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## Ministry with People in the Second Half of Life

### Part One

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Photo courtesy Luther Manor, Wauwatosa, Wisconsin

*The first of a two-part series covering everything from substance abuse, dementia, and Alzheimer's Disease to forgiveness, legacy, narrative theology, and the invaluable role congregations play in older adult ministry.*

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# Caring Connections Vol11 No3 Editorial

## EDITORIAL

**Don Stiger**

In just two months, I will turn 63. Did I just write “63”? How can that be?!

Like so many fellow baby boomers, I still feel about 35. And yet, there can be no denying the empirical confirmations: eligibility for Social Security, the ‘empty nest’, that welcomed discount at McDonalds, those two nightly trips to the bathroom ... you know the litany.

Despite internally feeling that my body is still back in the 1980s, I’m now externally regarded as a “senior,” an “older adult,” even an “elder.” In other words, like most boomer colleagues reading this editorial, I’m well into the second-half of life; in reality, more like the fourth quarter of life.



I have lots of questions. Will this final season be filled mostly with blessings or burdens? Or, will it be much like the same unpredictable mix of blessings and burdens I experienced 30 years ago? Will I become a burden to others? Will these last decades of life be experienced much like that which The French philosopher La Rochefoucauld described: “As we grow old, we become both more foolish and more wise?” Maybe it will mostly reflect what one of my cherished mentors, Joan Chittister, OSB, describes of her own experience of aging: “These are the capstone years, the time in which a whole new life is in the making again” (*The Gift of Years*). Or, will I be more realistically prepared by heeding some rather sobering words from Susan Jacoby (*Never Say Die*): “Inflated expectations about ‘successful aging’ can lead to real despair...we need to pay less attention to expensive fantasies (of aging) ... we cannot continue to base our image of old age on the extraordinary person, blessed by a combination of affluence and physiological hardiness, who remains ‘sharp as a tack’.”

Amidst these relative unknowns, at least two things remain clear and certain. They bring comfort and meaning. One, I certainly won’t be alone in the journey. As cited in the most

recent issue of *The Atlantic*: “The number of Americans 65 or older - 43 million today - could reach 108 million in 2050. That would be like adding three more Floridas, inhabited entirely by seniors(!). The 'oldest old' cohort, those 85 and older, may increase at least fivefold, to more than 6 percent of U.S. citizenry. Social Security will rack up \$8.3 trillion in unfunded obligations.”

Secondly, it's my fervent hope to both actively give and receive meaningful, life-giving forms of care throughout the remaining journey ahead: whole-person care that touches and blesses our God-given coherence of mind, body, and spirit. I continue to believe that God's love and presence reside at the very heart of that same care. That really matters to me, as I know it does countless others. And that's really what the following, back-to-back issues of *Caring Connections* are all about.

I write “back-to-back” because, thanks in large part to the exceptional initiatives of Brian McCaffrey, member of the *Caring Connections* Editorial Board, a veritable cornucopia of articles, book reviews, and other resources have come pouring in to Chuck Weinrich and myself - all shining light on some dimension of the bio-psycho-social-spiritual realities of aging. Though all inform pastoral/spiritual care, we decided to ‘bundle’ those more focused on physical, behavioral, and relational dimensions in this particular issue, followed by those more centered on theology and spiritual care in the succeeding issue. The rich offerings you will discover in this two-part series cover everything from substance abuse, dementia, and Alzheimer's Disease to forgiveness, legacy, narrative theology, and the invaluable role congregations play in older adult ministry.

As we often share in New York City, “L'Chaim”. Here's “to life”! And here's to the most fulfilling second half of life each of us can experience.

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As always, if you haven't already done so, we hope you will subscribe online to *Caring Connections*. Remember, subscription is free! By subscribing, you assure that you will receive prompt notification when each issue of the journal appears on the *Caring Connections* website. This also helps the editors and the editorial board to get a sense of how much interest is being generated by each issue. We are delighted that the numbers of those who check in is increasing with each new issue. Please visit [www.caringconnectionsonline.org](http://www.caringconnectionsonline.org) [1] and click on “Click here for free subscription” to receive automatic notification of new issues..

Finally, when the Inter-Lutheran Coordinating Committee disbanded a few years ago, the money from the “Give Something Back” Scholarship Fund was divided between the ELCA and the LCMS. This endowment makes a limited number of financial awards available to individuals seeking ecclesiastical endorsement and certification/credentialing in ministries of chaplaincy, pastoral counseling, and clinical education. Applicants must:

- Have completed one [1] unit of CPE.
- Be rostered or eligible for active roster status in the ELCA or the LCMS.
- Not already be receiving funds from either the ELCA or LCMS national offices.
- Submit an application, along with a financial data form, for committee review.

Applicants must complete the Scholarship Application forms that are available from Judy Simonson [ELCA] or John Fale [LCMS]. Consideration is given to scholarship requests

after each application deadline, August 15 and February 15. Email forms to Judith Simonson at [jimmonson@pennswoods.net](mailto:jimmonson@pennswoods.net) [2] and to John Fale at [John.Fale@lcms.org](mailto:John.Fale@lcms.org) [3].

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# Caring Connections Vol11 No3 - Letters

## Letters

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### Correspondence regarding our last issue - Vol 11 No2.

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Dear Mr. Weinrich,

I have read through your most recent issue of *Caring Connections* ([Volume 11, number 2](#) <sup>[1]</sup>), and enjoyed it, particularly the view from multiple professionals, each of whom has a slightly different take on advance care planning.

Ms. Maser's piece for the Lutheran Services of America *Caring Connections* "Advance Directives: Relieving End of Life Anxiety for Individuals and Their Families" is a complete yet succinct review of advance directives. I have, however, identified a few errors that I want to share with you for your future awareness.

"Contrary to what the name implies, patients are not choosing treatments that will sustain or continue life; they are choosing which treatments they do not want at life's end, when recovery is no longer a medical possibility." This statement is incorrect. In order to be a form that complies with National POLST standards ([polst.org](http://polst.org)), Section A must include a choice of Yes OR No to DNR in case of cardiac arrest. Section B allows patients to indicate what level of care they prefer in case of other medical emergencies, and ranges from comfort care only through limited interventions to full medically indicated treatment.

The subsequent article by David McCurdy has it right: "It is common to assume that POLST orders always aim at limiting treatment. That assumption misplaces the emphasis. The POLST paradigm seeks first of all "to ensure that seriously ill or frail patients can choose the treatments they want or do not want" (National POLST 2014b). This could sometimes mean more treatment rather than less. For example, the form offers the option to elect rather than forgo CPR in the event of an arrest. Therefore a provider should always consult the form to see whether or not the physician has ordered that CPR be attempted."

Also, the addended chart has some incorrect information about Illinois: 1) the only AD that requires 2 signatures now is the LW. POAHC only requires one. 2) Divorce does in fact invalidate POAHC in Illinois:

(755 ILCS 45/2-6) (from Ch. 110 1/2, par. 802-6)

Sec. 2-6. Effect of disability-divorce. (a) All acts of the agent within the scope of the agency during any period of disability, incapacity or incompetency of the principal have the same effect and inure to the benefit of and bind the principal and his or her successors in interest as if the principal were competent

and not disabled. (b) If a court enters a judgment of dissolution of marriage or legal separation between the principal and his or her spouse after the agency is signed, the spouse shall be deemed to have died at the time of the judgment for all purposes of the agency. (Source: P.A. 85-701.)

Could you please pass this information on to Ms. Maser for her information? If, in addition, you feel any part of this warrants publication as a "letter to the editor," please feel free to do so.

Best wishes,

Julie Goldstein, MD  
Medical Director, Clinical Ethics and Palliative Medicine  
Advocate Illinois Masonic Medical Center, and Chair, POLST Illinois Task Force

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Dear Mr. Weinrich,

Thank you to Dr. Julie Goldstein for her readership and her interest in matters relating to Elder Law. I am grateful for the opportunity to respond to the letter she recently submitted in response to my article in the Vol. 11, No. 2 issue of *Caring Connections* Online.

The article's statement that, "Contrary to what the name [POLST] implies, patients are not choosing treatments that will sustain or continue life; they are choosing which treatments they do not want at life's end, when recovery is no longer a medical possibility," is not written to serve as an inventory of the content contained in a POLST form. Given that she proceeds in her letter to provide a list of items that appear in Sections A and B of the form, it appears that this is what Dr. Goldstein believes I am doing in the quote above.

What I am actually elucidating in my statement, and what Dr. Goldstein misses, is the confusion that stems from the acronym, "Physicians Orders for Life Sustaining Treatment." When doctors tell patients that it is time to complete a POLST form, it is not because his or her life is to be sustained. The situation is quite the opposite – doctors complete POLST forms with their patients when death is imminent. In fact, polst.org acknowledges that these forms are meant to address treatments that "the patient would like to receive at the end of his/her life" ([www.polst.org/about-the-national-polst-paradigm](http://www.polst.org/about-the-national-polst-paradigm) [2]), even though the name, "POLST," suggests otherwise. What I am ultimately proposing in my aforementioned statement is that a more appropriate name for the POLST would better clarify for its users the impending outcome.

When faced with the issue that POLST forms are completed when the patient is hurt or ill, under duress, possibly working against the clock, and utilizing a confusing document to boot, it becomes clear that Advance Directives, which are freer in form and executed when a person is healthy and clear-minded, are better for expressing a patient's wishes. This is why I argue that readers should execute an Advance Directive and that doctors ought to utilize a POLST form strictly on the condition that the patient has no Advance Directive available.

Dr. Goldstein also notes that Mr. David McCurdy accurately portrays in his article the POLST's form and function when he writes,

It is common to assume that POLST orders always aim at limiting treatment. That assumption misplaces the emphasis. The POLST paradigm seeks first of all "to ensure that seriously ill or frail patients can choose the treatments they want or do not want" (National POLST 2014b). This could sometimes mean more treatment rather than less. For example, the form offers the option to elect rather than forgo CPR in the event of an arrest. Therefore a provider should always consult the form to see whether or not the physician has ordered that CPR be attempted.

I agree with Dr. Goldstein that this excerpt is useful for understanding the POLST. As Mr. McCurdy notes, the key component is getting a patient's wishes on paper for doctors to follow, not to limit treatment. However, Mr. McCurdy's explanation does not highlight anything that the POLST is capable of accomplishing beyond that which is achieved by an Advance Directive, and considering the advantages that Advance Directives hold over the POLST, I will continue advocating their use.

Last but not least, additional thanks are due to Dr. Goldstein for her information regarding Advance Directive laws in the state of Illinois. As is emphasized in the article, it is best to consult with an Elder Law attorney since Advance Directive laws vary from one state to the next.

Sincerely,

Kris L. Maser

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# Caring Connections Vol11 No3 - Shabahangi

## The Poetics of Aging

Nader Robert Shabahangi

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**To call aging poetic seems, at first glance, an attempt to sugarcoat what is commonly regarded as a burden we humans need to bear.**

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Photo courtesy AgeSong

### Our Modern Day Attitude Towards Aging

If I look around, I observe a culture replete with reminders of such burden awaiting us with age and old age. Much of the public and political discourse talks about aging as a load we must carry, which costs us individuals and our society large amounts of money and resources. In short: our human race would be better off if we did not need to face this phenomenon called aging and had to get old.

Such an attitude stands in sharp contrast to the scientific understandings and wisdom traditions of human history. In fact, recent anthropological research shows that it is the rise of the elderly which was the main force in the so-called 'cultural explosion' establishing some 30,000 years ago our advancements in human civilization. How could it be otherwise? The more mature a person in years, the deeper the source of experience and knowledge this person can pass on to those younger in years. This insight deserves

emphasizing: the more a society affords us human beings to mature through the aging process, the more such a society advances in the achievement of what is commonly referred to as civilization.

Anthropologists Rachel Caspari and Sang-Hang Lee state this point in the carefully guarded language of the social sciences, namely that “the increase in adult survivorship would have considerable evolutionary impact.” Stressing the importance of transgenerational relationships, they continue to conclude the following: “Increased adult survivorship strengthens those relationships and information transmission by extending the time over which people can learn from older individuals and by the increase in the number of older people, which promotes the acquisition and transmission of specialized knowledge such as that reflected in the Upper Paleolithic.”

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**I believe - along with many others - that older people constitute the very foundation of our present civilization.**

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### **Elders – The Foundation of Our Civilization**

Following the assertion of these anthropologists, I believe – along with many others – that older people constitute the very foundation of our present civilization. To become an older person we need to age. Aging is the prerequisite to becoming older. That this needs to be stated in a language and fashion more becoming of a two year old child shows the degree to which the present equation of aging as undesirable has permeated our culture and, so it appears, all levels of human learning and intelligence. However, paraphrasing Friedrich Hoelderlin, the 18th century genius of a poet, danger itself gives rise to what can save us. The current rapid shift in demographics, also variably termed the population explosion among older Americans or the ‘time bomb’ exploding our global economy in the years ahead, might just present the answer needed to face the plethora of planetary, economic, and spiritual crises present today.

To be ‘saved’ from the danger of our glaring misunderstanding of the value of our aging process, to ‘hear’ the answer this shift in demographics offers us searching for new ways of coping and living in today’s world, requires us to listen to what this new development wants to express. From a phenomenological point of view – literally, allowing what manifests speak for itself – this means that our elder population has a message in need of being heard. It is my bias here that the values and priorities of old age, substantially different from those of our younger, formative years, present our society with some of the potential answers able to save what we can of planet and people. I call the required attitudinal shift this viewpoint requires ‘the poetics of aging’. It is a shift that understands aging as maturation and elderhood as important and distinct a phase in human life as the phases of child and adulthood.

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**Using the metaphor of poetry, the many stanzas of our life undergo a continual process of re-writing and editing.**

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### **The Poetics of Aging**

The use of the word poetic derives its meaning from the Greek word *poein* which means to make, to create. In this sense all of us are poets who write the verses of our lives, specifically here the verses of our final years. Most good poems are composed of multiple stanzas that form a complete whole. Similarly, the

final years or verses of a human life are also needed to fully appreciate a person's poem of life. The recent emergence of the discipline of narrative psychology refers to us humans continually writing and rewriting our life stories in order to create meaning for ourselves. This implies that the way we understood our lives from the perspective of youth is different from the way we look at our lives when we are older. Using the metaphor of poetry, the many stanzas of our life undergo a continual process of re-writing and editing before we are ready to submit our final poem in our later years.

While the poetics of aging refers to the individual human being working creatively on their own process of aging, that is living, it also refers to the collective poem or story we are writing as a society. For individuals are not creating their stories in a vacuum. Rather, along with many people now entering the decades of our 'older years', we are also creating a poem together. Collectively new verses are formed expressing a changed awareness about life and living. This awareness and insight contribute to what some have referred to as the making of an elderculture, of presenting America with the potential to deepen, to become a wiser, more compassionate nation and people.

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**... priorities set by elders are shaped by a more mature understanding of life.**

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### **Understanding Life Differently**

The poetics of aging speaks to creating a new set of priorities for life. These new priorities are not meant to substitute the concerns of present day. Rather, they are meant to augment and enrich the often narrow and more surface oriented viewpoint of a culture based principally on values expressed through youth and materialism. This view marginalizes our human finitude and mortality, ignores the depth of the soul of the world, the anima mundi. As a result we remain unaware of what is otherwise important and essential for living our lives. In contrast to this constricted view, priorities set by elders are shaped by a more mature understanding of life. This understanding, made possible through this journey we call aging, is grounded in life experience. It is a process that entails a tempering of the human soul through the continual exposure to the vicissitudes of life, to the joys and sufferings no human can escape. A life that is poetic in nature awaits each new struggle with a receptivity that can already anticipate the richness such experiences will bring for the writing of the next verse. The poetics of aging shuns routine and monotony. It stays open to the richness of experience. It does not waste its suffering, does not neglect to celebrate its joys.

### **Towards a Sustainable Future for Planet and People**

The poetics of aging looks at our aging as the vital process necessary for humans to mature and deepen, to become truly wise and human. The process of aging allows for the time needed to make who we are, to 'create' what the world needs from us. This stance might just represent the saving element able to alter the destructive course we humans seem to have taken vis-à-vis ourselves and the planet, our home. Such a stance is foremost characterized by the understanding of our interconnectedness to all life, that at our hidden core we discover an essential relationship to all beings. This discovery brings forth a deep recognition that as we harm the outer world, so we harm our own selves. As we look at the world through eyes of love, we nurture and love our own selves. Corollary, as we destroy life, we destroy our own being. The old dictum 'as without so within' expresses this reciprocity. Categories of outer and inner wane, labels intend to describe what shows itself to us dissolve.

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**For only if we suspend our desire and belief**

## **in knowing does what we call 'awe' appear.**

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The very idea of knowledge able to illuminate the unfathomable mystery of our existence has turned into a fable. Elders have learned the important statement of "I do not know." The awareness of not knowing turns into an attitude towards life and world perhaps best captured with the word 'awe'. For only if we suspend our desire and belief in knowing does what we call 'awe' appear. As we stand in awe facing the mystery of our own being and of Being itself, our senses and sensibilities now experience what presents itself to us as the miracle it really is. Once we allow ourselves to experience the miracle of life, we stop manipulating others and ourselves thinking we know best about directing our lives and filling our needs. We stop harming others. We begin relating and connecting with what is in us and with what is around us. Along with St. Francis, all of nature, inner and outer, begins to be seen as a mirror of the divine.

### **Renewing our Trust in Being: The Potential of an Elderculture**

Many a thinker has referred to the twentieth century as the Age of Anxiety. This ought not be a surprise, as we feel anxious in the face of the unknown. The increased secularization over the last few centuries has shifted the origins of our existential burden squarely on the individual. We cannot make anyone but our own selves responsible for successes and failures. Worse yet, we cannot make sense of the vicissitudes of life, as within such a secular framework they must be interpreted as random, without meaning and purpose. We feel responsible for our own life and stay on guard against 'bad' things happening to us and those we love. Yet, the continued awareness of so-called catastrophes occurring all around us cannot help but fuel the anxiety that, ultimately, we are not in control of our lives. Within a religious framework – religion understood here as a connection to something larger, a respect for the sacred – humans share the burden life invariably presents with an unknowable force often referred to as God, the divine, Krishna, the Tao, or Nature. Here we believe in meaning and purpose of life, speak of trusting that there is something right about the events that occur, that a larger force will 'know' best what wants and needs to happen. The argument here is that as we grow into our older years, into elderhood, there is a natural tendency to move away from a belief in the individual shaping his or her own destiny to an understanding that much of life has really been out of our control and shaped by unknown forces. The process of time, of aging and maturation, thus allows for a deeper comprehension of the intricacies and complexities of human life, demands a needed respect for the unknown, the mystery, perhaps even the sacred.

Elders often teach us that we belong to a larger Being which directs our lives as much as we believe we direct our own. Such a teaching is urgently needed for generations growing up with the conviction that they need to look out for Number One, that they need to advance at all costs lest they will be considered a failure. This attitude places so much emphasis on individual achievement that the larger whole is neglected: people and planet are simply seen as tools to get ahead. Seen as tools, people and planet are instrumentalized. They lose their soul dimension. As such, this viewpoint leads to a disconnection with the world. We feel separate from it, we feel separate from our fellow human being.

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**... by valuing elders as wisdom keepers and teachers, we once again allow ourselves to deepen into the dimensions of our soul.**

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The root cause for much of our present world situation can be found in this disconnection. The way we care or do not care for our planet, the way we care or do not care for one another, all derive from the sense of connection and relationship we feel for people and planet. Is our life to be driven by personal

achievement or collective well-being? Is our life governed by our own decisions or are we subject to larger forces? That these questions are unanswerable is not the point. That the questions are no longer questions being asked is at issue here.

The poetics of aging states that with valuing the aging process as maturation, by valuing elders as wisdom keepers and teachers, we once again allow ourselves to deepen into the dimensions of our soul. It is this deepening that allows us to find the perennial questions that might just offer the answers for changing the course of our present direction, for understanding more deeply who we are as people and planet.

## **AgeSong, Inc. – Growing Corn**

Does it grow corn? This is the question native Americans would ask someone who spoke many a word in a row. Stated differently, can you actually translate those nice sounding words into practice? Can you make the abstract concrete? Certainly, it is easier to speak of a world of deep human and soulful relating than to make it happen, have it grow corn. For twenty years AgeSong has been managing eldercare communities in the San Francisco Bay Area, trying to put into practice its lofty ambition to help change the face of aging and to re-establish the role of eldership in our society. To start, such an undertaking seems overwhelming. A world where aging is welcomed and elders are revered for the amazing human beings they are, can hardly be imagined, let alone actualized. Moreover, to recreate eldership as a role in our society to which we humans aspire seems even more far-fetched given our present day attitudes. Yet, from the beginning, most goals seem unattainable.

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**Learning in an elder community is of depth,  
not information, of wisdom, not knowledge.**

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Let me try, thus, to paint some broad brush strokes as to how AgeSong is trying to attain its vision in everyday practice.

Foundationally, AgeSong conceives of itself as a learning organization. Herein lies the idea that all of us are continually learning, at all times and everywhere. This needs to be highlighted in a world obsessed with expertise and knowledge, a world where, all too often, we look to others to tell us what to be and do. Learning in an elder community is of depth, not information, of wisdom, not knowledge. The teaching we receive from elders is that the world is unknowable, will always remain mysterious. This awareness is so precious that it leads us to approach the world and others with a fundamentally different attitude from the one we learned in our mainstream upbringing and education: instead of thinking we need to know, we are directed by curiosity; we enjoy a beginner's mind.

At AgeSong we literally practice saying that 'we do not know'. Carepartners, interns and managers are reminded that not knowing is a higher state of understanding than pretending that we know. Such reminders set a tone of humility within the elder community. This tone signals to the world of elders that they are our teachers in this deep learning about the mystery of the world. It allows elders to be en par with those younger in years. Rather than feeling less, elders sense that they have something to give. Being able to contribute to the community of people surrounding them, our elders feel valued, respected, and seen.

Such a shift in attitude requires continual training and teaching. Every Wednesday afternoon the AgeSong community of staff and elders, of interns, volunteers and public, come together in our AgeSong Café to discuss topics ranging from our humanistic attitude towards aging, the difference between custodial and relational approaches to eldercare, the emphasis on following a person's process rather than labeling, and

a phenomenological approach to capturing experience. These topics try to speak to a different way of looking at the world and our elders, a world where all can be questioned and where a person's personal experience has priority over intellectual understanding, categories and labels. Involving everyone at all times – from young interns, to Carepartners, volunteers, staff and our own resident elders – creates an air of inclusiveness, of valuing everyone's participation and voice.

The AgeSong Gero-Wellness program of some thirty master and doctoral level psychology students learning to become psychotherapists establishes a school environment where sitting and listening to others – rather than task-list orientation and constant busyness – are seen as important attributes of care. Carepartners and staff notice that conversation, being with, is valued as much as doing, that going slow is as much appreciated as going fast, that listening is valued as much as speaking. These shifts seem subtle, at first. But over time they create an atmosphere wherein elders feel like people, not objects in need of care; feel relaxed rather than on guard; feel loved and appreciated rather than endured or tolerated.

Further emphasizing the attitude that elders are our teachers are continual public education programs that bring scholars and teachers into our eldercare communities. Such programs help to humanize and revision elder communities by creating alive centers of learning and creativity. Those who visit AgeSong often remark how their image of an elder community was quite different from what they experienced in our communities.

As important as our approach to elders and eldercare is our understanding that we are educators for the families of our elders. These families often feel a large burden when they have to place mom or dad into a care community. Helping these families through this transition by highlighting how their loved ones continue to teach our larger community of people with their rich experiences of life, that they are valued and cherished for who they are now as much as for who they have been, helps shift their attitude to aging and old age. They begin to look at their mom or dad differently. Many times, they become more engaged and interested in what mom and dad still have to offer them. This learning enriches the elder as much as it does the family. Moreover, these families now share their experiences within their own circle of friends and relatives and thus a slowly but steadily changing attitudinal shift towards aging and being an elder occurs within our smaller and larger communities of people. Thus, we hope that the AgeSong vision takes root and grows corn beyond the limits of our own communities here in San Francisco.

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*Dr. Nader Shabahangi is CEO and cofounder of AgeSong. As CEO, Dr. Shabahangi ensures that the company's vision drives its decisions and plans for elder care services. In 1992, he also founded the Pacific Institute, a nonprofit organization that defines its mission as one of helping elders live meaningful lives through an existential-humanistic approach to care. Dr. Shabahangi is a frequent guest lecturer, including presenting at international conferences focusing on aging, psychotherapy, and forgetfulness (dementia). In 2003, he authored Faces of Aging, a book challenging stereotypical views of the aging process and of growing old. In 2008, he co-authored Deeper Into the Soul, a book aimed at de-stigmatizing and broadening our understanding of dementia. In 2009 he co-authored Conversations With Ed, a book challenging readers to look at dementia in different ways and in 2011 he wrote Elders Today, a photo essay describing the opportunities awaiting us in our second half of life. In the same year he also*

*edited Gems of Wisdom, a book of poems written largely by elders living in assisted living communities throughout California. In 2012 he published Encounters of a Real Kind, a compilation of stories highlighting his innovative Gero-Wellness program where young psychotherapy interns work hand in hand with often very frail and forgetful elders in elder communities. His recently released book Ambiguity of Suffering (2014) outlines his research on the importance of understanding the underlying meaning of psychological as well as physical symptoms for individuals and the world they inhabit. Dr. Shabahangi received his Doctorate from Stanford University and is a licensed psychotherapist.*

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## Caring Connections - Vol11 No3 - Basting

### TimeSlips: How the Imagination Can Connect Us

*Editor's Note: LSA member Luther Manor was a pilot site for TimeSlips back in 1998. Since then, Luther Manor has become a national training site for other aging services individuals and organizations interested in implementing this creative program. According to Luther Manor Adult Day Services Director Ellen Nocun, "Our arts engagement programs have expanded widely since, especially with our More Than Memory class and The Penelope Project." For those interested, Ellen and Luther Manor would be happy to share the dynamic impact creativity has had on the people that live, work, and visit Luther Manor.*

*Photos courtesy Luther Manor.*

#### Anne Davis Basting

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**In 1996, I began volunteering on a locked "Alzheimer's wing" of a nursing home.**

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I had been writing extensively about the power of theatre to transform the way we perform aging (or "act our age"), and I wanted to test these ideas with people with profound disabilities. Could theatre have the same transformative effect on people with the symptoms of Alzheimer's disease? After many failed attempts with reminiscence exercises, I shifted toward "making it up" together. This shift toward the imagination had sudden and profound impact. My little group went from very little talking or eye contact to laughing, singing, and communicating in any and every way we had.

The power of improvisation with people with memory loss was made very clear in those first storytelling circles. Rather than quizzing someone about what they remember (I hold the "truth" and they risk failing with the wrong answer), improvisational storytelling creates a shared common ground of imagination. When people feel safe to experiment with communication, they can express themselves in new ways and connect with each other. Isolated islands become connected archipelagoes. Over several years, I worked with care providers and people with memory loss to ritualize this imagination-based storytelling process until it was clear, concise, and easily replicable. That is how TimeSlips was formed.



## **Improvise storytelling creates a shared common ground of imagination.**

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Since those early days, the TimeSlips team has created in-person and online trainings to bring the method into the hands of all those who wrap care around a person with memory loss – including family members, friends, spiritual leaders, professional caregivers, and students – the next generation of caregivers. In 2011, we created free, web-based interactive storytelling software that enables people to do creative storytelling wherever they live. Over 100 prompts on the website lead to story pages with open-ended questions that guide visitors through story making. Storytellers can tell a story themselves, write one as a group, or invite a friend via email to tell it with them. Visitors can read thousands of stories from around the world.

When I present TimeSlips approach and share stories of its impact, people often ask me if I see it as spiritual healing. I don't tend to think in those terms, so this question sent me on an internal journey. I can say that I have experienced profound connection with people with dementia who are commonly assumed to have no "self" by the medical settings in which they live. How does it work?

TimeSlips invites the person with memory loss to be author of his or her own imagination. Facilitators are taught to ask open-ended questions based on a prompt (an object, a question, a song, and most commonly, an image) that invite imagination, rather than dictate or guide it. Facilitators echo all responses to demonstrate that they are truly hearing every component of the storyteller's answer – tone, emotion, pitch, word, gesture, and facial expression. Facilitators write down all responses and read them back as the story builds. It is a simple approach with considerable impact on all those involved in the process. It is a reciprocal process – one that nourishes the facilitator as much as the storyteller.

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## **I believe that creative engagement builds communication, thereby enabling people with memory loss to reconnect to others in a non-judgmental way.**

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Because of the challenges of doing large-scale research on creative engagement interventions for people with dementia, very little data exists about the mechanisms behind the anecdotal/experiential success stories that are so clear to the people who work in the field. There is growing momentum behind efforts to support research on creative engagement, which is promising. Until then, however, we can only guess. I believe that creative engagement builds communication, thereby enabling people with memory loss to reconnect to others in a non-judgmental way. It can also make people feel useful and important – which contributes to a sense of purpose and meaning. Improving the attitudes of people who surround the person with memory loss can help enrich the environment and conditions of care. These factors in return can reduce anxiety and increase a sense of pleasure/purpose in life, which might, in turn, be linked to improved cognition.

Improving the quality of life of people with dementia demands that we change the way all of us think about and act toward people with dementia. We should certainly continue to explore bio/chemical interventions. But reducing the toxicity of the care environment can also have an immediate effect on the quality of life of people with dementia. We need to ask ourselves, how can we be part of improving the social conditions in which one experiences dementia?

## Students

Our online training enables TimeSlips to be incorporated into classrooms as “service-learning” elements of courses ranging from Psychology to Theatre, from English to Social Work. At the University of Wisconsin-Milwaukee, the Center for Community-based Learning, Leadership, and Research coordinates undergraduate volunteers from all across campus to train in the method and team up to practice it at six different area care communities (see [www.creativetrustmke.com](http://www.creativetrustmke.com) for more information on this program). Over the years, simple pre-post surveys on attitudes toward dementia and aging have helped assess the impact of the service learning programs on students. Recently, Dr. Daniel George published a study about his use of TimeSlips in service learning with 22 fourth-year medical students at the Penn State College of Medicine. Dr. George found preliminary evidence that suggests that learning to communicate in the open, positive model of TimeSlips improved the students’ attitudes about engaging with people with dementia.

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### **An activity like TimeSlips ... helps give students a richer sense of who the person was and what made them tick.**

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“In talking with my students, they consistently express their anxieties about medical school training them to see patients as a diagnosis rather than as a fully-fledged person,” George said. “An activity like TimeSlips, which emphasizes the creative spirit in people with fairly advanced dementia, helps give students a richer sense of who the person was and what made them tick.” (Science Daily, June 18, 2013)

The challenge of recruiting students to work with older adults is well known in academia. We hunger for geriatric social workers, nurses, dentists, and doctors. The financial reward for such work is certainly a disincentive – one that is difficult to change. But the attitude that working with older adults is “depressing” can be changed by creating positive experiences such as TimeSlips for students in all disciplines.

## Staff members

Over the past 15 years, TimeSlips Master Trainers have conducted hundreds of training sessions. These involve an on-site demonstration of the method with residents of that care community. It can be unnerving to go into a new setting and work with people you’ve never met, only hoping that the magic of improvisation works yet again. At one training in Saint Paul several years ago, the training coordinator arranged for a live web feed of my demonstration session in the nursing unit to be screened in a nearby training room, where nearly 100 people were gathered. There was a staff member of the nursing unit who helped arrange the storytellers in a semi-circle and then helped me by echoing some of the answers that I couldn’t hear from across the circle.

The magic of improvisation flowered yet again – and storytellers were laughing and responding with ease as they wove a fantastic story. When I went back down to the training room, I asked the trainees to tell me what they observed and what questions they had. One person asked, “How do you choose who should participate?” Before I could answer, the staff member who had helped me on the unit said, “Can I answer that? Pick the names out of a hat!” She explained that she was embarrassed to admit that before the session she had assumed that some of the people in the group were “too far gone” to participate and that she didn’t expect anything from the session. “But instead, they were the leaders of the whole group,” she said, with a tone of astonishment. “I will never look at them in the same way again.”

In a 20-nursing home study, our team of researchers found that on the 10 units in which TimeSlips was

embedded, the quality and quantity of engagement between staff and residents improved. The person-centered, engagement-based approach models a positive way to engage with people with dementia that spills over to improve the relationships even of those who did not participate in the training or the storytelling groups themselves (Fritsch, 2009).

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## **... the imagination can be a point of connection and communication for people with memory loss.**

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### **Family Caregivers**

Several years ago now I held a training workshop in TimeSlips in Sheboygan, WI at the John Michael Kohler Art Center. The structure of the training workshop (and online training) is simple. First we focus on what creativity feels like for ourselves. We play and enjoy. Then we shift toward understanding how to facilitate creative expression with people with memory loss, and practice the elements of the method. Finally, we imagine how we might share the stories with others to help them understand that the imagination can be a point of connection and communication for people with memory loss.

As we turned the corner from playing to learning the specific steps of the method, a gentleman who was part of the training group started to look uncomfortable. His grimacing continued for a few minutes until I finally had to ask him, “Are you okay?” He paused. And then he said slowly, as if discovering the meaning as the words came out “I’m just realizing -- that for the last year I have been driving my wife away.” He went on to explain that he would constantly correct the wrong words, dates, and names. He was finding a way back to her – simply by shifting to a shared sense of imagination and away from an insistence on fact and literal language. He has since gone on to work with his daughter (a pastor), to create a family foundation that models TimeSlips to other family caregivers. “Instead of insisting on calling ketchup by the right name,” his daughter wrote me in an email, “now we make up new names for it. Now we play together. And my son loves it too.”

### **Other Settings**

TimeSlips’ improvisational approach can be integrated into daily conversations. It is more than an activity to be programmed into a calendar - it is a way of being in relationship to someone with memory loss. TimeSlips now has a “mini-story kit” that can fit in a purse and enables families to bring images, questions, and a tiny journal to restaurants, airports – anywhere people need or want to connect. The approach is also being woven into museums, libraries, and other cultural institutions as a way to invite families with memory loss to respond to paintings, photographs and other artifacts in their collections. The Minnesota Historical Society is now a certified TimeSlips organization. In their training, the staff learned how to select images from their collections and engage families of people with memory loss in conversations that invite imaginative responses, and pepper in historical information as well. The Minneapolis Institute of Art offers “Discover Your Story” tours. Some tours focus on traditional approaches to engaging with art history, and others invite creative stories to emerge from the works. Incorporating creative engagement into museum educational programming and everyday engagements with people with memory loss help point us toward a day when memory loss is treated as a disability to be managed, rather than a tragedy to hide in shame. By bringing creative engagement into the public sphere, we begin to



make the world welcoming and accessible to people with memory loss.

## Conclusion

With appropriate study designs and adequate funding of research studies on creative engagement techniques in dementia care, we can work toward a time when we can answer the question about what mechanisms are at play with the experiential evidence we observe in the field. For now, these easy to learn approaches have no side effects, and both data and experience suggest that they have a positive impact on improving the entire 360 degree circle of care surrounding the person with dementia, as well as students, family caregivers, audience members, staff, and the people with dementia themselves. No pill can do that – only people can.

The playfulness at the root of the TimeSlips improvisational storytelling technique can teach us to focus on the person with dementia – to recognize their personhood and their capacity for growth, meaning, engagement, and giving to others.

## Sample Story

### The Golden Guitar



Portia is playing the guitar and singing! No one is listening. She is serenading herself and the birds. She is in a park in Mount Wilson. There are a lot of trees and leaves. It's autumn. She is singing "The Falling Leaves." Everybody sings, "The Autumn leaves drift past my window, the autumn leaves of red and gold." Portia lives there. It's her sanctuary. She is looking at her guitar because she is seeing bubbles coming from her guitar. She is hoping to record a long-playing CD. She is worried whether her guitar will keep working. Maybe somebody comes to teach her to play the guitar.

The birds come down and join her. She throws her guitar on the ground because it won't work properly. She jumps on it. She feels sad. She goes there to play guitar and she is waiting for her boyfriend. You can see her friend's reflection in the guitar. Her friend steps out of the guitar. She is a fairy godmother who fixes the guitar and everything is happy again. (This story was created by Mena, Mary, Win and Elvira in the Calvary Rehabilitation Ward on July 29, 2013.)

### Questions

- How can you incorporate imagination into activities of daily life?
- What prompts might be around your house or work place?
- How might you invite someone to participate in creative storytelling?

### Recommended Readings

*Forget Memory: Creating Better Lives for People with Dementia* (2009) by Anne Basting

[www.TimeSlips.org](http://www.TimeSlips.org) <sup>[1]</sup>

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*Anne Basting is Professor of Theatre at the University of Wisconsin-Milwaukee where she teaches courses on storytelling and community-engaged arts practices. She is the founder of TimeSlips Creative*

*Storytelling (timeslips.org) and author of two books, including Forget Memory: Creating Better Lives for People with Dementia. Basting is currently at work on a book about The Penelope Project ([www.thepenelopeproject.com](http://www.thepenelopeproject.com) [2]) and on the Islands of Milwaukee ([www.islandsofmilwaukee.org](http://www.islandsofmilwaukee.org) [3]), a program that aims to bring meaningful engagement to older adults living alone or under-connected to community. [basting@uwm.edu](mailto:basting@uwm.edu) [4].*

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[2] <http://www.thepenelopeproject.com>

[3] <http://www.islandsofmilwaukee.org>

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## Caring Connections - Vol11 No3 - McFadden

# The Role of Congregations in Dementia-Friendly Communities

**Susan H. McFadden and John T. McFadden**

The phenomenon of dementia is among one of the most pervasive pastoral and theological challenges facing the Western church at the beginning of the 21st century. (Kevern, 2009, p. 408)

The church is the only place where there is truly any hope of understanding and responding to the affliction of dementia. (Barclay, 2012, p. 98)

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**In 2013, we were privileged to attend the annual meeting of Alzheimer Europe, a consortium of policy makers, researchers, and program providers from all over Europe and indeed, the world.**

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The theme of the conference was dementia friendly societies. Because creating a dementia-friendly community in northeast Wisconsin is the central goal of the Fox Valley Memory Project, the organization that we helped launch in 2011, we knew we had to be there. Never in our long married life did we imagine we would visit the island nation of Malta, but when we learned about the theme of the Alzheimer Europe conference, we knew we had to find a way to get there. We met creative, passionate people from many countries who are rallying communities to enable people with dementia to live well with a progressive, terminal condition that is highly stigmatized and often narrowly discussed through a biomedical depiction of brain failure.



*Photo: The Gathering Place.*

Coinciding with the aging of the baby boom generation, attention to the need for dementia-friendly communities has grown worldwide since the turn of the 21st century. Brookmeyer et al. (2011) estimate that by 2050, over 13 million Americans will be living with Alzheimer's disease (AD), the most commonly

diagnosed form of dementia. Many other Americans will have different dementia diagnoses (e.g., vascular dementia, Lewy Body Disease, fronto-temporal dementia and mixed forms of these and other types that can co-occur with AD). Those interested in estimating the number of persons in their counties who may have AD can use 2010 US Census data and do some simple math using findings from a study by Hebert et al. (2013). About 4% of persons age 20-64 may have diagnosable AD, some with the inheritable young onset type which begins when people are in their 30s and 40s, and some with the early onset type which starts in the 50s and 60s. Even more may be living with presymptomatic AD, meaning that changes occurring in the brain have not yet been expressed symptomatically. (This is currently a major focus of biomedical research aimed at finding a cure or at least a way of preventing symptoms.) About 13% of persons age 65-74 fall into the category of having AD; 44% of persons age 75-84 may have AD and among those 85 and older, Hebert et al. (2013) state that 38% have AD.

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## **The Christian story reframes dementia as being "as much relational and social as it is neurological."**

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Pastors can do similar calculations on age data from their congregations. Because no cure or even effective long-term treatment exists, and none is expected for at least a decade or more, communities—including some faith communities—are recognizing the need to address a condition that causes painful social exclusion of persons with the diagnosis and their care partners. This exclusion exacerbates the cognitive challenges experienced by people with dementia (Kitwood, 1997) and can produce depression and anxiety in care partners. If we truly are committed to good quality of life of our family members, friends, and neighbors living with dementia, then we must make our communities more welcoming and inclusive.

In this paper, we offer a widely used definition of dementia-friendly communities and show how ten key components fit well with the Christian call to “bear one another’s burdens” (Galatians 6:2) and love our neighbors as ourselves. We then share some practical advice on how congregations might get started in becoming more dementia friendly, note potential barriers to this process, and conclude by showing how the Christian story offers us the reasons and the resources for becoming dementia friendly. As theologian John Swinton has said, Christianity presents a “counter-story” to the familiar biomedical story of loss and dissolution. The Christian story reframes dementia as being “as much relational and social as it is neurological” (Swinton, 2012, p. 71) and it teaches us that we can enjoy relationships of laughter, pleasure, joy and love with persons living with dementia even as we also acknowledge and lament their pain, loss, and suffering.

### **What is a Dementia-Friendly Community?**

For several years, researchers with the Alzheimer’s Society of the United Kingdom have studied what people living with dementia want from their communities. In their detailed report, they state:

A dementia-friendly community is one in which people with dementia are empowered to have high aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them. (Alzheimer’s Society, 2013)

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## **Dementia may take a toll on memory and**

## **cognitive ability, but it cannot take away our relationships with God, family and friends.**

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The Alzheimer's Society lists 10 key areas for communities to address if they are attempting to become dementia friendly. None relate specifically to faith communities, but we believe that all can be useful to congregations striving to be dementia friendly and to provide leadership to their communities on new ways of providing hospitality and inclusion to persons living with dementia.

**Involvement of people with dementia.** The disability rights movement has long embraced the slogan "Nothing about us without us." Congregations seeking to become dementia-friendly should always insure that people with this diagnosis and their care partners are included in discussions of how to achieve that goal.

**Challenge stigma and build understanding.** Congregations have many forums in which they can do this: through worship and preaching, educational programs for all ages, and community programs.

**Accessible community activities.** Is there anything structural or programmatic about the church that excludes persons with dementia, especially those who are less mobile? Can they hear and see when they attend worship and other church activities? Because most persons with dementia are 65 and older, what congregations do to improve accessibility for elders should benefit those with dementia.

**Acknowledge potential.** Persons with dementia can make positive contributions to their faith communities. Certain adaptations may be needed. For example, an individual might be able to read Scripture during worship if an assistant points to the lines.

**Ensure an early diagnosis.** Countries around the world are emphasizing the importance of early diagnosis but this can only be beneficial if there are accessible, appropriate programs and support services in place. Faith communities can offer reassurance in the face of people's fears of rejection over a dementia diagnosis and they can advocate for better, more compassionate approaches to diagnosis and follow-up care.

**Practical support to enable engagement in community life.** This kind of support benefits both the person with dementia and the care partner. For example, through congregational befriending programs, trained volunteers can take people with dementia to events in the congregation and the wider community.

**Community-based solutions.** The Alzheimer's Society frames this key area in terms of supporting people with dementia living in environments ranging from private homes to locked memory care facilities. An example of a faith community-based approach to promoting mental and physical well-being is the parish nurse.

**Consistent and reliable travel options.** Many congregations face the challenges arising when people can no longer drive and public transportation is unavailable. Safe, reliable, respectful options are needed.

**Easy-to-navigate environments.** Are bathrooms accessible? Can older people get to fellowship halls located below the sanctuary? Is there a place where people can be safely dropped off near the entrance of the church? Are walks kept clear of ice? Can people with walkers and wheelchairs navigate to find comfortable seats in the sanctuary?

**Respectful and responsive businesses and services.** The Purple Angel program is an international effort to train people working in retail stores, restaurants, and public venues in offering hospitality to people with memory loss and confusion. Churches can display Purple Angel decals indicating that their

staff and members are “dementia-aware” and they can encourage others to receive the brief training to do likewise.

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## **A congregation that is moving toward being more dementia friendly should start with a self-assessment.**

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### **Practical Advice: Where to Start**

A congregation that is moving toward being more dementia friendly should start with a self-assessment, or, in other words, the inward turn. That should be followed by an outward turn toward the community to identify potential collaborators and even possible funding sources.

**The inward turn.** There are many good toolkits available to help organizations and communities assess their dementia friendliness. One comes from the Minnesota organization, Act on Alzheimer’s. Their toolkit can be adapted by congregations to identify needs of people with a dementia diagnosis and their care partners.

One place to begin would be to identify those persons known to be living with dementia, whether as a diagnosed person or a care partner. This will sometimes be a challenge because social stigma often influences people to keep the diagnosis hidden. People who we might identify as care partners to someone with dementia may not be ready to accept that role designation. Thus, the process of becoming aware of dementia in church members needs to be approached with sensitivity.

The congregation should be sure to include persons living in various care settings, ranging from assisted living to memory care facilities. In addition, because people with dementia sometimes move to be closer to adult children, congregations should also determine whether it is important to stay in contact with them and their families. Would they and their families appreciate receiving reminders that the church still remembers them and cares about them?

As noted as one of the “key areas” of a dementia-friendly community, it is important to assess the physical space, as well as the church’s printed materials. Can people with memory loss and confusion easily navigate them? We often do not realize how much liturgy and educational offerings privilege high levels of cognitive acuity. Aileen Barclay, who cares for her husband with dementia reflected on this situation by saying:

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## **Whether formal or not, the liturgy is most often presented in cognitive form ...**

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Whether formal or not, the liturgy is most often presented in cognitive form with little attempt made to address the needs of those in our midst unable to do so. It is as if to be a human person loved by the God of the Cross to which we direct our worship means to have the cognitive abilities to think and reason. (Barclay, 2012, p. 89)

Of all the organizations in our society that offer opportunities for persons to get together in person, faith communities stand out as one of the few that include people of all ages. This means that churches are

well positioned to provide education about dementia and God's abiding love for persons rejected in our society because of their cognitive status. These educational offerings should not be confined to the church school or adult education programs. If a church has several members who live in some form of long-term care, programs can be provided at those locations. These can be very important because we find that some of the worst ageism and negative attitudes about dementia are expressed by elders. We related a story in our book about a group of women living in an assisted living facility who told us that they needed to learn kindness because they observed that their neighbors were not always kind to one another (McFadden & McFadden, 2011). Many congregations have deacons and other visitation teams. However, these individuals may be reluctant to visit persons living with dementia. They would benefit from guidance on how to communicate with individuals who may not remember their visit, but who will enjoy the interaction in the present moment. One book specifically written for congregations gives advice on how to visit people in their homes, in nursing homes, and hospitals (Goldsmith, 2004). Similarly, pastors would benefit from this guidance as they often hesitate to visit elders with dementia. Seminaries are woefully negligent in training clergy about aging and dementia, and one sometimes hears ageist remarks from clergy who doubtless feel anxious about their own aging. In a book he co-authored with Jane Thibault, Richard Morgan observed:

Often clergy tell me they are too busy or unprepared to do pastoral care for their members with dementia at home or in locked memory care facilities. One pastor remarked to me, "Why are you wasting your time with those people? They're out of it. They will never remember your name, and in ten minutes they will forget that you ever came to see them." But no act of love is ever wasted! (Thibault & Morgan, 2009, p. 52)

Christian churches need to be in conversation about the growing theological literature that addresses dementia. One place to begin would be the work of Scottish theologian, John Swinton. He has published many journal articles on dementia as well as an excellent, accessible book (Swinton, 2012). British theologian, Peter Kevern, became interested in dementia after his mother received the diagnosis. He is also doing excellent theological work on dementia. A university library could offer assistance in locating his publications.

Scottish pastor, Malcolm Goldsmith, summarized the need for theological reflection on dementia like this:

We therefore need a theology of patience, of suffering and of "failure". We need an open-ended, non-judgmental and merciful theology. Not a theology of certainty, but of tentative exploration, for we are confronted by a strange and foreign world, and it really does challenge us as to whether it is possible to sing the Lord's song in it. (Goldsmith, 2004, pp. 203-204)

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**Many creative possibilities await those congregations willing to commit to offering programs and services to serve not only their own members, but others as well.**

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**The outward turn.** Once the congregation has evaluated its own dementia friendliness, and identified ways it can improve ministry with and by persons experiencing memory loss and other cognitive problems, it may make a decision to reach outward to the community at large. Many creative possibilities await those congregations willing to commit to offering programs and services to serve not only their own members, but others as well. An excellent example in Wisconsin is St. Paul Lutheran Church in Sheboygan Falls. Some years ago, this congregation developed The Gathering Place, a day services program for people

with memory problems. Amazing Place, in Houston, TX, is an example of what can happen when congregations collaborate to care for individuals with dementia. Founded by a Methodist pastor, it now has its own building and over 20 staff persons.

Several faith communities in Wisconsin have asked the Fox Valley Memory Project about our memory cafés. Memory cafés are programs rather than places, as they can be as easily held in church fellowship halls, public libraries, or nature centers, as in private cafés. They offer people diagnosed with dementia and their care partners the opportunity to gather for two hours of socializing and fun without any stigma regarding a person's confusion or inability to remember (McFadden & Koll, 2014).

Funding for dementia-friendly programs that reach beyond the walls of the church will be a challenge. However, given increasing public awareness of the number of persons having dementia, funds are available to launch—if not to sustain—programs. We have been very fortunate to receive grants from our local community foundation and from a large private, family foundation. A congregation would have to collaborate with some kind of community social service organization if it identifies funders that do not support religious organizations.

### **Potential Barriers to Becoming Dementia-Friendly**

The lack of seminary training about aging and dementia has been a problem for decades. Rabbi Dayle Friedman, author of many books and papers offering Jewish perspectives on pastoral care of elders (e.g., Friedman, 2008), edited a special issue of the *Journal of Religion, Spirituality, and Aging* with 13 papers on various aspects of seminary training (Friedman, 2011). This was the first time in 20 years that a major journal had addressed the topic of education for ministry with older persons. The list of training needs is long, and the road to providing them is rocky, as demonstrated by several excellent programs that failed due to lack of funding. Too often, seminaries and the congregations served by their graduates assume that the bulk of pastoral energies need to be focused on youth and young families when in fact, it is elders who make up the largest age group of the church. Even congregations that appear not to have many older people (e.g., some of the so-called “mega-churches”) serve persons who are caring for parents and grandparents with dementia.

In her article lamenting her husband's dementia, Aileen Barclay wrote about another barrier to churches becoming dementia friendly: Individuals living with the diagnosis may not feel like their difficult situation is taken seriously by congregants or pastors who insist on always being cheerful and positive. She said, “I withdrew from my lively church, just unable to face people who keep telling me what a wonderful person my husband is” (2012, p. 80).

Finally, some individuals are extremely reluctant to have anyone know that they are living with dementia, either as a diagnosed person or a care partner. A study of elders' feelings about their spiritual identities once they were diagnosed found that most people talked about their faith giving them strength and hope, a sense of not being alone, support for a positive attitude, and valuable support from fellow congregants. Faith communities can produce toxic gossip that is intrusive and painful. One woman with dementia told the researchers,

I really don't like my private information being bandied about and occasionally being the object of church gossip. That's pretty much what these prayer requests are. They think, “Oh poor courageous man to be bearing so much from her for so many years.” (Sullivan & Beard, 2015, p. 80)

By honestly facing their own ageist assumptions and behaviors, their fears about dementia, and their insensitivity to individual differences in how people feel about having their personal information shared, faith communities can begin to eliminate the barriers to becoming dementia friendly.

## **Dementia undeniably changes our ability to produce or contribute in conventional terms.**

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### **Why Should We Do This?**

The secular world too often defines persons' worth in terms of what they can produce or contribute. Elders in particular sometimes sigh "I'm just no good to anybody anymore" or "I never want to be a burden on my children." Dementia undeniably changes our ability to produce or contribute in conventional terms. But does that mean that people living with dementia no longer have value or worth?

In Jesus' time, personhood was generally defined in terms of corporal being—the body was the person—which is why leprosy was the most dreaded of diseases. Our own era is sometimes described as "hypercognitive" (Post, 1995) because personhood is so strongly associated with the ability to think logically and exercise autonomy. This explains why elders fear dementia more than cancer or heart disease.

Congregations should look to scripture and Christian tradition to expose the inadequacy of these definitions of personhood. We might begin with the Holy Trinity: Christians believe that God is defined by the internal relationship between the persons of the Father, Son, and Holy Spirit. We do not understand God as a corporal body: "No one has seen God" (John 1:18). Nor can we comprehend the mind of God in terms of human cognition: "Even so the thoughts of God no one knows..." (1 Cor. 2:11). We understand God through relationships—our relationship with the God who loves us perfectly no matter what our condition or circumstances, and God's internal relationship expressed as Holy Trinity.

Fourteenth century mystic Meister Eckhardt, in speaking of the Trinity, wrote "when the Father laughs to the Son and the Son laughs back to the Father, that laughter gives pleasure, that pleasure gives joy, that joy gives love..." Laughter, pleasure, joy and love: these are the expressions of the relationships, human and divine, which define our personhood. In its course, dementia may take a toll on memory and cognitive ability, but it cannot take away our relationships with God, family and friends. There can still be laughter, pleasure and joy, and love can still be both given and received. A person with dementia remains fully a person, and can continue to be engaged with the life of the faith community.

Older persons in general are too often reduced to caricatures of personhood by our society—the "cranky old coot," the "sweet old lady." Congregations are also guilty of describing their older members in reductionist language—not "our cherished members residing in long-term care facilities," but "our shut-ins." If dementia becomes a part of the journey of aging, a layer of stigma is added and our language becomes even more dismissive: "he's just an empty shell now." As we have shown, too often these members of the faith community are treated as no longer worthy of our time and attention. They might be remembered in a generic prayer, or even receive an occasional bouquet of leftover altar flowers and a cursory visit. However, where else but in congregations can people learn how to be present to them as friends, sharing laughter, pleasure, joy and love? Theologian Stanley Hauerwas has taught us that congregations should function as schools for friendship, including friendship with persons with dementia (McFadden & McFadden, 2011).

Given the demographics of aging in our society, more and more friends will be making the journey of dementia. As persons of faith, we need not have them to make that journey alone. The person with dementia is a beloved child of God and a member of our community. We need to include them in our common life—worship, mission and fellowship—to the fullest extent possible. We need to support our

members caring for someone with dementia, living Paul's calling to "bear one another's burdens (Galatians 6:2)." We must be a strong moral voice in a society that stigmatizes dementia and fears aging. We must affirm, and help create, the goodness of life in all circumstances.

Dementia undeniably brings suffering—for the person diagnosed, for family members, and for friends and community. The church must be a setting where suffering is acknowledged and addressed. When a member of our community is diagnosed with dementia, it should be treated as any other medical condition that will bring suffering and, ultimately, death. We should pray for and with our friends, and give them the opportunity to express the fear and anxiety which inevitably accompany the diagnosis. This will become even more essential as persons are diagnosed with dementia at a younger age in the coming years. As noted by Kevern, "there is a good case to be made for developing a person's spiritual resources as they come to terms with the early stages of dementia" (2011, p. 384). Above all, people need to know that the journey will not be made alone, that the community will be there for them in each stage of dementia. We cannot remove the fear, but we can be present as faithful friends.

As the disease progresses, people will have increasing problems with memory. A point may come where they no longer remember our names, or our faces, and they may no longer recall their own stories. But because we have shared the joys and challenges of life with them over time, we remember, and we can tell their story for them. Memory is not solely an individual possession, but is shared in community. We can keep our relationship grounded in our friend's narrative, because "it is narrative that makes for meaningful connection between people, with or without dementia" (MacKinlay, 2012, p.80).

People with dementia should be encouraged to continue in the worship life of the congregation. Even if cognitive loss makes it difficult to comprehend a sermon, God's presence can be experienced through the familiar hymns, texts and liturgy. Their continuing identity is affirmed when long-time friends smile and greet them by name.

Likewise, people with dementia can share in many of the "housekeeping" tasks essential to the life of the congregation—assembling Sunday bulletins or folding newsletters—which offer opportunities for social interaction and service with fellow members. They can still be spiritually fed by Bible study, even if critical reflection on the text is no longer possible. Scripture can speak to us in all circumstances, providing comfort and hope, and simply being a participant with others is an antidote to loneliness and isolation. Congregations too often dwell on the things that persons with dementia can no longer do, rather than focusing on the many things that remain possible and can keep them feeling connected and valued by their congregation.

It is essential for congregations to support care partners of persons with dementia. As Richard Taylor (a clinical psychologist living with dementia) has noted, if we want to help our friends with dementia, we should help the ones providing the primary care for our friends (Taylor, 2007). The care partner's world has been turned upside down, filled with daily challenges. Participation in "normal" activities can become a rare and cherished occasion. To have dinner with long-time friends who are sensitive to the circumstances can be a wonderful blessing. To have a friend come to the home to sit with the person diagnosed while his or her care partner runs errands, or simply sits in a park and reads, can be restorative.

Congregations also need to provide support and appreciation to those who work in aging services, particularly long-term care. In a society that treats elders who are physically frail or experiencing dementia as no longer having worth or value, the persons who care for them are also told in various ways that the care they provide has no real worth or value either. As Malcolm Goldsmith noted about long-term care staff, "they maintain the fabric of this world and their work is their prayer" (2004, p. 173). Above all, congregations need to become educated about dementia and educate those outside the church. We must counter the stigma by telling a different story about dementia than the one told by the secular culture. We must counter the message of fear with a message of hope. We must counter the lie that the person with

dementia is “no longer with us” with the truth that personhood, and the dignity and worth that accompany it, can never be lost. “For I am convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord” (Romans 8:38-39).

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*with dementia*. Nashville, TN: Upper Room Books.

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## Caring Connections - Vol11 No3 - Ramsey

# “I Give Him to You”: A Case Study in Aging and Forgiveness

Janet Ramsey

When I met “Grace” I was immediately impressed with her resiliency.

She had come to see me for help with caregiving (her 96 year old mother-in-law had advanced Alzheimer’s disease), but in the process of our conversations I heard numerous references to a great sorrow. Grace grew up in a close family that seemed, to her and to her community, healthy and whole. Then, at the age of forty, she discovered a dreadful secret—her father had, for many years, sexually abused several family members. She was horrified by this revelation and found the days that followed far more difficult to endure than those following the discovery of her first husband’s infidelity. Trust in the father she knew and loved was shattered. She grieved, feeling robbed of her family memories, her present peace of mind, and her dreams of a father-daughter relationship in the future. For many years, she struggled with emotional and spiritual pain, exacerbated by her inability to speak openly of what had happened in order to protect the abuse victims. She often thought that forgiveness after someone we love has been hurt is far more difficult than when we ourselves are the victims. Several years later, she chose not to attend her father’s funeral, but spent the day outdoors, reading and praying for those he hurt. Only gradually was she able to move into a more healthy and whole life, realizing slowly that painful grief work was a necessary time of lament.



Today, at 70, Grace is calm, happy, and appears ready to withstand the demands of caregiving with relative ease. She has remarried, found a meaningful vocation, and been nurtured by the love of children and friends. Central to her strength is her spiritual life. During the weeks she came to my pastoral counseling office, I heard a variety of ways in which the stories, symbols and practices of faith have intersected with her need to move past anger and hurt—at her father, her former husband, and at herself for making foolish choices. I heard wisdom in her narratives that has helped me in my own aging process,

and with my own efforts to forgive. Many of our stories are not so dramatic as Grace's, but all of us who engage in life review during the last third of life come face to face with the struggle to forgive. It is impossible to go beyond the very early days of childhood without feeling disappointment and hurt, and, if we have lived long, we have many memories of both. Difficulties with family members and friends tend to accumulate over the life span, and interpersonal problems multiply. Both minor disappointments and major difficulties add up. They challenge our ability to forgive others, ourselves, and God.

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## **All of us who engage in life review during the last third of life come face to face with the struggle to forgive.**

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However, this accumulation is no cause for despair, for the passing of years also brings increased opportunities for wise personal contemplation. In some people, like Grace, these reflections result in increased empathy, broader perspectives, and deeper humility. Although serious hurts can remain so poignant that an older adult speaks of an incident that took place many years ago as though it had just happened yesterday, these wounds do not inevitably lead to endless ruminating and a sense of victimhood. Forgiving, resilient elders are able to “re-story” their lives<sup>1</sup>, clinging to hope in the face of changed realities.

Perhaps because it impacts our past, present and future so profoundly, forgiveness calls forth the strongest and most complex human emotions we endure. Nevertheless, the process of forgiveness, research suggests, becomes highly important to us during the last third of life when time and energy are limited.<sup>2</sup> Gerontologists have theorized that, when time is running out, adults are more likely to give priority to emotional goals, rather than to knowledge-related goals, as in the younger years.<sup>3</sup> Thus for elders, there may be a desire to forgive because of the positive feelings it creates. Conversely, they make efforts to avoid unforgiveness because it is such a painful burden.

As Grace's story reveals, forgiveness is complicated, messy, and painful. Although after minor relational problems, forgiving can be quick and easy (more like overlooking), after deep violations of trust the process can take years of effort and prayer. There are times, I believe, that forgiveness may not even be the best language to use. When accompanying persons like Grace, to speak of “healing” or “laying down a burden” may be more helpful and appropriate.

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## **Forgiving, resilient elders are able to ‘re-story’ their lives.**

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### **What forgiveness is not, at any age**

Personal experiences, combined with my research and clinical work, have convinced me that many common myths about forgiveness are simply wrong. Forgiveness, for example, does not mean condoning or excusing harmful acts. When someone we counsel has been gravely hurt, it is both hurtful and morally wrong to imply that forgiveness is a “get out of jail free” card. God gave us the law as well as the gospel, the gift of justice as well as mercy. To condone an evil act, or to insist that forgiveness be prematurely given, cheapens suffering and is insulting beyond words to a victim. Neither does forgiveness remove all pain from human memories, nor take us back in time to the person we were before. Grace will, no doubt,

shed tears about her father off and on throughout her life, as she continues to grieve the many losses he caused to those she loves. She will continue to think back to the trip she made to confront him (he confessed, but made a very weak, self-centered apology). She described that painful day to me as a kind of loss of innocence, a moment when she changed her perceptions of not only her father but of the entire world.

Grace also taught me to refute another myth, that forgiveness requires an apology. It is lovely when it happens, but getting an adequate apology falls into the category of desirable but not necessary. Grace wrote a letter to her former husband while they were learning to co-parent after the divorce, telling him she forgave him. He responded that he had no idea what she was talking about. Nevertheless, she chose not to wait impotently for him to understand or respond—she decided that his indifference would not hold her in bondage, year after year.

Perhaps the most important myth to refute, however, is that forgiveness and reconciliation always occur together. This is a dangerous myth, and has often been used, for example, by nominally Christian men or women who abuse their partners. It is neither wise nor “spiritual” to deliberately place oneself in harm’s way. The best a victim can hope for in dealing with a violent perpetrator is to seek safety and stay away to heal. Restored relationships are typically impossible in situations of extreme harm, such as murder or sexual abuse.

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**But being resilient, or spiritually resilient,  
does not mean that forgiveness comes  
easily or cheaply.**

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### **Forgiveness and letting go**

It makes intuitive sense that spiritually resilient people would also be forgiving people, and the narratives I hear conducting my own research confirmed that hypothesis.<sup>4</sup> But being resilient, or spiritually resilient, does not mean that forgiveness comes easily or cheaply. Many speak of it as a painful journey, or find other metaphors more helpful than definitions.<sup>5</sup> At first, victims may feel separated not only from other people, but from God, asking “why” questions. Then, as time passes, the resilient begin to create more complex and nuanced narratives. For Grace this meant recognizing that not all men were abusers or adulterers. She was motivated to change the plot of her story because she wanted peace and love in her life, and unforgiveness stood in her way. But getting there was not a smooth trajectory; some days she felt calm, but on others the anger and pain returned.

Grace shared a moment in her forgiveness process that has stayed with me and become a resource in my writing and teaching. One day, about ten years after she began struggling to forgive her father, she was standing in church, singing the words of the liturgy, “Lord have mercy, Christ have mercy, Lord have mercy.” Suddenly she began to pray, “I can’t do anything more with this man, Lord. He’s all yours. I give him over to you.” She experienced a strong sense of peace and calm at the end of the service that has not left her. “It was almost like an exorcism,” she told me. This experience was her way of moving on and, for her, it was enough. Grace envisioned her father, from that time on, as God’s responsibility. She believes that his sins are part of the burden Christ carried to the cross. It was enough.

### **Implications for pastoral care**

Grace’s experience points to the embrace that is God’s to give, and to the power God shares to make the

impossible, possible. As we age and participate in spiritual community, we have a place where forgiveness—an alternative to violence—is spoken, practiced and embodied. As we hear, over and over again through the years, the biblical stories of God’s costly love, as we worship together as sinners and saints, and as we envision new and creative ways to live together, we are far too busy preparing to be Christ’s presence in the world to be stuck in either guilt or victimhood. Forgiveness, for women like Grace and for all people of Christian faith, is not an isolated act—rather, it is a life-long way to be in the world. It leads, researchers tell us, to increased physical and spiritual health—a particular blessing as we age. Even better, it is the only effective antidote to what Tillich called the structure of the demonic. Grace’s vision of turning over both her pain and her father to God was only possible because she knew the story, worshiped with the community, and dreamed dreams of the Kingdom of God. This path to forgiveness flies in the face of sentimental, cheap conceptions of forgiveness in our culture. This woman has suffered profoundly, but now, because she understands that Christ died for both victims and perpetrators, she has the freedom she needs to live with joy and to care for her mother-in-law and others. She can never change the past, never completely leave behind her hurt and pain, but she is not stuck in despair. Life in community will continue to nurture her and her vision of the Kingdom of God, even as she confesses her own sins and allows God to re-create her, daily.

Being a forgiving person is both a developmental and a dispositional feature of resilient lives. Life span psychology has taught us that there is no smooth, unidirectional path towards wisdom and peace, and this is true of forgiveness as well. Pastoral caregivers, of course, never hear the full and complete story of a long struggle to forgive. But we do meet remarkable elders who have the capacity to embrace others, envision a better future, and embody Christ’s love. Even as our culture remains fascinated with stories of revenge and violence, we have the holy privilege of listening to those who can teach us how to live through the messy struggles of broken human relationships. Perhaps that, too, is enough.

## Footnotes

<sup>1</sup> McAdams, D. (1993). *The stories we live by: Personal myths and the making of the self*. New York: Guilford Press.

<sup>2</sup> Cheng, S.T., Yim, Y.K. (2008). Age differences in forgiveness: the role of future time perspective. *Psychology of Aging*, 23:676-80.

<sup>3</sup> Carstensen, L.L., Isaacowitz, D.M., & Charles, S.T. (1999). Taking time seriously: A theory of socioemotional selectivity. *American Psychologist*, 54, 165-181.

<sup>4</sup> Ramsey, J. & Blieszner, R. (2012). *Spiritual resiliency and aging: Hope, relationality, and the creative self*. Amityville, NY: Baywood Publishing. For example, a group of Liberian pastors I worked with in the Twin Cities preferred the metaphor of forgiveness as a bridge.

<sup>5</sup> Tillich, P. (1967). *Systematic theology*. Chicago, IL: University of Chicago Press.

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## Caring Connections - Vol11 No3 - Brossoie

# Chemical Dependency in the Second Half of Life

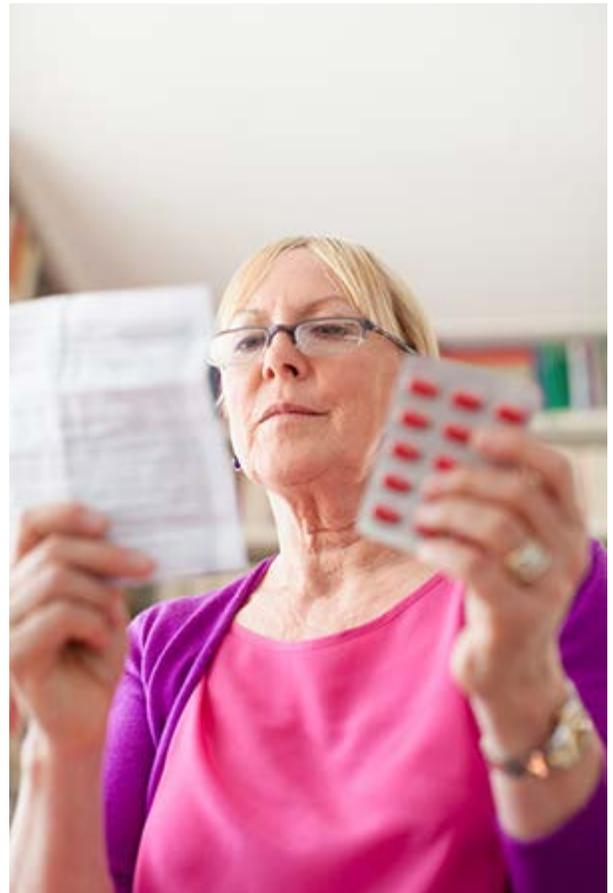
Nancy Brossoie

**Whenever the subject of alcohol and drug abuse among older adults comes up, a common reaction is to characterize users as homeless people, eccentric characters, or burned out Hollywood celebrities.**

Yet dependency on alcohol and other drugs (AOD) is a hidden and growing problem for many older adults. Despite a common belief that adults “mature out” of heavy drinking and drug use as they age and take on more responsibilities, the fact is that many adults never stop using AODs and some begin to rely on them (intentionally or unintentionally) when faced with new and difficult life transitions such as retirement, chronic health problems, care giving responsibilities, or death of a loved one.

The path to dependency may start innocently enough with a drink or a pill to relieve stress, pain, or loneliness. But with continued use the body becomes accustomed to the drug and builds up tolerance to it, requiring increasingly higher doses to achieve feelings of normalcy. Without the drug, users feel flat, lifeless, and depressed, so they take more. Dependency or addiction begins when the user relies on the drug just to feel normal.

Growing public interest in chemical dependency in late life is the result of rising rates of AOD use. Today, an estimated 17% of American aged 55+ are suspected to have problems with alcohol and drugs, which have mostly gone untreated. The annual National Survey on Drug Use and Health data indicates that this growing problem is largely attributed to aging baby boomers (born 1946-1964). As a group, boomers have had more exposure and experience



with AODs and share a greater acceptance of AODs than previous generations. More importantly, they are bringing their drinking and drugging habits with them as they enter the second half of life. In 2012, approximately 7% of adults aged 50-54 and 4% of adults aged 60-64 reported current use of illegal drugs (e.g., marijuana, cocaine, and heroin). Over 1 in 10 adults aged 65+ reported exceeding recommended drinking limits for alcohol and among them 20% were heavy drinkers. Within assisted living facilities, problems with alcohol may be worse. In a study on nurse aides working in assisted living facilities, aides estimated that nearly 69% of residents drink alcohol and the health of 19% of residents were being hurt by their current drinking habits.

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## **Dependency on alcohol and other drugs is a hidden and growing problem for many older adults.**

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However, the fastest growing problem among older adults is prescription medication misuse. A large number of medications prescribed for treating common conditions include controlled substances, which are highly addictive drugs. For example, opioids are prescribed for pain relief and benzodiazepines are prescribed for anxiety, depression, and insomnia. The danger of developing a chemical dependency and creating further health problems is especially high for women. Their smaller body size and partiality towards using medications to treat aches and pains rather than tough it out (like men prefer to do) help explain women's current abuse of opioids at three times the rate of men.

When medications are combined with alcohol, health risks increase as alcohol reduces or amplifies a drug's intended effect. Despite drug warning labels that contraindicate its use, 60% of older adults referred for prescription drug treatment also report drinking alcohol.

Perhaps most alarming is the changing face of prescription drug misuse that includes selling prescription medications. Once thought to be only a problem involving youth selling stolen medications, older adults have begun selling their own medications, especially painkillers. Increasing numbers of reports are surfacing through drug task force personnel about older adults selling their medications for cash and then often purchasing illegal drugs (e.g., marijuana or methamphetamine) to treat their health problems.

Recognizing when an older adult has a problem with AOD is challenging, as a number of medical conditions have at least some symptoms that can mimic those of intoxication or drug use. Signs and symptoms of chemical dependency affecting physical health include dizziness, disorientation, memory loss, sleep problems, falls, and incontinence. Health conditions with symptoms that can mimic AOD dependency include epileptic seizures, dementia, hypoglycemia (low blood sugar), and stroke. Conditions such as hearing loss, multiple sclerosis, hypoxia, and traumatic brain injury include impairments that can appear to be the result of AOD use. Chemical dependency can also mimic or enhance mental health issues including anxiety, depression, confusion, and mood swings. With the interplay of so many signs and symptoms, it is easy for an observer to assume that reported changes in health, behavior, and social relationships are the result of health problems rather than chemical dependency.

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## **The fastest growing problem among older adults is prescription medication misuse.**

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“Why didn’t they tell me or go get help?” is a common question uttered by shocked family members and friends when they learn of an older person’s problem with AOD. The answer is simple, yet complex. Most adults aged 65+ were raised in a social environment that encouraged them to keep their personal and family problems private. They grew up understanding that hard work, family honor and self-sacrifice were hallmarks of adulthood. If you stumbled, you picked yourself up and continued moving forward. You didn’t bring shame on the family name and you took care of problems yourself without burdening other people. Sharing a private problem like chemical dependency is no one else’s business, and if word got out, it would cause embarrassment and humiliation to the family. Thus, the lives of older adults dependent on AOD are isolated; and, as their worldview shrinks, their interactions with friends and family deteriorate as they attempt to hide their problems.

In spite of the general belief that older adults will divulge personal information to their family doctors, the opposite is true. Studies suggest that 87% of older patients see their physician regularly, yet most will not reveal sensitive problems, even if the doctor can help. Among older adults with a drinking problem, only 60% will reportedly reveal their problem to their physician. By the same token, healthcare providers report not screening older adults for AOD use because they are afraid of offending them and losing their trust. As a result, discussions about AOD use are not normalized in healthcare settings, making the conversation more difficult if it were to arise.

Older adults will also not jump at the opportunity to reveal personal problems to members of their faith community. Acknowledgment of a chemical dependency is an admission of failure – a failure to uphold one’s responsibilities to God, church, and family.

*Older men are to be sober-minded, dignified, self-controlled, sound in faith, in love, and in steadfastness. Older women likewise are to be reverent in behavior, not slanderers or slaves to much wine.... Show yourself in all respects to be a model of good works, and in your teaching show integrity, dignity, and sound speech that cannot be condemned, so that an opponent may be put to shame, having nothing evil to say about us. (ESV Titus 2:2–8)*

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**... for older adults, engaging in therapy is another acknowledgement of personal defeat and admission that they are incapable of managing their own problems.**

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Unfortunately, if an older adult wanted to seek professional help, limited addiction resources and treatment options currently exist. For young adults and young baby boomers, attending therapy or counseling sessions are acceptable forms of self-care. But for older adults, engaging in therapy is another acknowledgement of personal defeat and admission that they are incapable of managing their own problems. Thus, advising an older adult to go for drug counseling is likely to be viewed as an unreasonable request. For older adults willing to talk to their physicians about their dependence on alcohol, brief interventions (5-10 minute conversations about the effects of alcohol misuse provided during regular office visits) have been shown to be effective in curbing drinking behaviors for up to 12 months among older patients who developed alcohol dependencies late in life. However, healthcare providers need to be trained to conduct brief interventions using motivational interviewing techniques, to facilitate any change.

If an older adult agrees to enter an addiction treatment program, their options are also limited. Few age-appropriate treatment protocols have yet to be designed and tested for older adults, so most treatment

programs are designed and targeted towards the lives and experiences of young adults. Among the programs that are available, few providers are willing to treat addiction with co-existing health conditions, which most older adults experience. If a program is able to treat addiction and health problems, and Medicare coverage is available, the scope of care for addiction remains limited. For example, Medicare covers methadone for pain in an inpatient hospital setting, but does not cover it in outpatient settings when prescribed for opioid addiction. In the future, as part of the Affordable Care Act, 80% of mental health services will be covered through Medicare Part B, which should help alleviate some disparities in addiction care for older adults. Until then, older adults will need to pay out-of-pocket for services.

The road to recovery from chemical dependency poses multiple challenges for those in recovery and the people helping them. Even though older adults dependent on AOD may feel alone and isolated, addiction is no longer viewed as the result of personal weakness or moral failing. It is a disease that benefits from an array of treatment services and support provided by healthcare professionals, addiction counselors, spiritual leaders, family members and friends.

*No temptation has overtaken you that is not common to man. God is faithful, and he will not let you be tempted beyond your ability, but with the temptation he will also provide the way of escape, that you may be able to endure it. (ESV 1 Corinthians 10:13)*

During the recovery process, the underlying reasons for engaging in AOD use must be uncovered, examined, and treated using approaches that acknowledge and embrace the complex relationships existing between body, mind, and spirit. Community support groups like Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) can potentially help older adults in examining one's life and addiction—especially when fellow members are older adults. Also known as 12-step groups, these member-led programs are based on common principles, which members are asked to follow to regain control of their lives. Members are also encouraged to take 12 specific steps to heal their body, mind, and spirit, including:

- Admitting loss of control over the addictive drug
- Recognizing that a higher power exists and can give strength
- Examining past mistakes with the help of members
- Making amends for past mistakes and transgressions
- Learning to live life without addiction
- Helping others who deal with addiction.

Although AA boasts over 1.3 million members in the U.S. and Canada, there is limited scientific evidence to suggest AA and other 12-step programs significantly increase abstinence at any age. Nonetheless, growing memberships suggest that the groups may play an important role in the road to recovery and they may be the most available option for older adults. Although the recovery process may take time, include relapses, and frustrate helpers to the point that they wonder if their input is useful, their support does make it possible for healing to occur. If you are considering reaching out to an older adult dealing with a chemical dependency, the help you provide as a church member can be significant. Research in addiction recovery has shown that the role of the faith community in supporting members in recovery is that of support, fellowship, and forgiveness, which make it possible for members to travel successfully down the road to recovery.

Pay careful attention to yourselves and to all the flock, in which the Holy Spirit has made you overseers, to care for the church of God, which he obtained with his own blood. (ESV Acts 20:28)

For more information – for yourself or others – visit the following websites:

Alcoholics Anonymous: [www.aa.org](http://www.aa.org) <sup>[1]</sup>

## A Brief Guide to Alcoholics Anonymous

“Originally designed for use in schools... In simple language, it describes our program and offers general information on A.A.”

[http://www.aa.org/assets/en\\_US/aa-literature/p-42-a-brief-guide-to-alcoholics-anonymous](http://www.aa.org/assets/en_US/aa-literature/p-42-a-brief-guide-to-alcoholics-anonymous) [2]

National Institute on Alcohol Abuse and Alcoholism: [www.niaaa.nih.gov](http://www.niaaa.nih.gov) [3]

## Harmful Interactions: Mixing Medications and Alcohol

“This pamphlet lists medications that can cause harm when taken with alcohol and describes the effects that can result.”

<http://pubs.niaaa.nih.gov/publications/Medicine/medicine.htm> [4]

National Institute on Drug Abuse: [www.drugabuse.gov](http://www.drugabuse.gov) [5]

## Drugs, Brains, and Behavior: The Science of Addiction

“This booklet aims to fill that knowledge gap by providing scientific information about the disease of drug addiction, including the many harmful consequences of drug abuse and the basic approaches that have been developed to prevent and treat the disease.”

<http://www.drugabuse.gov/publications/science-addiction/preface> [6]

Substance Abuse and Mental Health Services Administration: [www.samhsa.gov](http://www.samhsa.gov) [7]

## TIP 26: Substance Abuse Among Older Adults

“Offers practice guidelines for the identification, screening, assessment, and treatment of the elderly for alcohol abuse and abuse of prescription drugs or over-the-counter drugs. Discusses outcomes and financial, ethical, and legal issues.”

<http://store.samhsa.gov/product/TIP-26-Substance-Abuse-Among-Older-Adults/SMA08-3918> [8]

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*Dr. Nancy Brossoie is the Senior Research Associate for the Center for Gerontology at Virginia Tech, conducting research with vulnerable older adult populations. She has authored book chapters and consumer materials on alcohol and illicit drug use in late life and has developed a training program for police officers on how to address the subject with community members. She serves as chair of Southwest Virginia's Alcohol and Aging Awareness Group sponsored by the VA Alcohol and Beverage Control Dept. and participates in Screening, Brief Intervention, and Referral to Treatment (SBIRT) trainings to educate healthcare professionals on how to address alcohol abuse in their practices.*

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[3] <http://www.niaaa.nih.gov>

[4] <http://pubs.niaaa.nih.gov/publications/Medicine/medicine.htm>

[5] <http://www.drugabuse.gov>

[6] <http://www.drugabuse.gov/publications/science-addiction/preface>

[7] <http://www.samhsa.gov>

[8] <http://store.samhsa.gov/product/TIP-26-Substance-Abuse-Among-Older-Adults/SMA08-3918>



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# Caring Connections Vol11 No3 - Book Review: Goff

## Book Review

# Where Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease

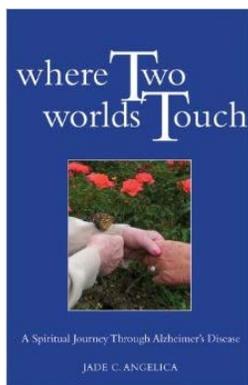
By Jade C. Angelica

Reviewed by Bradford Goff

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**For the newcomer to Alzheimer's Disease, encountering this relentlessly progressive and deadly disease is always at first like the colliding of worlds - known versus unknown, health versus disease, hope versus despair, life versus death, faith versus darkness.**

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So, when a book comes along that addresses this life-shattering disease, such as *When Two Worlds Touch: A Spiritual Journey Through Alzheimer's Disease*, one certainly must admit there is something immensely appealing that such a notion can come out of this shadow-filled "valley" called Alzheimer's.

In her sad but sweet, learned, and ultimately inspired guide for entering the "valley" - with an invitation to follow and potentially come out at the other end kinder, wiser, and more spiritually fulfilled - Rev. Jade C. Angelica takes us through her very personal ten-year experience as caregiver to her mother during her course with Alzheimer's disease, to her death. Rev. Angelica, who has a Masters of Divinity degree from Harvard Divinity School and is founder and director of the Healing Moments Alzheimer's Ministry, is clearly a wise and caring theologian but also a skilled researcher, teacher, writer and expert in this field of Alzheimer's study and treatment.

For any of us who may be dealing with parishioners, patients, or loved ones – or might read this book because we too may someday suffer this affliction personally – this book is always soundly based with up-to-date information about the illness and is filled with well-annotated quotes and references to many clinical

and spiritual experts in the field. And, although the disease still remains terminal for all, this book's core premise that this can be a life-filled and rewarding process from the beginning to the very end – for both caregiver and Alzheimer person – obviously has profound health and spiritual implications for any reader. Even though never sugar-coated in its messages, this easily readable, intentionally lay-oriented book is designed to reduce anyone's deepest fear of even opening the cover. But it never shies from the reality that this process is long, painful, frightening, infuriating, at times fraught with helplessness and even despair, and ultimately requires compassion, acceptance, and surrender, before reconciliation. But still for the caregiver, family member, and loved one, there is promise herein for the potential rewards and greater appreciation of life's mysteries, in spirit.

Clearly, the facts of this still poorly understood disease are not easy to hear. There are currently estimated to be 5.2 million Americans of all ages with Alzheimer's disease, and future projections remain staggering: an estimated 7.1 million by 2025, and then between 13.8 million to 16 million by 2050. Clinical studies have led us to several highly suspicious proteins that accumulate and produce abnormal plaques and clumps in brain cells of the majority of victims, but strangely not all. Genetic makeup is proving to be a profound contributor, which may ultimately guide researchers to identify pharmacological "silver bullets." But even the most promising of drugs in stage 2 trials fail to reduce cognitive decline compared to placebo. However, one study does support reasonable improvements in cognition and global functioning in patients with mild disease, which inspires hope. But with such mixed data, drug companies are reluctant to continue research in the face of equivocal findings, even on potentially promising drugs, given massive costs of clinical trials. This begs for widespread advocacy to continue all efforts.

We are still far away from anything akin to a cure. Yet, as Rev. Angelica aptly points out in one of her early chapters, there can be "healing when there is [still] no cure." How can this be? To find this out, she had to not only make her way to a "healing" for her progressively deteriorating, terminal mother, but also a personal healing. Not an easy course, as she had lived in a family where her mother was continuously alcoholic, often ungrateful, and critically rejecting for years into the author's adult life, leading Rev. Angelica to sever ties for many years. She discloses her history of alcoholism and recovery, entry into the ministry, and pursuit of her personal, professional, and spiritual journey as her mother's illness was diagnosed and required increasing attention and intervention. Hers was a big decision to risk re-opening old wounds and re-engage in her mother's life, at first long-distance in Boston. But, after a surprisingly loving reception from her impaired mother, she made an even riskier choice to return to Iowa to oversee her mother's care during the final three years of life. The choice was life-changing for her and ultimately paved the way toward discovering "healing" interventions.



She introduces us to some tools that helped her engage a person in progressive cognitive decline, with failing organized thinking, memory, and the verbal skills for logical expression. Despite cognitive losses, still present were the myriad of wild emotions and responses to ongoing everyday life experiences and the same wide array of internal reactions and drives, just without cognitive boundaries - sadness, joy, gratitude, libido, anger, fear, rage, hurt, and love. The challenge was how to be with these feelings in the moment and promote meaningful engagement, even a deepening love.

Rev. Angelica happened upon improvisational theater techniques as a means for connecting in positive ways. She teaches us that improvisation is about "accepting the offer that has been extended to you by your scene partner, considering it valid, and then doing or saying the next logical thing." Furthermore, "no-saying" can more often than not be "blocking the offer," leading inevitably to "a very bad scene." By

implication, the "dance of yes and no" in dealing with a person with Alzheimer's, perhaps most clearly represented in our common clinical intervention of "reality orientation" for persons with dementia, may not be the most helpful approach, "as it is about changing people and correcting people." And "being constantly corrected is annoying." How profound, and simple, and begging for practical implementation in the theater of life!

This book is filled with dozens of simple yet profoundly wise examples, demonstrations, and creative improvisations that beautifully provide affirmations to persons profoundly impaired, but still profoundly human, and worthy of all that they might want and need each day of living. Rev. Angelica writes, "learning that saying yes in the context of Alzheimer's is not necessarily about agreement or approval. It's about adopting an attitude of acceptance and affirmation."

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## **This is a story of hope, inspiration, beauty, dedication, and finally spiritual love.**

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The author joins other experts in dispelling the notion that the person with Alzheimer's is "gone," an empty vessel, and therefore useless. Clearly, this may be true from an economic standpoint, so the Alzheimer's person may easily be seen as a burden on family or society. But she points out, "If a person is considered 'gone,' spending limited time and attention elsewhere becomes an easier choice. How I wish everyone could see what I see looking back at me from the sea of wheelchairs: beauty within vulnerability, in-the-moment happiness, gratitude for any kindness, earnest efforts to engage in life at every opportunity, and especially for Mom and me, celebration of one more day together."

This book, in many ways, is a full celebration of life in all its aspects. It is about the unpredictability of life, anticipation of the good future, hope for health and recovery, healing of old wounds, getting desperate news, appreciating the present, deepest loss, absolute helplessness, complete surrender, sorrow, precious memories, forgetting, forgiving, reconciling, and moving on. There are no points left untouched in this self-less, giving, and uplifting tribute and memoir – which would seem from its simple title to at least offer some basic tips in making it through one of life's most challenging and devastating disease processes, a grueling endurance test where life just leaks away, leaving nothing in the end. No such thing! This is a story of hope, inspiration, beauty, dedication, and finally spiritual love. One can only be left thanking Rev. Angelica for this gift to us all - loved ones, family members, caregivers, present and future persons with Alzheimer's - all of us. She lifts us up with her dedication, inspiration, and spirit.

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*Bradford M. Goff, M.D., has served as chairman of the Department of Psychiatry and Behavioral Health Sciences of Lutheran Medical Center in Brooklyn, NY since 2001. Throughout this time period, Dr. Goff has also served part-time at a private practice of psychiatry. He is also a consulting psychiatrist with Calvary Hospital. Prior to joining Lutheran Medical Center, Dr. Goff was the director of Inpatient Psychiatric Services at North General Hospital. Dr. Goff received his medical degree from State University of New York, Downstate Medical Center and completed an internship at the Baylor University Medical Center in Dallas, TX, with residency training at the Timberlawn Psychiatric Hospital in Dallas, TX. Dr. Goff is a Distinguished Fellow of the American Psychiatric Association, and is a member of the New York District Branch of the American Psychiatric Association, the Medical Society of the State of New York and the American Society for Emergency Psychiatry. Dr. Goff is Board Certified in Psychiatry and Neurology.*

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# Caring Connections Vol11 No3 - Book Review: McCaffrey

## Book Review

## Your Legacy Matters

## Harvesting the Love & Lessons of our Lives: A Multi-Generational Guide for Leaving a Legacy

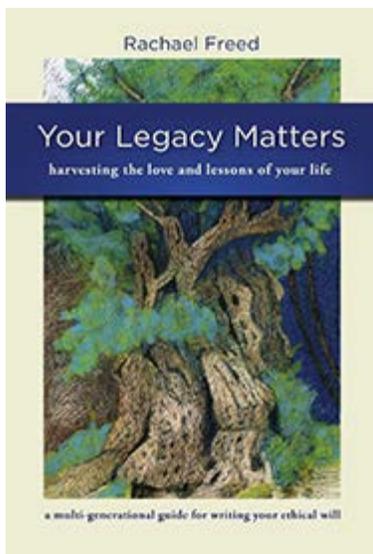
By Rachael Freed

Reviewed by Brian McCaffrey

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**“But for legacy writers of every age, it is urgent to write legacy letters to one another, other loved ones, and to future generations now, given the uncertainties of life and the momentum of change in our times.” (pg.2)**

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“It takes a village to raise a child”; but at what stage of life do we not need a village? My observation is that our emphasis on independence has left the “civil contract” a bit tattered. One might say that many have forgotten how to be a village. We are a village in the midst of wilderness wanderings. A nomadic people need the experience of those in the second half of life to survive. Those in the second half of life have experienced the intricacies of relationships, and have adapted to the wide ranging changes that have always been and always will be part of surviving.

Rachael Freed, through her years of legacy work, teaching, speaking, and writing has become an experienced guide. Through *Your Legacy Matters* she helps us to do so much more than survive; she guides us in uncovering the treasure that we have accumulated over the journey. This treasure becomes the legacy of values we offer through the writing of legacy letters in which we offer stories and blessings to those we know and love, as well as those who

come after.

The first two chapters of *Your Legacy Matters* offer history and a basic definition of legacy writing, the central role of blessing, as well as the similarity and differences between legacy writing and ethical wills. Rachael emphasizes the fact that we all have the ability to bless one another, which seems to be a challenging belief for some. Throughout *Your Legacy Matters* is the belief that we all desire to be blessed. And we all yearn to be whole.

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## **Rachael emphasizes the fact that we all have the ability to bless one another.**

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The next ten chapters create a process raising topics, giving examples asking questions that projects a picture of our life experience: people, relationships, places, events. She has us look at our own name, our family name, stories of our heritage, the immigrant experience, the strengths and dysfunctions passed-on through our families and our hope for future generations that puts our stories in context. In the chapters the wide range of experiences - of making a life, of love, celebration, heartbreak, forgiving, asking to be forgiven, and mourning - become the source of our legacy letters. Rachael brings us further below the surface facts of our lives, giving voice to the inner life where we find our core values and truth. I so appreciate that *Your Legacy Matters* gives room to explore the ways that we nurture our soul. We get to say where we find meaning. The offered examples in each chapter are from real people who have given permission for Rachael to share. I would say that these letters mentor us, they reveal hearts that are blessing the life of another.

Throughout the book Rachael offers very concrete and practical advice as to how to do this work of reflection, where to look for some clues, how to create a midrash with the bits and pieces of facts, keeping copies and sending letters. I particularly appreciate her practical work on tying up loose ends and dealing with our “stuff”. I know as a Long Term Care chaplain that when someone moves into a nursing home, each and every personal item – photos, paintings, knick-knacks, furniture - becomes a symbol of so much more, which is not realized by others until the stories are told.

She guides us through some of the conversations that we don't want to have:

- What kind of medical care do we want and not want.
- Where wills and other important papers are kept.
- Who should be our medical spokesperson.
- Who should have power of attorney.
- Wrangling over who is going to get what, after the folks are dead, has driven a wedge between countless siblings. So, actually talking about who wants what and making sure that everyone knows becomes a load lifted off many shoulders.
- Plans for the funeral.
- Talking about changes as we age.

*Your Legacy Matters* offers what is necessary for people to recognize they have a legacy worth leaving to the next generation. The world needs people who are growing not only older, but wiser. Rachael offers us a process that lets us reflect upon the big picture of our lives. Wisdom is not about learning anything new but rather gaining a different perspective. The process of reflection and writing offers us new vantage points from which to look upon our lives. Through questions and examples she sharpens our awareness of where we have come from, who have been our companions on the way, what experiences and ideas have shaped us. A photo in an album with a name and a date does not remain a bare fact, but becomes a

full story. A chance encounter, a piece on the news, a song on the radio, a sunrise shared are identified as transformative moments. Even more comes to life as we look to the future, revealing our hopes and dreams for the ones we love as well as the ones yet to come. We say what we have found important. We bear witness to lives lived fully. The letters that we write and the blessings that we offer become the treasures of another generation.

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## We get to say where we find meaning.

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Through working the process in *Your Legacy Matters* we recognize that we have not been alone in our wilderness wanderings. We may find that some of the stones we've stumbled over and cursed have turned out to be exceedingly valuable; our experience, strength, and hope allows us to take our place among the villagers, to draw together in a celebration of life as we offer encouragement and support to each other and those yet to come.

Rachael Freed, founder of Life-Legacies, is a Senior Fellow at the University of Minnesota's Center for Spirituality and Healing, a Licensed Clinical Social Worker, and emeritus Marriage and Family Therapist. Her work, transformed from the ancient ethical will, is explained on her website. Her writing about Legacy appears regularly on The Huffington Post-GPS for the Soul, DrWeil.com, and LegacyConnect.com. She is the author of *Women's Lives, Women's Legacies, Passing Your Beliefs and Blessings to Future Generations, The Legacy Workbook for the Busy Woman*, and *Your Legacy Matters: a multi-generational guide for writing your ethical will*. Freed also writes a monthly subscription e-offering, Legacy Tips & Tools. Subscriptions at [www.life-legacies.com](http://www.life-legacies.com) [1]. Freed has trained cardiac professionals internationally to support cardiac families. Her book and journal, *Heartmates: A Guide for the Partner and Family of the Heart Patient* and *The Heartmates Journal: A Companion for Partners of People with Heart Disease*, are the only resources available supporting the emotional and spiritual recovery of families coping with heart disease. For more information, visit [www.heartmates.us](http://www.heartmates.us) [2].

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*Rev. Brian McCaffrey, Chaplain at Lutheran Care, Clinton, NY, also serves as the chair of the Northeast Forum on Spirituality and Aging, and on the editorial board of Caring Connections. He invites anyone who would like to join the discussions at the LinkedIn Group: Aging and Spirituality - Second Half of Life Ministry.*

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[1] <http://www.life-legacies.com>

[2] <http://www.heartmates.us>



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## About Caring Connections

*Caring Connections: An Inter-Lutheran Journal for Practitioners and Teachers of Pastoral Care and Counseling* is written by and for Lutheran practitioners and educators in the fields of pastoral care, counseling, and education. Seeking to promote both breadth and depth of reflection on the theology and practice of ministry in the Lutheran tradition, *Caring Connections* intends to be academically informed, yet readable; solidly grounded in the practice of ministry; and theologically probing.

*Caring Connections* seeks to reach a broad readership, including chaplains, pastoral counselors, seminary faculty and other teachers in academic settings, clinical educators, synod and district leaders, others in specialized ministries and — not least — concerned congregational pastors and laity. *Caring Connections* also provides news and information about activities, events and opportunities of interest to diverse constituencies in specialized ministries.

**Editorial Office:** Editor, *Caring Connections*, c/o Lutheran Services in America, 100 Maryland Ave., Suite 500, Washington, DC, 20002, email: [cweinrich@cfl.rr.com](mailto:cweinrich@cfl.rr.com) <sup>[1]</sup> or [DStiger@lmcmc.com](mailto:DStiger@lmcmc.com) <sup>[2]</sup>.

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**News, Announcements, Events:** E-mail items to [Judith Simonson](mailto:Judith.Simonson@lutheranservices.org) <sup>[4]</sup> or [John Fale](mailto:John.Fale@lutheranservices.org) <sup>[5]</sup>.

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