objectifies people who have dementia and regards them as stages of disease and deficit. Needed instead are broader, more integrative medical approaches drawing upon an understanding of the holistic bio-psycho-social-spiritual dimensions that best support well-being.

Also confounding well-being for people living with dementia are social attitudes, misperceptions, barriers and stigma about dementia. The origins can be attributed

to a confluence of factors: (1) society looks to healthcare professionals for guidance and understanding about chronic conditions such as dementia but healthcare professionals often have a limited perspective and understanding about the lived experience of dementia; (2) the exclusion of people living with dementia and their informed perspectives from serving and thus having input on expert panels and other influential venues; (3) the disconnect about what constitutes success in terms of managing chronic conditions between traditional medical practitioners and people actually living with chronic conditions; (4) print, broadcast and film media’s propensity to sensationalize storylines; and (5) the use of fear-mongering tactics to elicit funding support.

While the white paper does not aim to be controversial, it is intended to be pragmatic and direct. We address the two elephants in the room — (1) traditional medicine and the failure of many healthcare practitioners and healthcare settings to address the needs of individuals living with dementia, and (2) societal misperceptions, attitudes and stigmas about dementia and the impact this has on well-being. A growing movement of consumers, consumer advocates, healthcare providers and practitioners, and policymakers among others currently champion what has become widely known as person-centered care because of the humanistic values and practices. Person-centered approaches encompass the integrated bio-psycho-social-spiritual dimensions of human existence that provide a context for well-being. Adopting a holistic, person-centered approach is an expansion upon rather than a rejection of traditional medicine. Person-centered practices are a response to the largely impersonal and highly fragmented health care system issues cited by the Institute of Medicine in its seminal report, “Crossing the Quality Chasm”.

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## **ABOUT THIS PAPER**

This white paper is intended for a broad audience including policy makers, healthcare practitioners, long-term service and support providers, researchers, and advocates among others. The consensus opinions expressed in the paper are a result of months of email and telephone exchanges, collaborative writing, and numerous rounds of feedback and editing.

# Living with Dementia: Changing the Status Quo

## INTRODUCTION

Curled up in a favorite chair with her cat purring beside her, Christine Bryden read a congratulatory letter from the publisher of her 1998 book, *Who Will I Be When I Die*, letting her know that the book had sold so many copies it was going into reprint. Christine's life had taken many unexpected turns since being diagnosed with Alzheimer's disease in 1995. Her neurologist had informed her that she would have *"about five years till you become demented, then a few years after that in a nursing home till you die"* (Bryden, 2005, p. 26-27). She initially envisioned herself living in a nursing home by 2000 and dead a few years later. Instead, Christine immersed herself in continuing to live her life as fully as possible with dementia. Christine has upended stereotypes about living with dementia and her can-do spirit led her to complete a post-graduate degree, remarry, and speak around the world.

Is Christine an outlier and is her experience living with dementia unusual? Thanks to the wide reach of the Internet, we are learning Christine's experience is not so unusual. More and more people in the early and mid-stages of dementia are openly writing and talking about their experiences of living with dementia. The result is an extraordinary global network of people living with dementia who are using social media to create online forums, websites and in-person get-togethers to help themselves, support others and to help seek public and private funding for local, state, national and global initiatives and programs. The following are some examples. The Young Onset Dementia Support Group is an online support group on Facebook ([www.facebook.com/YoungOnsetDementiaSupportGroup](http://www.facebook.com/YoungOnsetDementiaSupportGroup)); Forget Me Not is an online group supporting people with all forms of dementia ([www.forgetmenot.support](http://www.forgetmenot.support)); and Dementia Mentors and forMemory are examples of websites organized and operated by people living with dementia ([www.dementiamentors.com](http://www.dementiamentors.com) and [www.formemory.org](http://www.formemory.org)).

Jennifer Bute, a retired physician, shares her personal perspective on living with dementia at [www.gloriousopportunity.org](http://www.gloriousopportunity.org), and Kate Swaffer blogs from Australia ([kateswaffer.com/daily-blog](http://kateswaffer.com/daily-blog)). In the U.K., SURF Liverpool operates a robust Twitter account and meets once a month, and the Dementia Engagement and Empowerment Project (DEEP) coordinates many programs and activities ([www.dementivoices.org.uk](http://www.dementivoices.org.uk)). There is an international organization run for and by people living with dementia, Dementia Alliance International ([www.dementiaallianceinternational.org](http://www.dementiaallianceinternational.org)).

Often people living with dementia describe how family members assume that a dementia diagnosis immediately renders them dependent, incapable and helpless and may seek to take over decision-making literally days after a diagnosis. Richard Taylor, a retired university professor with probable Alzheimer's dementia, found that the stigma surrounding dementia led his family and friends to question his ability to make decisions affecting his everyday life — *"Can I be trusted to spend time alone with my granddaughter? Can I, should I handle my own money, answer the door?"* (Dupuis et al, 2011). The subject of a CNN Medical News series for the past three years, Alexander "Sandy" Halperin, a retired dentist finds, *"Stigmas about dementia can build massive barrier walls that can prevent us from having as fulfilled of a life as possible. Stigmas rob me of living my life to its fullest with dementia"* (Halperin, 2015).

In a study of family members whose loved ones had a dementia diagnosis, more than 50 percent believed life with dementia was not worth living and many considered the person socially dead (Sweeting & Gilhooly, 1997). Australian author and advocate Kate Swaffer coined the term 'Prescribed Disengagement' for this mentality. *"This (prescribed disengagement) sets up people with dementia to live a life without hope, without any sense of a future and destroys the notion of well-being. Prescribed Disengagement™ sets up a chain reaction of hopelessness and terror which negatively impacts a person's ability to be positive, resilient and proactive, ultimately affecting their well-being and quality of life"* (Swaffer, 2014b, p. 1).

Just as stereotypes about race, gender, socioeconomic status, ethnicity and aging can have a huge impact on the self-concept of individuals and their treatment at the hands of society,

so do stereotypes about dementia. There is abundant evidence that societies globally stigmatize and devalue people living with dementia (Brooker, 2008; Moyle et al, 2011; Swaffer, 2014a). A glance back at the history of medicine reveals that the stigma and misperceptions surrounding dementia are hardly unique. Societies stigmatize medical conditions that are feared, misunderstood or evoke social prejudices, and examples include cancer, mental illness, developmental disabilities, alcohol and drug addiction, epilepsy, obesity and HIV/AIDS. The results include shame, social isolation and inadequate care and support. While recognizing that societies have not set out to intentionally harm or devalue people living with dementia, the consequences of the stigma attached to dementia can foster what Swaffer calls Prescribed Disengagement™.

While living with dementia presents many significant and life-altering challenges, a common theme among individuals who are continuing to live fully is the necessity of developing a can-do spirit and positive mindset. Dementia is a long-term health condition and often people diagnosed with dementia can be otherwise physically healthy. After a person receives a diagnosis of dementia what he or she typically needs most is information about how to live with the physical and emotional aspects of the condition and the need for them to have strong emotional and social support. The majority of articles and information about dementia tend to focus on aspects of dementia that fan feelings of hopelessness and despair. Imagine the benefits of information that empowers individuals diagnosed with dementia to live as independently and meaningfully of a life as is possible. Might this type of paradigm shift encourage individuals with dementia to be proactive, focus on their strengths and engage the support of families and friends? Could this increase their resilience?

In Twitter fashion, Sandy Halperin uses 139 characters to describe living fully with dementia —

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*“Maintaining a fulfilling lifestyle under prevailing emotional
and physical circumstances, being engaged in what gives me joy
as I live in the gift of the present.”*

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## WHAT FUELS MISPERCEPTIONS, STIGMA AND STEREOTYPES

Stigma and misperceptions have negative cascading consequences affecting the person living with dementia as well as his or her family and/or care partners' perceptions and understanding of the condition. Social attitudes and stigma about dementia can be attributed to a confluence of factors: (1) society confers authority to healthcare experts about living with chronic conditions such as dementia but healthcare experts often have limited knowledge, perspective and understanding about the lived experience; (2) the exclusion of people living with dementia, with their informed living-with perspectives, from serving and thus having input on expert panels/conferences and other influential venues that define the public view of dementia and set directions for research and services; (3) the disconnect between medical providers and people actually living with chronic conditions as to what constitutes success in managing those conditions; (4) print, broadcast and film media's propensity to sensationalize storylines; and (5) the use of fear-mongering tactics to elicit funding support.

The general public typically looks to healthcare professionals for understanding of health conditions. Healthcare professionals' expertise often is focused on the physical health process and not on the full living experience. Thus, the information conveyed to the general public is symptom-related and incomplete in terms of living fully with a chronic condition. The general public, not realizing the information only pertains to the medical aspects of dementia, ends up with a medicalized perspective of what it is to live with dementia.

The informed perspectives and subjective experiences of people living with dementia provide what many consider as the most crucial. Unfortunately, people living with dementia have faced discrimination when it comes to serving on expert panels and in other influential forums despite the *Nothing About Us Without Us* movement which has successfully demanded equal and fair representation for other marginalized populations such as people with other intellectual and physical disabilities. A notable example of exclusion of people living with dementia is the National Alzheimer's

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Project Act (NAPA) Advisory Council. The formation of the NAPA Advisory Council is a result of legislation signed into federal law in 2011. The initial Advisory Council did not include any individuals living with dementia. After protest from the Dementia Action Alliance, among others, a former congressman living with dementia was added to the Council in 2013. All other stakeholder groups (e.g., healthcare practitioners, researchers, advocacy organizations) are represented by two individuals. The addition of only ONE person living with dementia continues to be discriminatory and inappropriately minimizes the representation of an important stakeholder group.

Print, broadcast and film media generally sensationalize the most dreaded aspects of living with dementia to titillate and attract audiences. This leaves the general public with a terribly lopsided perspective that further fuels misperceptions and stereotypes. Similarly, the fear-mongering fundraising tactics used by large advocacy organizations also contribute to a distorted understanding of what can be expected following a diagnosis of dementia. The following is one example of a fearmongering funding appeal that focuses on research and cure and not on care and support:

*[Redacted name of organization] doesn't want anyone else to have to face this nightmarish disease, which is the only disease among the leading causes of death with no treatment or cure. That's why we're fighting for a cure, and leading scientists say we're close. But ending this disease will take all of us working together, so we're asking you:  
Will you fight with us?*

***Please, donate \$5 or more before December 31  
to get your tax-deductible gift matched  
to end this horrible disease faster.***

## THE TRADITIONAL MEDICAL CULTURE

Traditional medicine is responsible for significant and life-altering advances in prevention, cure and management of many illnesses, and the valued work of healthcare professionals is deeply appreciated. Current medical models, however, often fail people and families affected by dementia. Once diagnosed with dementia, people's feelings, actions, and expressions can become symptoms with a problematized field of possibility (Mitchell et al, 2013). There tends to be a process of dehumanization that objectifies people who have dementia and regards them as stages of disease and deficit (Fazio et al, 1999). The traditional medical model and the current organization of health care delivery are not prepared to fully address the vagaries of dementia nor support well-being for people living with dementia and their care partners (Keady, 1996; Kitwood, 1997; Power, 2014; Sabat, 2009, 2001).

There is often a difference between medical practitioners and people living with chronic conditions in what constitutes success in terms of health. In managing chronic health conditions, most medical practitioners measure success in terms of decreasing the negative effects of the condition (Westphal et al, 2015). People living with chronic health conditions, however, do not think of success solely — or even primarily — in those terms. While they want to function as well as possible, their notion of overall quality of life includes non-medically oriented goals. On paper, the disconnection between the priorities of healthcare practitioners and people living with chronic conditions may seem a relatively minor issue, but in reality this difference of priorities can have huge consequences for the well-being of people living with chronic conditions.

The theory underpinning traditional medicine reflects the influence of the seventeenth century philosopher, Rene Descartes. Descartes believed the mind and body are two separate spheres and that matters of the mind were of secondary importance when it came to fixing the body (Russell, 2014). While emerging trends in thinking about health care increasingly acknowledge that health and well-being can be disrupted by stress and other emotional, psychosocial and economic factors, this insight is not fully integrated into existing medical practice or reflected in the information typically collected during the course of health care encounters.

In a widely cited article, psychiatrist George Engel criticized the traditional medical model as being excessively narrow and oversimplified, leading clinicians to regard people as objects and ignore the possibility that a person's subjective experience was responsive to scientific study (Engel, 1977). He championed a holistic focus on the medical, psychological, and social dimensions of health that has become known as the bio-psycho-social model. Dr. Engel reasoned that a bio-psycho-social approach not only could address health more comprehensively but could also reverse the dehumanizing and disempowering effects of the traditional medical model.

In 2001, the Institute of Medicine (IOM) released a seminal report, *Crossing the Quality Chasm* (IOM, 2001), documenting serious and widespread quality problems throughout American healthcare calling for its redesign and offering six overarching recommendations to improve the system. That the IOM report cited the traditional healthcare system as being largely impersonal and fragmented should come as no surprise. Dr. Engel rang this warning bell many years earlier. Excluding psychological, social and spiritual dimensions of health contributes to impersonal interactions and fragmented care. To counter these systemic problems, one of the IOM's key recommendations was to transition to a patient-centered approach to care. Given this recommendation, it is ironic that the IOM's process reflected a technocratic mindset. The blue-ribbon panel of healthcare experts that shaped the report excluded 'patients'.

Challenged by healthcare consumers and their families as well as reform-oriented physicians and other healthcare practitioners, the culture and practice of medicine has evolved to include some practitioners and settings that recognize the importance of social and emotional support and allow more collaborative, person-centered relationships between people and their healthcare providers. Examples include hospice care, more supportive settings for childbirth, abolishing institutional models for the care of persons with developmental disabilities, and the "culture change" movement in long-term care. Adopting a holistic, person-centered approach should be viewed as an

Adopting a holistic, person-centered approach should be viewed as an expansion rather than a rejection of medical practice as we know it today.

expansion rather than a rejection of medical practice as we know it today. Four contributors to this paper, geriatricians Rosemary Laird, Al Power, and Rollin Wright, and geriatric psychiatrist Soo Borson, are among the reform-oriented physicians advancing more holistic and comprehensive models of dementia care.

Yet the narrow focus on treating and curing physical disease remains dominant. This has significant consequences for people who have dementia. Since there are few effective medical treatments and no cure for dementia, many physicians are uncomfortable even discussing a diagnosis with patients and family members (Van Hout et al, 2006; Turner et al, 2004). One study found that as many as half of primary care physicians are not in favor of disclosing a dementia diagnosis (Franz et al, 2010).

It is important to also address the pervasive over use of medications to treat what are considered problematic behaviors exhibited by people living with dementia. While the prescribed use of antipsychotics may be appropriate for individuals with serious pre-existing mental illnesses and diagnosed neuropathologies, the widespread off-label use of antipsychotics is unwarranted (USDHHS Office of Inspector General, 2011). Besides potentially violating basic human rights, this practice is predictably ineffective and harmful (AGS, 2015a).

Donald Berwick MD, a former acting administrator of the Centers for Medicare and Medicaid Services and chief executive officer of the Institute for Healthcare Improvement, was one of the chief architects of the IOM report. He would have preferred his IOM colleagues take the concept of 'patient-centeredness' further than they did.

*"...we (patients, families, clinicians, and the health care system as a whole) would all be far better off if we professionals recalibrated our work such that we behaved with patients and families not as hosts in the care system, but as guests in their lives" (Berwick, 2009, p. w559).*

## PERSON-CENTERED APPROACHES

Although most healthcare professionals have not adopted the practice of treating patients as ‘guests in their lives,’ there is movement toward a more expansive understanding of ‘patients’ as people and the recognition that people are not continuously patients. A **person-centered** approach embraces a holistic bio-psycho-social-spiritual model of care. A person-

What is important to a person, including his or her goals and preferences, can be just as significant as his or her health status.

centered approach considers what is most important to the person, including his or her goals and preferences and seeks to actively promote well-being. For example, as a result of a recent policy change the Centers for Medicare and Medicaid Services (CMS) has begun requiring hospitals to provide patients with satisfaction surveys. Hospitals are gathering evidence and learning how important non-biomedical, psychosocial elements such as undisturbed sleep, watching a favorite TV show and a hair wash can be for well-being. Similarly, CMS is strongly encouraging nursing homes to abandon uniform schedules and instead allow residents to wake up, take their meals and go to sleep based on their own preferences.

In 2015, an interprofessional panel of healthcare experts convened by the SCAN Foundation and the American Geriatrics Society (AGS) developed a consensus definition of **person-centered healthcare and services for older adults** (AGS, 2015b) —

*Person-centered care means that individuals’ values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. This collaboration informs decision-making to the extent that the individual desires.*

It is noteworthy that two such respected organizations identified the need for a consensus definition as necessary to serve as a foundation for person-centered healthcare practices. As with the IOM’s *Crossing the Quality Chasm* report, older adults were not invited to

participate on the SCAN/AGS panel. Had older adults been included in this process, a somewhat different definition might have emerged.

Tom Kitwood, a geriatric psychologist from the U.K., is internationally credited as the father of applying the concept of person-centeredness based on humanism to dementia care.

Fundamental to Kitwood's theory was a rejection of the traditional medical approach to dementia and the belief that human beings are far more deeply affected by the social, emotional and environmental factors that surround them (Fazio, 2008). ). Kitwood and Bredin (1992) found the most disabling effects of cognitive impairment to be the threat to

The most disabling effects of cognitive impairment were found to be the threat to one's personhood — more than the actual functional impairment.

one's personhood — more than the actual functional impairment. From their extensive observations of people living with dementia, Kitwood and Bredin identified four global states needed for well-being: (1) personal worth/self-esteem; (2) sense of agency, the ability to control personal life in a meaningful way; (3) social confidence; and (4) hope.

In 2012, the Dementia Action Alliance (DAA) convened a group of thought leaders and people living with dementia to develop a consensus definition for **person-centered dementia care** including an operational framework for person-centered dementia care practices. A white paper, "Dementia Care: The Quality Chasm," details this information [[http://www.ccal.org/wp-content/uploads/DementiaCareTheQualityChasm\\_2-20-13-final.pdf](http://www.ccal.org/wp-content/uploads/DementiaCareTheQualityChasm_2-20-13-final.pdf)]. DAA's definition builds on Kitwood's and Bredin's formative work:

Person-centered dementia care and support is based on the fundamental belief that every person has a unique background, skills, interests and the right to determine how to live his or her own life. Person-centered dementia support is focused on nurturing the person's emotional, social, physical, and spiritual well-being. This is achieved through reciprocal, respectful relationships by:

- ❖ Valuing personal autonomy, choice, comfort and dignity;
- ❖ Focusing on the individual's strengths and abilities;
- ❖ Enabling opportunities for continuation of normalcy and growth of self; &
- ❖ Enhancing individual purpose, meaning, enjoyment *and belonging*.

Since developing the DAA’s consensus definition, SCAN/AGS conducted a systematic literature review to help inform their person-centered care work described earlier (Kogan et al, 2015). Six prominent elements of person-centeredness emerged from this review: holistic or whole-person care, respect and value, choice, dignity, self-determination, and purposeful living. All six of these elements are embedded in the DAA’s person-centered definition.

The first element for person-centeredness that emerged from the systematic literature review — holistic or whole-person care — is indeed noteworthy. Person-centeredness is based on a ‘holistic or whole-person’ orientation that, by definition, is bio-psycho-social-spiritual and not singularly medical.

It is not possible to achieve person-centered outcomes solely with traditional medical approaches. This is hugely important and bears repeating — **it is not possible to achieve person-centered outcomes solely with traditional medical approaches.**

It is not possible to achieve person-centered outcomes using the traditional medical approach to care.

As previously described, person-centeredness holistically encompasses all dimensions of well-being as opposed to a singular focus on physical health. To illustrate the difference, traditional medical practitioners view actions exhibited by people living with dementia as ‘behaviors’ while person-centered practitioners view these actions as ‘personal expressions’. While the word ‘behavior’ itself is benign, when used to describe actions exhibited by people living with dementia, it implies undesirable conduct. Since the very nature of dementia includes changes in cognitive abilities, emotions, and functions, actions — or the term the DAA recommends ‘personal expressions’ — should be anticipated and expected rather than considered to be undesirable conduct. The practice that considers actions expressed by people living with dementia as ‘behaviors’ is not person-centered while the practice that considers these actions as ‘personal expressions’ is.

While some may feel that this is no more than a matter of semantics, the words used are an indicator of the orientation of the practitioner. For instance, traditional medical practitioners address personal expressions exhibited by people with dementia from the mindset as



pathological behavior requiring an intervention - either pharmacologic or non-pharmacologic. The very nature of dementia includes changes in cognitive abilities and functions and potential alterations in how internal desires, feelings, and experiences are communicated. The classification of a response as “needing a non-pharmacologic intervention” medicalizes ‘living’ with a chronic condition and can debase the person’s humanity.

The person-centered approach addresses personal expressions by considering all causal factors including social and environmental considerations, pain, boredom, frustration, anxiety, and noise disturbances among other possible causes. Person-centered practitioners recognize personal expressions as a means of communicating/conveying needs that then require them to decode and understand the need. A 2012 radio program in Denmark with leaders in dementia care noted that outbursts by people with dementia were rare and when they did occur, were considered a failure of understanding or responding to the person’s need and not a disease process (Wells, 2012).

Playing soothing music and taking a walk to calm someone with dementia who has become restless are considered by traditional medical practitioners as non-pharmacologic interventions (Medeiros & Basting, 2013). The idea of considering music or a walk as an ‘intervention’ misses the mark altogether — these activities are part of usual human life and are shared by all people. Dementia may undermine a person’s ability to initiate such activities but not his or her enjoyment of them. In place of biomedical concepts and treatments, what is needed instead is a full understanding of the condition, compassion, skill in building strong relationships, and a mindset of trial and error to figure out solutions and best actions. Among many traditional healthcare practitioners there is even resistance to considering non-pharmacologic interventions because there is limited empirical evidence in the biomedical research literature to support their efficacy, and because they do not fall within their skill set.

“My conclusion is that non-pharmacological interventions as they are most commonly applied are attempts to provide person-centered care from a biomedical mindset. As such, it is only a half-hearted paradigm shift, and so it falls short.” (Power, 2015).

People living with dementia are speaking out publicly and explaining that the experience of dementia is dynamic and fluid and not, as typically portrayed, a progressive, irreversible decline in one’s humanity (Mitchell et al, 2011). Some individuals with dementia are describing that how others treat them can cause them distress and suffering. *“Our sense of wholeness and of hope is linked with how we and others view and judge our personhood (Malpas, 2012, p. 11).”*

## WELL-BEING

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“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being.” ~ Atul Gawande (2014, p. 259)

Dr. Gawande’s statement signals the need for a major departure from traditional biomedicine. Well-being is fundamental to the quality of one’s life. The oft-cited Preamble to the Constitution of the World Health Organization (WHO) defines well-being as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO, 1947). The goal of individual well-being transcends infirmity and is more comprehensively focused on all dimensions of humanness — mind, body and spirit.

The goal of individual well-being transcends infirmity and is more comprehensively focused on all dimensions of humanness — mind, body and spirit.

Well-being is ‘true north’ on the compass point for person-centeredness. There are many definitions of well-being but there is not one definition that is widely accepted. In order to have a common basis to understand and discuss well-being for people living with dementia, we offer a definition that builds upon the WHO’s Preamble and the definition of well-being used by The Eden Alternative: **Well-being** — *a state of mind, body and spirit identified by seven primary domains including personal identity, connectedness, security, autonomy, and opportunities to experience meaning, growth and joy.*

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*“We often hear of cancer survivors, people who have defied the odds by lasting much longer than doctors have expected them to. And we applaud their bravery, their courage, in this struggle to survive. But when we people with dementia don’t decline as quickly as you think we should, or seem to last longer and speak out for longer and to be active, then you question our diagnosis...Why can’t you cheer the dementia survivors? Maybe many of us would survive better and longer if we did not have to battle against the stereotype of dementia. Maybe many of us find it easier to give up and act like you expect us to, not speaking much or really ‘being there’.”*

Christine Bryden, (2005, p. 50)

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Christine Bryden raises fundamental questions that go to the heart of well-being and living fully with dementia.

Why doesn’t society cheer for people with dementia who are living full and meaningful lives? Why do those with dementia have to battle against stereotypes when their

energies could best be deployed focused on living well with this chronic health condition? For example, Richard Taylor was frequently questioned about whether he actually had dementia when his cognitive decline didn’t follow the average trajectory some people imposed on him.

“Maybe many of us find it easier to give up and act like you expect us to, not speaking much or really ‘being there’.”

Christine and Richard were early self-advocates speaking out against the stigma that marginalized and devalued them. These and other pioneering self-advocates have catalyzed a new generation of people living with dementia and their families and friends to demand change. They are teaching the world how to live full and purposeful lives with dementia.

What if dementia was viewed as a disability and people living with dementia as “differently-abled” rather than hopelessly damaged? Dementia may indeed shorten life expectancy, but it is a long-term condition and there continues to be much life to live. A ‘differently-abled’

perspective on dementia is oriented to well-being and making adaptations that support living as fully as possible.

‘Living well’ with dementia or other health conditions does not necessarily mean ‘well’ in the medical sense, i.e. free of disease. Kate Swaffer views dementia as a disability explaining, *“It means others enable me to live the best life possible”* (Swaffer, 2015). When she decided to earn a degree at the University of South Australia after being

Living well with dementia does not necessarily mean ‘well’ in the medical sense, i.e. free of disease. “It means others enable me to live the best life possible.”

diagnosed with young on-set Alzheimer’s, she met with a Disability Adviser who worked with her to develop a Disability Access Plan. *“This Access Plan evolved as the symptoms demanded, changing in the same way it would if I had an acquired brain injury, or a disease like multiple sclerosis where symptoms are regularly changing. I was treated as a whole person, with support for the disabilities”* (Swaffer, 2014b, p. 3). Kate went on to earn three degrees — two Bachelor’s degrees and a Master’s.

People with disabilities endeavor to lead self-affirming lives and define themselves according to their personhood (ideas, beliefs, hopes and dreams) and not have the disability viewed as their sole-defining feature (Sweeting & Gilhooly, 1997). Dementia defines only one aspect of a person’s humanness. *“I am Richard who seeks to live a purposeful and purpose filled life up to and through my last breath”* (Taylor, 2009). Brian LeBlanc has a succinct and telling saying — *“I have Alzheimer’s, but it doesn’t have me”* (LeBlanc, 2016).

Depending on the form of dementia, many executive function abilities may be lost fairly early on in the condition. Executive functions are brain-controlled abilities such as judgment, problem solving, task initiation, planning, organization, and prioritization. Some impairments in executive function are subtle and difficult to detect. For example, it took losing 40 pounds for Brian LeBlanc, who learned he had Alzheimer’s disease a year ago, to realize he was forgetting to eat during the day when he was by himself. He set up a daily reminder on his smart phone to prompt him to eat lunch. While Brian was able to easily program his phone reminder and

is a master at social media, tasks many people who do not have dementia have difficulty with, he needed compensatory help with this executive function to remind him to eat lunch.

Brian and his wife, Shannon, are taking a proactive approach to living with his dementia. First, the effects of Brian's dementia caused him to forget to eat lunch when he was by himself. His reaction was to find a way to solve the problem rather than dwell on the fact that his brain wasn't triggering him to eat. Brian's wife thought that programming his phone as a reminder was great which made him feel good and productive. Brian and his wife could have responded quite differently such as the following scenario. Instead of being proactive about lunch, Brian ruminates over this cognitive change and worries about what other abilities he may soon lose. He confides his worries to his wife, who becomes concerned. Brian's worry is reinforced by his wife's concerns. Rather than being proactive and solution-oriented, they both expend energies being worried and concerned about something they cannot control.

Brian and his wife are instinctively attuned to being proactive and supportive. Understandably, not everyone is so attuned. Education about the impact and beneficial effects being proactive can have on living with dementia provides a valuable lesson about this component of well-being.

While there has not been specific research focused on studying the effects of positive emotions and dementia, there are abundant anecdotes from people living with the condition about the benefits and values of being positive and proactive. Researchers have found beneficial effects of positive thoughts and emotions in general populations and there is vast scientific literature on how negative emotions harm the body. Some health benefits that positive thinking may provide include (Mayo Clinic, 2016):

- ◆ Lower rates of depression
- ◆ Lower levels of distress
- ◆ Better psychological and physical well-being
- ◆ Better coping skills during hardships and times of stress

WORDS MATTER

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*“The words we use not only strongly influence how others treat or view people with dementia, perhaps more importantly, words can impact how individuals view themselves and relate to others...*

*Words have the potential to promote and empower, enable and increase self-esteem, and encourage one’s ability to self-help, or words can demean, devalue, disrespect and offend”*

Swaffer, 2014a, p. 710

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Many of the words used to describe dementia continue to focus on the loss of abilities experienced by the person living this condition. Focusing only on losses promotes misperceptions and fosters a culture of treating people with dementia as diminished. One nationally acclaimed dementia caregiver training program uses the term ‘demented’ throughout embedding discriminatory perceptions about dementia among new learners.

Use of stigmatizing language fosters a culture of treating people with dementia as diminished.

“Escaping dementia doesn’t mean we escape the 100 percent terminal condition of being human, words count. This article included fear-drenched language: ‘robs,’ ‘dreaded,’ ‘erosion,’ ‘nightmare,’ ‘burden’ and ‘in some ways worse (than death)’” was Nicole Burton’s Letter to the Editor reaction to an article about Alzheimer’s published in *The Washington Post* (Burton, 2015). *“The term ‘demented’ is horrendous; it implies something which is not even human,”* commented Ann Johnson, a person living with dementia (Sabat et al, 2011, p. 295).

There are precedents for addressing harmful language through public policy. For example, Rosa’s Law, federal legislation passed in 2010, was created for the purpose of addressing the pejorative use of the word ‘mentally retarded’ (GPO, 2010). Rosa’s Law mandates the use of

the term 'intellectual disability' instead of 'mentally retarded' in federally connected work. Many of the words and terms used today for and about people living with dementia, such as 'victim,' 'sufferer,' and 'demented,' are the discriminatory equivalent of 'mentally retarded'.

In advance of co-hosting the 2015 Alzheimer's Disease International conference, Alzheimer's Australia published "Dementia Language Guidelines" in order to draw attention to this important issue. Building upon the strong work of Alzheimer's Australia and conducting many interviews with people living with dementia about appropriate and preferred language, the DAA published an online guide, "Living Fully with Dementia: Words Matter (<http://daanow.org/living-fully-with-dementia-words-matter>).

Traditional medically-based terms such as '*symptoms*,' '*interventions*,' and categorizing interventions as being either '*pharmacologic*' or '*non-pharmacologic*' are viewed by many people living with dementia as well as reform-minded advocates as dehumanizing and marginalizing because the words reduce people to their pathologies. It debases humans to reduce their experience of living with a chronic health condition to medicalized terms.

For example, in the traditional medical context a kind word or a gentle touch is viewed as a 'non-pharmacologic intervention'. The marginalizing term 'non-pharmacologic intervention' is in stark contrast to the caring, relational aspect of the kind word or gentle touch action that can and should be part of ordinary human exchange. A 'non-pharmacologic intervention' is not the appropriate mindset to address fundamental

'Individualized approach' focuses on a comprehensive understanding of the individual and their condition, the building of strong relationships, compassion and having a mindset of trial and error to determine the best courses of action.

human needs whether the person has dementia or not. The DAA recommends using the person-centered phrase 'individualized approaches' instead of 'interventions'. 'Individualized approach' focuses on a comprehensive understanding of the individual and their condition, the building of strong relationships, compassion and having a mindset of trial and error to determine the best courses of action.

The term '*behavioral and psychological symptoms of dementia*' (BPSD) (Osser & Fischer, 2013) is frequently used by healthcare practitioners, researchers, and policy-makers. This term is another example of the stigmatizing nature of medically-based words. While the word 'behavior' itself is benign, as noted previously, when used to describe actions exhibited by people living with dementia it implies undesirable conduct. The term is not appropriate as it reduces a person's reactions and behaviors to his or her dementia condition without considering causes of distress including relational and environmental factors. Christine Bryden suggests retaining the acronym BPSD but changing what it stands for to ***bio-psycho-social distress*** (BPSD) (Bryden, 2015). Not only is this term more precise, but it can serve as a reminder to determine the cause of the distress rather than assuming the behavior is simply an aspect of the dementia condition. The actions of persons with dementia express important aspects of their experiences in the world.

Instead of BPSD standing for 'behavioral and psychological symptoms of dementia,' Christine Bryden recommends retaining the acronym but change what it stands for to '**bio-psycho-social distress**'.

Another word issue concerns the ubiquitous and seemingly interchangeable use of the term 'Alzheimer's' to refer to any symptoms of dementia. While Alzheimer's is the most prevalent type of dementia, there are other types of dementia with high incidence rates such as Lewy Body dementia that affects over 1 million Americans (Lewy Body Dementia Association, 2015). Some other common forms of dementia include vascular and frontotemporal dementia. The DAA recommends the use of the term 'dementia' as it is inclusive and does not favor, bias, or overlook any type or causes of dementia.

Depending on the stakeholders, a variety of terms can be used for the 'person-centered' and relational context including 'person-directed,' 'resident-centered,' 'person-focused' and 'relationship-centered.' The most common term used and recognized globally is 'person-centered.' To avoid using a term not yet widely recognized, the DAA has decided to use the term 'person-centered', but relationship-centered and other terms may be equally or more appropriate.

Some people feel strongly about including the word ‘family’ and use the term ‘person- and family-centered’ to acknowledge the value and inclusion of family. However, the word ‘family’ can be perceived as limiting, since some people may not have ‘family’ while others may feel more emotionally connected to ‘friends.’ In addition, the word ‘family’ excludes the relationship bond that can exist with paid care partners. The DAA’s definition of ‘person-centered’ embeds *all valued others* since a person’s social network is a vital aspect of his or her well-being.

One final but important comment about words. The DAA recommends the full term **bio-psycho-social-spiritual** over bio-psycho-social. Since George Engel’s time, the spiritual dimension has become widely recognized as an important aspect of health and well-being (Davison & Jhangri, 2010). Some people may bristle at its inclusion based on a sense that ‘spirituality’ connotes religion. However many people view spirituality in a much broader context: immersion in art, music, loving community, service to others, and nature are among the experiences that allow humans to feel deeply connected to something larger than themselves. As such, the DAA believes that spirituality is an important element in in the holistic bio-psycho-social-spiritual framework.

TRANSITIONING TO A BIO-PSYCHO-SOCIAL-SPIRITUAL CULTURE

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*“We’re caught in a transitional phase. However miserable the old system has been, we are all experts at it. We know the dance moves. With this new way, in which we together try to figure out how to face mortality and preserve the fiber of a meaningful life with its loyalties and individuality, we are plodding novices. We are going through a societal learning curve, one person at a time.”*

Atul Gwande, (2014, p. 193)

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As science advances, many beliefs about dementia are changing. It used to be believed, for example, that neural brain cells were not able to regenerate. It is now known that neural brain cells do, indeed, regenerate (neurogenesis). The emerging science of neuroplasticity is discovering ways neural reserves can possibly be ignited to generate new neural connections to bypass neural areas impaired by dementia pathology. Formerly, all types of cognitive impairment were believed to progress to an advanced stage. This is now known to be untrue; mild cognitive impairment, for instance, does not always progress to dementia.

Some areas of healthcare such as childbirth and cancer treatment have already begun the transformation to a bio-psycho-social-spiritual culture of care. If knowing that traditional medical practices can marginalize people living with dementia is insufficient rationale for changing the culture of dementia care, compelling demographic and financial realities should provide the tipping point.

The U.S. is experiencing unprecedented growth in the number of aging Americans overall and especially individuals who have dementia. One in nine people 65 and older are estimated to be living with dementia — over 5 million Americans (Alzheimer’s Association, 2015). Approximately 10,000 baby boomers in the

Dementia has become the most expensive healthcare condition in the U.S., costing more than heart disease and cancer.

U.S. turn 65 every day and this will continue at this pace for the next 15 years meaning the numbers of Americans living with dementia will continue to greatly increase over this period (Pew Research Center, 2010). Dementia has become the most expensive healthcare condition in the U.S., costing more than heart disease and cancer (Hurd et al, 2013).

Transforming the medical culture of care to one that supports life affirming well-being is not as simple as flipping a switch; it will require strategic, coordinated actions and resources at both the public and private sector levels. The U.S. faces a number of challenges greatly hampering transition efforts: (1) insufficient political will to bring about transformative changes; (2) lack of public and/or private funds to support the work to lead and conduct coordinated public-private efforts; (3) absence of public and private sector leadership to guide the work; and

(4) strong resistance from adherents to the traditional medical culture within practice, policy and research sectors. In addition, the long-term political dysfunction miring the U.S. Congress and, by extension, the federal administration offers little hope that political enterprise will be a catalyst to advance transformative change anytime in the near future.

The Obama Administration has nevertheless successfully initiated a number of important efforts that will impact the culture of U.S. healthcare, including:

- The landmark passage of the Affordable Care Act (ACA) legislation in 2010 includes some elements aimed to begin transforming the traditional medical culture of care (ACA, 2010).
- A January 2014 CMS final rule to states requires service provider recipients of monies for home and community-based services (HCBS) under Medicaid's 1915(c) waiver program, 1915(i) state plan option, and 1915(k) Community First Choice to implement a person-centered planning process that reflects clients' preferences and goals (Federal Register, 2014).
- Current CMS efforts to revise the conditions for participation for nursing homes that receive federal dollars (Federal Register, 2015). The proposed revisions will be the most wide-sweeping nursing home reforms since the Omnibus Budget Reconciliation Act (H.R. 3545, OBRA 1987). A key aspect of these reforms embeds person-centered practices into nursing home operational culture.

These are laudable achievements that admirably represent progress. Other federal efforts, however, remain deeply rooted in the non-person-centered, traditional medical culture including:

- **National Alzheimer's Project Plan (NAPA)** signed into federal law in 2011 (GPO, 2011) created mandates to address Alzheimer's in the U.S. As previously noted, the initial Advisory Council excluded the stakeholder category of people living with dementia and still includes only one person living with dementia. This is discriminatory and marginalizes arguably the most important stakeholder category. Additionally, although person-centered practices are considered the global standard

by the World Health Organization and the Institute of Medicine and other notable organizations, the first NAPA National Plan released in 2012 and all annual Plans since are silent in appropriately addressing person-centered practices.

- The **Administration on Community Living (ACL)**, an agency within the U.S. Department of Health and Human Services, is developing its first person-centered train-the-trainer program for the aging and disability sectors. Despite advocacy support for including older adults and people living with disabilities including dementia (among other person-centered experts) in an advisory capacity, the ACL only sought input from their consulting contractors in developing the materials. This action is especially ironic given the ‘person-centered’ nature of the materials developed.
- CMS launched a national initiative in 2012, the **National Partnership to Improve Dementia Care**, focused on improving and expanding the use of non-pharmacologic approaches to care and reducing antipsychotic medication use for long-stay nursing home residents with dementia. CMS set a goal of a 20% reduction of antipsychotics by the end of 2014. While a 19.4% nationwide reduction was achieved by the close of 2014, the reduction in antipsychotic usage resulted mostly from trimming prescriptions rather than addressing the causes of personal expressions. Instead of using reduction goals to incentivize changes in care practices, CMS simply established new goals for nursing homes: a 25% reduction by the end of 2015 and a 30% reduction by the end of 2016. There is both concern and anecdotal evidence that reductions in antipsychotics are being achieved by switching to prescribing a different class of mood altering drugs.

CONCLUSION AND RECOMMENDATIONS

Almost 40 years ago, Dr. George Engel started ringing the warning bell for the need to transition to a more integrated, holistic bio-psychosocial model of care. The IOM recognized the problems caused by impersonal and fragmented traditional medical care in its landmark 2001 report, “Crossing the Quality Chasm.” Since then, other nationally recognized physicians such as Donald Berwick and Atul Gawande have rung the bell for needed change, yet impersonal and diminishing traditional medical mindsets and practices continue almost unabated.

While recognizing that society in general and the healthcare system in particular have not intentionally set out to harm or diminish people living with dementia and those who care about them, the lack of concerted efforts to change harmful and diminishing behaviors and practices has the same effect as being intentional. There is no time to delay. As already noted, 10,000 baby boomers a day for the next 15 years are turning 65. One in nine of them will learn they have some form of dementia. Additionally, many people younger than age 65 are learning they have an early on-set form of dementia. Even if the humanistic and human rights concerns are not sufficient motivation, the fact that dementia has become the most expensive healthcare condition alone should propel our nation’s leaders to immediately address current attitudes, practices and the need for dramatically increased funding for care, cure and treatment. Knowing better demands that we, as a nation, must DO better.

Knowing better demands that we, as a nation, must DO better.

Where to start? Looking historically, HIV/AIDS is a strong example of a community that came together around a health condition and was highly successful and effective in obtaining ample funding resources and that changed medical mindsets and societal attitudes, improved care practices, and developed a comprehensive infrastructure for the care, treatment and support for people to live fully with the condition. The federal government’s funding allocation for HIV in 2016 is more than \$25 billion: \$18.4 billion for support, care and treatment; \$3.2 billion for cash/housing assistance; \$2.9 billion for research; and \$800 million for prevention (Kaiser Family Foundation, 2015). The 2015 HIV funding allocation represents an increase

of almost \$5 billion dollars over the past five years alone. Breast cancer is another example of a health condition whose advocates have been effective in garnering attention, heightened awareness, education and funding to foster change and improvements for that condition.

The 2016 federal government funding allocation for dementia is a historic high of \$936 million (Alzheimer's Association, 2015). There are currently 1.2 million Americans living with HIV compared to over 5 million Americans living with dementia. How is it that dementia, a health condition with almost five times the number

How is it that dementia, a health condition with almost five times the number of Americans affected than HIV, receives so much less federal funding?

of Americans affected than HIV, receives so much less federal funding? There are a number of factors that make HIV more politically compelling for the disproportionate federal funding than dementia.

Initially the methods of transmission of the HIV/AIDS virus (e.g., unsafe sex, intravenous drug use, tainted blood transfusions) were not understood causing widespread alarm that anyone could be infected. Until treatments were found, the highly contagious virus infected a wide age range of people including newborns and young children and the course of the virus from infection to death was fairly short. There were heart-wrenching, emotionally captivating stories about young children affected. Few will forget the gripping story of Ryan White, a 13-year old hemophiliac who contracted the HIV/AIDS virus through a blood transfusion. Ryan came to national attention after being barred from attending public school because of fear of transmitting the virus. This charismatic young man, who died when he was 18, won America's hearts including lawmakers. In 1990 the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act was signed into law. The legislation has been reauthorized four times since — in 1996, 2000, 2006, and 2009 — and is now called the Ryan White HIV/AIDS Program. The Program is funded at \$2.3 billion for 2016.

Unlike HIV/AIDS, the majority of people affected by dementia are older adults. While being a highly distressing behavior, society, nonetheless, appears to place a much lower value on older adults as compared with younger populations. This is likely because older adults are in life's twilight years and older adults are not actively contributing as much to society during their later years. Another difference is dementia is not a transmittable condition. While the causes of the various forms of dementia are not yet clearly known, it is not an infectious condition. Thus, people are not panicked about being infected as was and continues to be the case with HIV/AIDS.

During the peak years of the HIV/AIDS epidemic, people affected with the condition as well as many family members, friends and other advocates took to the streets in non-violent media-visible civil protests to demand attention and dollars. Although there are over 5 million people in the U.S. living with dementia, they and their advocates have not turned out on-mass and have yet to get the attention of our nation's leaders, even though there has been significant media attention about the dementia crisis facing our nation. While elderly individuals with dementia are unlikely to take to the streets in civil protest, there are an estimated 200,000 Americans living with younger onset forms of dementia (Alzheimer's Association, 2015) which is comparable to the number of people affected by HIV/AIDS at the height of those protests.

The lack of dramatic media-visible civil protests have relegated dementia advocacy efforts to almost invisible status for society in general and for elected federal and state officials in particular. The media spotlight on the recent Ebola crisis illustrates the power of media to generate a national response. In remarkably fast turnaround, President Obama and the U.S. Congress created and passed legislation authorizing \$5.4 billion in emergency funding to address Ebola. The actual number of Ebola cases in the U.S. can be counted on one hand making the largesse of the federal funding response especially baffling.

There is a robust and diverse dementia community of organizations, coalitions and initiatives dedicated to dementia in the U.S. including the Alzheimer's Association, the Alzheimer's Foundation of America, the Association for Frontotemporal Degeneration, the Dementia Action

Alliance, Dementia Friendly America, LEAD (Leaders Engaged in Alzheimer’s Disease), the Lewy Body Dementia Association, UsAgainstAlzheimer’s, and state-based initiatives such as ACT on Alzheimer’s in Minnesota. Imagine what could be accomplished if all these entities collaborated and marched together, hand-in-hand, in civil protest on Capitol Hill versus each group speaking to the members of the U.S. Congress individually.

The DAA believes that it is time to: garner ample federal funding for dementia supports, care, services, treatment and research for prevention and cure; address and work to eliminate dehumanizing, stigmatizing and discriminatory attitudes and practices; develop a comprehensive infrastructure for the awareness, education, support, services and care needed so people can live fully with the condition; and transform the traditional medical systems and practitioners’ culture and practices to address the humanistic needs of people and families affected. The Dementia Action Alliance stands ready to collaborate with all willing to make a united effort a reality.

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*“We seek to work towards transforming our culture to one honoring human dignity...Let’s be companions together on this journey.”*

Friedell and Bryden, 2001

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APPENDIX I

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APPENDIX II



Person-Centered Dementia Values and Principles

- ◆ I am a person*. Know me and relate to me as a person with a unique background, life history, interests and capabilities. [*Words matter. When you call me a ‘patient,’ ‘victim,’ or ‘sufferer,’ I feel minimized.]
- ◆ Understand that my autonomy, choices, dignity, reciprocal relationships, privacy and self-determination are fundamental to my well-being.
- ◆ Support my holistic emotional, social, physical and spiritual dimensions.
- ◆ Promote ways I can continue to experience personal growth and development through purpose, meaning, relationships and enjoyment in my daily life.
- ◆ Recognize that my personal goals, measures of success and interests may change over time and may not be the same as yours.
- ◆ Recognize that choice may have risks — a normal part of everyone’s life.
- ◆ Partner with me, utilize my strengths and provide the right amount of support and opportunities I need to achieve my goals.
- ◆ I am trying to communicate the best I can; understand that my verbal and physical expressions are my way of communicating. I may say or do something I regret.
- ◆ Understand that my personhood may become increasingly hidden but not lost.
- ◆ Place my needs before tasks and understand that we need to work together at my pace.
- ◆ Help me stay connected to what is important to me.

The DAA “Person-Centered Dementia Values and Principles” were inspired by the Pioneer Network’s set of Values and Principles.

