

**Aging, Dementia, and the  
Faith Community**  
*Continuing the Journey of Friendship*

**JOHN T. MCFADDEN, M.DIV.**  
*Chaplain, Appleton Health Care Center (Appleton, WI)*

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*CONTINUING THE JOURNEY OF FRIENDSHIP*  
By John T. McFadden

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**W**E ARE an aging society. Each day, more people in the United States turn 85 than babies are born. By 2030, roughly 20% of the US population will be 65 or older, and in most congregations that percentage will be much higher. Although some congregations devote a large proportion of their resources to ministries with children and youth, claiming that they represent “the future of the church,” the future of many congregations actually lies with their older members. Congregations in our time are called to learn how to age together in grace, joy, friendship, service and faithful discipleship.

For some of us, the journey of aging will include the reality of dementia, the progressive loss of cognitive function. By age 65, approximately one person in seven is already experiencing the changes in the brain that may ultimately lead to the symptoms of Alzheimer’s disease or some other form of dementia. At age 72, one person in three experiences measurable cognitive loss and at 85 up to half of us will be living with some form of dementia. How do we continue to share a joyous, meaningful Christian friendship when our friend no longer remembers the story of our friendship? How can congregations extend hospitality and practice inclusion with cherished members who are journeying into progressive memory loss? How will we serve those outside of our congregations who experience dementia, or care for someone who does? As the 77 million members of the baby boom cohort move into late life, these questions will be critical to the mission and identity of the church.

## A FEW WORDS ABOUT DEMENTIA

A full description of the various progressive, cognitive diseases that are collectively termed dementia lies beyond the scope of this pamphlet, but a few words may prove helpful. It is not uncommon for the word “dementia” to be used interchangeably with “Alzheimer’s disease” which, while far and away the most common form of dementia, is but one of many, including Lewy Body disease, frontotemporal lobar dementia, the dementia associated with Parkinson’s disease, vascular dementia, and others. The primary focus here will be on Alzheimer’s disease, because if we include the cases where it co-occurs with another form of dementia, it accounts for up to 70% of all dementias.

Biomedically, Alzheimer’s disease (AD) is marked by changes in the brain that often begin ten or even fifteen years before symptoms appear. Most researchers believe these changes are caused by the accumulation of excessive quantities of two proteins. One, the beta amyloid protein, forms a plaque that lies outside of neurons and interferes with their ability to communicate. The tau protein forms what are termed “tangles” within the neurons themselves. These changes inside and outside of neurons eventually lead to cell death.

As the disease progresses, it becomes harder for people to retain memories of recent events. There is often a decline in “executive function;” the ability to make plans and follow through, or to carry out routine activities (balancing a checkbook, preparing a meal, etc.) They may become lost while walking or driving a familiar route. Over time, even the persons to whom they are closest may no longer be recognized (although, as we will see later, “recognition” may still be possible in important ways, even if the specifics of the relationship are no longer remembered).

Why do these proteins accumulate in some persons and not others? We don’t know. Only one form of AD—“Young-Onset AD,” which typically occurs at a much younger age than “standard”

AD—has been definitively demonstrated to have a genetic tie. But we have growing evidence that not everyone who experiences the brain changes associated with AD will develop the symptoms at the same rate or with equal severity. A wide range of lifestyle practices—regular exercise, healthy diet, non-smoking, controlled weight, social engagement, etc.—may slow the progression of the disease or mitigate its severity. Persons who self-describe as “religious” also tend to fare better than average (but interestingly, not those whose religious beliefs breed anxiety). An ongoing longitudinal study of an order of nuns, the School Sisters of Notre Dame, suggests that they experience the symptoms of dementia at an extraordinarily low rate, even though brain autopsies performed after death show the changes in the brain associated with AD at about the same rate as the overall population. Likely many factors contribute to this. They are a teaching order, so life is marked by intellectual stimulation. They eat a healthy diet and exercise regularly. Their daily life is marked by structure and ritual, they share bonds of loving support, and their lives are centered in God rather than themselves. In other words, their lives are deeply relational, with strong connections to God, to other persons, and to the created order. While there may be loss in an individual’s memory (as there is to some degree for all elders), the collective memory shared by the community enfolds them in a manner that helps to compensate for individual loss.

Of course it is entirely possible to do everything “right” and still develop dementia, but there is growing evidence that lifestyle choices can make a difference in many cases, and that the more connected we are with sources of meaning beyond ourselves the greater the possibility that dementia will develop more slowly or be experienced less severely.

Will we ever have a medical cure for AD and other dementias? As a culture we have high expectations that science and medicine can prevent or cure our diseases, but currently AD defies tidy categorization as a single disease that can be prevented or cured

by a pharmacological “magic bullet.” There are some who argue that categorizing AD as a disease at all is unhelpful; these scientists insist that cognitive change and memory loss occurs across such a wide spectrum that hard categories serve only to increase fear and stigma.

Presently several medications offer modest but meaningful benefit for some persons with early-stage AD, at least for a few years. These medications have been in use for almost twenty years, and there are no new “miracle drugs” on the near horizon. Most current research suggests that once the brain has been damaged sufficiently to be expressed in the symptoms of AD, it is too late for meaningful pharmacological intervention. The hope in the long term is that we will develop “upstream” interventions—medications that can be employed many years before symptoms appear that will delay their onset or lessen their severity. Such interventions will demand new diagnostic techniques to detect distinctive biomarkers for AD that may be present in blood or spinal fluid.

### **DIAGNOSIS: DO WE WANT TO KNOW?**

Currently, diagnosis of dementia is possible only after symptoms have presented. A full cognitive evaluation is a lengthy, thorough process that must be administered by a person—usually a psychiatrist, neurologist, or a psychiatric nurse—who is highly trained and skilled. We are woefully lacking in settings where such assessments can be properly performed. Only one person in three with dementia is ever diagnosed at all. Of those who are, on average the diagnosis takes place two years after symptoms first appear. This delay can be attributed in part to anxiety about being diagnosed, either on the part of the person or the part of family members who wish to deny the changes. But even when a person seeks a diagnosis, it is not uncommon to face a six-month wait for an appointment. These are months, or years, where meaningful interventions (especially in the form of lifestyle changes) could be taking place.

A proper assessment will be done with sensitivity and respect for the person, and the diagnosis—often expressed in cautious terms such as “probable Alzheimer’s disease”—will be framed in hopeful terms rooted in the conviction that life can continue to be rich, joyous and meaningful. Unfortunately, this is not always the case. Some physicians look past the person and tell a family member “Your mother has Alzheimer’s.”

As new techniques become available to allow early diagnosis based on biomarkers, many people will struggle with the question “Why would I want to know if it cannot be prevented or cured?” Early diagnosis has value for many reasons. It allows the person diagnosed to make realistic plans for a future that will bring many changes, but can still be good. It also permits planning for a good death, because AD is a terminal disease whose course typically runs seven or eight years from diagnosis, although some persons may live, and live well, for a far longer period. It provides an incentive to make lifestyle changes that may slow the progression of symptoms and will certainly improve overall quality of life. It encourages people to focus on the things that matter most, including their relationships with God, family and friends. And it permits the journey to be shared in community with others, rather than undertaken (as it too often is in our culture) as a private and personal “tragedy” marked by stigma and isolation.

### PERSONHOOD, THE DIVINE IMAGE, AND DEMENTIA

AD has sometimes been termed “the theological disease” because of the fundamental questions it raises about selfhood and the *imago Dei*. In the time of Jesus, selfhood and the divine image were strongly associated with corporality, which is why leprosy was so widely feared. The physical disfigurement caused by Hansen’s disease robbed its victims of their essential identity as the “self” they had known. Additionally, those with leprosy were barred from

entering the Temple because they were no longer perfect offerings—no longer fully formed in the divine image—limiting direct access to the presence of God. Purity laws also removed them from their normal role in the web of relationships that constituted community; lepers were unclean, and therefore barred from physical contact with friends and neighbors. When Jesus touched lepers, as he so often did, he provided healing in multiple ways, restoring their selfhood, affirming their relationship with God, and restoring their relationship with the persons who constituted their community.

In our era, selfhood and the *imago Dei* are almost exclusively associated with cognition: “I think, therefore I am.” Cognition is essential to the abilities we have been taught give our lives worth and meaning: productivity, autonomy, independence, etc. Dementia is the most feared illness among persons over the age of 65 because it threatens our identity as selves and our role as productive, contributing members of the community. The constructs of modernity tell us that “becoming a burden on others” marks us as a failure at the task of successful aging.

Even as those with leprosy were barred from the Temple and removed from social relationships with others, the shame and stigma too often associated with dementia can lead to similar isolation. Friends may stop calling or visiting, mumbling phrases like “he’s just an empty shell of the man he used to be.” Family members may cease bringing the person with dementia to participate in worship, claiming “she really doesn’t get anything out of it anymore.” Too often we fail the tests of friendship and community, treating the person living with dementia as one who has already passed from this world.

But Christians have a different story to tell about what gives our lives worth, value and meaning. Personhood is not defined solely by our corporal bodies or our cognitive abilities, but rather by our relationships with others. And we are creatures created in the divine image not because we physically or intellectually re-

semble the Almighty One, but because God remains in faithful relationship with us in all circumstances and conditions. God's goodness can be experienced within the reality of cognitive loss, even as it can be within physical disability, chronic pain or heart-rending grief.

Some question whether persons with dementia can continue to live their faith if they are no longer able to remember God. They can, because faith is not dependent upon individual memories or cognitive ability. If we should forget God, God will not forget us. And if we forget God, our community of faith can remember us to God and bring God's presence into our lives through means that do not require us to grasp that presence cognitively.

## DEMENTIA AND THE PRACTICES OF CHRISTIAN COMMUNITY

The practice of corporate worship is central to the life of the congregation. We earlier noted that it is not uncommon to hear the excuse "she really doesn't get anything out of it anymore" to explain the absence of a cherished member from the worship life of the church. Translated, this means "she is not able to follow the pastor's exquisitely reasoned sermon." Preachers would ruefully acknowledge that if this were the sole criterion for "getting anything out of" worship, perhaps a third of the persons present on a given Sunday get nothing out of it. But what of a liturgy that has been so deeply practiced for many years that its comfort and truth speak to us on levels deeper than cognition? What about singing the familiar hymns (and singing often remains possible, and enjoyable, even when speech becomes limited) and hearing the scriptures that have formed and shaped our being? Does the person with dementia "get nothing out of" these components of worship? Surely they do, even as all of us are spiritually fed by dimensions of worship, especially the sacraments, which we apprehend through channels far deeper than mere cognition.

Corporate worship also provides us with the important experience of being a part of the gathered community of friends whose lives are deeply interwoven with our own, friends who call us by name and greet us with a smile or an embrace. If our own memory has faded, is it not a wonderful thing to gather with persons who know us in deep, abiding ways, friends to whom we have entrusted portions of our own experiences, and therefore of our memory?

Sometimes family members are embarrassed to bring a cherished one with dementia to worship for fear that the person will behave “inappropriately.” Dementia sometimes brings a loss of social inhibition expressed, for example, by bursting into spontaneous speech or song. Of course, this also describes the occasional behavior of the children we are glad to welcome into our worship life. The experience of corporate worship can remain central to the life of the member with dementia. Indeed, the social engagement alone may have a significant impact on the person’s well-being well into the new week.

Many congregations have found creative ways to accommodate the needs of members with various disabilities, and dementia is likewise a disability that can be accommodated. In one congregation, a beloved member with mid-stage AD was able to read one of the scripture texts to the congregation so long as a companion ran a finger down the page to keep the reader’s attention focused on the line being read. It is entirely possible that an hour later the person no longer remembered reading the lesson, but while doing so she was fully engaged in the experience of leading the congregation in its act of worship. The failure to include our friends with dementia in the worship service is largely a failure of creative imagination.

It is also possible to design a complete worship service specifically for persons with dementia. Here the focus will be upon familiar texts, prayers and hymns—the things so deeply learned through long practice that they continue to reside in the depths of the soul when cognition is diminished. Persons who are largely

lost the ability to speak may still be able to recite the Lord's Prayer or the 23<sup>rd</sup> Psalm, even as persons with advanced dementia may retain the ability to play a musical instrument. Sacraments can play a central role in such services. A man attending Roman Catholic Mass in a nursing home showed no evidence of knowing where he was or what was happening around him until he was approached with the Host. He immediately opened his mouth, in his daughter's words, "like a small bird in the nest about to be fed." Deep encounter with holy mystery remains possible within the reality of dementia. Such a service needs to allow room for spontaneity and the unexpected, which is to say it must remain open to the workings of the Holy Spirit. Such services can also result in the spiritual growth of the pastor, who is likely to be healed of the sinful conceit that he or she was ever "in control" of a worship service.

Likewise the member living with dementia can be incorporated into the mission and service activities of the congregation. Too often we regard elders in general as being beyond the obligation to serve others, depriving them of their identity as Christ's disciples. We assign them to reductionist categories—"our shut-ins" or "the home-bound"—that make them the objects of pity rather than fellow members of the faith community who have stories to tell and gifts to share. Particularly when cognitive loss enters the picture, we assume that they can only be the recipients of care from others rather than persons actively engaged in Christian service.

Abraham Joshua Heschel taught that it is through the experience of being obligated that we truly exist, and many elders living with dementia wish to continue to serve others in meaningful ways. In one setting, people with dementia tutor small children in reading. They may not remember the name of the child from visit to visit, but remain capable of reading aloud and coaching their young readers. In a Jewish extended care facility, residents with dementia make crafts whose sale supports scholarships for students in Israel. Perhaps the dollar amount is small, but they are able to fulfill their obligation to serve others, affirming their faith identity.

The pastor of a church in Wisconsin spoke of the cognitive decline in the woman who chairs their stewardship committee: “She loves doing this and is a faithful giver to the church; I just couldn’t tell her to resign. We work around it.” It is an ethical requirement of Christian community to support one another’s effort to live the commandment “love your neighbor as yourself.” Dementia does not reduce our capacity to love, or our need to give that love expression in caring for others.

Worship, fellowship, Bible study and prayer groups, mission and service: members with dementia can share in, and contribute to, many dimensions of church life. As they do, they will offer profound gifts to those of us not (yet) on the road to cognitive loss, not the least of which is to teach us to reject the stigmatization of dementia and to overcome our own fear of it.

Some persons with advanced dementia will ultimately need the higher level of care provided by a memory care unit in a skilled nursing facility. But even in such circumstances, they remain members of the faith community. They must remain in our prayers, and as faithful Christian friends we are called to bring the presence of God to them by sharing time with them. Christian friendship continues to be our obligation, and our joy.

## THE PRACTICE OF FRIENDSHIP

Aristotle described two forms of incomplete friendship. The first is friendship centered in *utility*: how can this person be useful to me and what must I give in return in order to receive these useful services? In this model, our “friends” are the people who can advance our career or social life, or those who can drive our children to hockey lessons. We seek to provide similar services in return so that the relationship of mutual benefit can continue. Friendship of this sort resembles a series of business transactions, where what we give and receive has value to both parties. But, noted Aristotle,

such friendships are ultimately disposable. When I no longer find my friend “useful,” I am free to end the relationship.

So prevalent is this model of utilitarian friendship in our culture that one of the most frequently expressed fears of older persons is that of becoming “useless” or “a burden to others,” and having friends fall away as a result. Although Paul instructed us to bear one another’s burdens, we resist acknowledging our vulnerability and dependence upon one another (even though our vulnerability and dependence upon others define our very humanity). The fear of developing dementia is in part the fear of being abandoned by friends because we will no longer be able to contribute anything “useful” to the relationship.

Aristotle’s second form of incomplete friendship is centered in *pleasure*, in which friendship is defined by sharing mutual tastes and interests and enjoying one another’s company. Our friends are the people who cheer for the same sports team, vote for the same political party, or purchase the same consumer goods. They are the people “just like us” whose company we enjoy. But if pleasure is the sole basis of friendship, Aristotle cautioned, we are likely to withdraw from the relationship when we no longer find it pleasurable to be in that friend’s presence, for we have no deeper loyalty to bind us to one another in a time of conflict, loss or pain. We have no particular motivation to support our friend in illness or grief, or to take the risk of calling our friend to accountability when he or she engages in hurtful or destructive behaviors, for such things are not enjoyable. Like those centered in utility, friendships of pleasure are disposable, and therefore incomplete.

For the person journeying into dementia, the fear of no longer being enjoyable to others is added to the fear of no longer being useful. Friends will sometimes find it awkward or uncomfortable to be in the presence of someone with dementia; they are uncertain of what to say or do, and therefore find excuses to avoid visiting.

The only form of friendship that is complete, said Aristotle, is the friendship of *virtue*, friendship whose goal is to help one another live good and ethical lives. Such friendship will have components of the incomplete forms of friendship—that is, we will seek to help one another and would hope to enjoy one another—but is centered in genuine commitment to help one another become better people. Aristotle described at length the features that characterize such a virtuous friendship: we wish good for our friends, we seek to guard and protect them, we commit to spending time with them, we share common choices and decisions centered in our efforts to live virtuous lives, and we share in our friends’ joys and sorrows.

If Christian community is, as it must be, a web of virtuous friendships, then we are not free to abandon our friends who journey into dementia. But it is one thing to carry the intention to continue our friendship, and quite another to know how to do so, particularly when dementia has reached an advanced stage. The friendship we have shared for many years was formed by common experiences that have now become shared memories. How can I be a virtuous friend to someone who no longer remembers the story of our friendship, a friend who may no longer even recognize me by name or face?

Too often, we are unwilling to give our friends permission to enter into the world of confusion and memory loss. We greet them (often in an overly loud voice) with a string of questions. “Do you know who I am? What day is it? What did you have for breakfast?” Consciously or not, we are attempting to pull them back from memory loss and orient them to the cognitive universe they formerly inhabited. But in such efforts, we usually succeed only in creating anxiety and agitation.

For many people, the journey of dementia is one from a world shaped primarily by reason to one shaped by emotion. Persons living with AD can often pick up on subtle cues to the emotional state of others in ways we do not fully understand. Joy tends to

be more joyous and sorrow more sorrowful, and both states can persist long beyond the event that precipitated them. To share in a virtuous friendship with someone experiencing dementia, we need to learn to be present to them emotionally in ways that bring them comfort, joy, and freedom from anxiety.

When we visit our friend (particularly one whose dementia is in a fairly advanced stage), whether in the friend's home or a care facility, we should greet her gently and positively. Do not ask "do you know who I am?" but rather announce who you are. "Hello, it's your friend John. You look good today! Is this a good time to visit?" Even these few words may not be fully processed cognitively, but a positive emotional tone has been established.

Learn the practice of being in the present moment with your friend. Conversation may flit from topic to topic rapidly, and at times you may not know precisely what the topic is. Simply allow the conversation to flow where it wishes to go. To your surprise, you may find yourself taking great pleasure in a conversation that might appear nonsensical to others. The greatest joy of conversation with a dear friend lies not in the topics discussed, but in the emotional connection formed in the process. When spending time with your friend who is living with dementia, you will likely not discuss world affairs or great ideas; you can read the newspaper when you get home. In the present moment, you and your friend are simply enjoying the pleasure of one another's company.

Because you have shared a common story with your friend, perhaps for many years, you know important things about your friend that he may no longer know about himself. You know his interests, his passions, the things that bring him joy. Listen together to a piece of music he loves. He may no longer recognize the composer, but that will not diminish the pleasure it brings. Take a walk together and appreciate the goodness of the created order. Look through books of photographs or family albums. Do not engage in a game of twenty questions. When you point to a picture, do not ask "Who is this?" for your friend may not know,

even if it is a close friend or family member. Rather, ask: “What do you think she is doing?” Creativity and imagination can flourish within dementia.

Will your friend know who you are? Perhaps not, at least by name. But this does not mean that your friend does not know you as one who cares, and who brings comfort and pleasure. A woman who ached terribly because her beloved mother no longer recognized her told with delight of the morning her mother, who was rarely verbal, looked directly at her and said “I don’t know who you are, but I love you!” The soul continues to know those it cherishes, even if the brain can no longer supply a cognitive context.

There may be days where your friend does not receive you gladly, and your presence appears to cause agitation rather than pleasure. It likely has nothing to do with you; perhaps something happened earlier in the day that has left your friend in a distressed state. Accept this, and try another day.

You may be initially surprised to discover how much pleasure you take in these visits. Within the very real losses brought by dementia, those things that form the core of our personhood abide. You friend may occasionally deliver a “zinger” that takes you by surprise, and forces you to challenge the cultural assumption that your friend is now an “empty shell.” You will find yourself laughing with more abandon than you are accustomed to, because your friend’s joy is so deep and infectious. Yes, your friend is living with dementia, but your friend is still your friend. And your friend has much to give you and to teach you, especially the critical teaching that we are most fully alive when we slow down to live joyously in the present moment.

## SHARING THE JOURNEY IN COMMUNITY

Learning to be present to a friend with advanced dementia is easier if we have shared the journey with her from the time of her diagnosis. Too often dementia is regarded as a shameful private

matter, shared only with immediate family. It was not so many years ago that the word “cancer” was whispered (if spoken at all), as if the very word could infect others, and the person diagnosed with it withdrew from communal life. Now it is dementia that carries this kind of stigma and is surrounded by fear. Congregations must reject this stigma and learn to regard dementia for what it is: a part of the journey of aging for up to half of us. We must create communal settings of trust where all of the circumstances of our lives, including cognitive loss, can be comfortably shared in the expectation that our friends will grieve with us, plan with us and support us on a journey with many unknowns.

The congregational practices that provide a hospitable, supportive environment for friends journeying into memory loss are the same practices that make the life of the community rich for all who participate. Among these are:

**Attentive listening**—Sometimes a person with early-stage AD will have difficulty with word-finding; the thought he wishes to share will be perfectly clear in his mind, but critical words needed to express that thought will sometimes lie just beyond his reach. It is quite understandable that his friends will be tempted to fill in the missing word for him, sometimes making multiple guesses. This can be frustrating and even frightening for the person struggling to find the appropriate word. Rather than completing his sentence for him, it is more helpful to touch his arm softly and encourage him to take his time. Our friends with memory loss can help the entire congregation learn how to enter the fullness of the present moment together; to listen attentively and be fully present to one another.

**Patience and kindness**—One of the most common early symptoms of AD is to have short-term memory lose its “stickiness.” New information is not easily retained. He may ask you a question he asked just minutes earlier with

no knowledge of the previous transaction. She may tell you something for the second or third time in a short space of time. Again it is an understandable response to wish to say “You already told me that!” which again leads to frustration or anxiety. Sharing the goodness of life with friends contending with early-stage AD means calmly answering the same question or hearing the same story again.

**Focus on ability rather than limitation**—We have already discussed some of the ways that members with memory loss can contribute to congregational life. We could add many more. Since music is one of the “deeply practiced” things that can abide well into the journey of dementia, persons living with dementia often remain active in church choirs for many years after diagnosis. Many of the “housekeeping” tasks essential to all faith communities—preparing communion elements, arranging altar flowers, assisting with office functions, etc.—remain not just possible, but enjoyable, particularly in the social interactions that accompany sharing a task with one another. Perhaps he can no longer manage the church finances, but there remain many ways for him to contribute to the life of the community.

**Provide needed practical support**—As dementia progresses, practical needs will increase. A time will come when the person can no longer drive an automobile safely, and will need transportation to the grocery store, doctor’s appointments, church, etc. If she is living alone, she may require assistance in keeping her home clean and organized. If he is living with a spouse or child, that primary caregiver will require occasional respite care. If the journey is being shared openly and honestly with the community, the person with dementia can—and should—share in making decisions about new forms of support that are required.

**Maintain an environment free from stigma and anxiety—**

The shared life of the congregation should be a primary setting where persons journeying into dementia (and their care partners) should always know that they are among people who know them and love them, and among whom they need not attempt to disguise the symptoms of dementia. Such a stigma-free environment is in itself a powerful agent of healing. Simply to be able to relax and enjoy the company of others without the need to apologize or explain makes a dramatic impact on the quality of life. In this sense, the church can manifest Christ's healing presence in its day-to-day life.

**Involve the entire community, including children and youth—**

Misguided people have the notion that the young must somehow be “protected” from the reality of dementia. In truth, the young are in some ways more open to appreciating and enjoying the presence of elders living with dementia. The very young do not need complex explanations beyond “Mrs. Smith has some problems with her memory” in order to appreciate her gifts. Members with AD can continue to volunteer in church schools, support youth mission projects, etc. The young and the old have important gifts to share with one another, and faith communities should enable such intergenerational friendships.

**The role of pastoral leadership—**

Sadly, there are pastors who are reluctant to speak of dementia in sermons, sometimes out of their own fears and sometimes because of anxiety that addressing this issue honestly and faithfully will make others uncomfortable. Confronting the manner in which our culture surrounds dementia with stigma is an essential prophetic task. Pastors must also provide leadership by extending themselves in pastoral love to those who are living with dementia and those who provide their care. If pastors regard persons with

dementia as not worthy of their time and attention, the congregation is not likely to think or act differently.

## ADVOCACY AND EDUCATION

A narrative of fear about dementia is pervasive in our culture, notably in fund-raising materials soliciting contributions for research. We are told that the baby-boom generation will spend their retirements either “ravaged” by the “living death” of AD or caring for someone who is “fading away.” Alarmists say that millions of people will soon be diagnosed with AD, and that they will overwhelm our health care system and bankrupt Medicare.

The church must counter this narrative of fear with a narrative of hope. We are not speaking of the hope that a vaccine or miracle drug will be developed quickly if we invest sufficient funds in research. Such research is certainly desirable, but even if effective pharmacological interventions are developed they will likely not be of help to those already living with AD. The narrative of hope is centered in another vision: communities that open up hospitable space in which both the persons diagnosed and their care partners may flourish; of a society that has replaced fear and stigma with friendship and support; and a culture that honors, respects and values its elders who are experiencing cognitive loss.

The narrative of hope begins with education. A congregation that has learned to understand dementia as a disability within which a person’s life may still flourish rather than as a stigmatizing disease may in turn educate others so that we can create “dementia-friendly” communities that are fully inclusive of persons journeying into memory loss rather than isolating them in their homes or in skilled-care facilities.

Some of us remember a time in our society when children born with physical or cognitive disabilities were routinely declared wards of the state, residing in institutions geographically removed from their families and communities. It was believed that their

parents were not equipped to meet their needs. Unspoken was the assumption that “these kinds of people” could not be successfully integrated into the community, and that their presence might be disturbing to others. We look back on that era and think “how barbaric!” Persons living with disabilities are now present in our workplaces and public spaces; physical facilities are required by law to accommodate their special needs. Our society is richer and healthier because persons with disabilities are included in its fabric.

Dr. Richard Taylor, an advocate for persons with dementia who is himself living with AD, argues that dementia rights are 40 years behind disability rights. We no longer stigmatize cerebral palsy, but we continue to stigmatize dementia, and in ways both subtle and direct exclude those living with it from the shared life of the community.

Some forms of disability can be accommodated with a wheelchair ramp or an automatic door. Dementia can be accommodated with patience and kindness. The great majority of persons truly want to be kind and hospitable, but fear of the unknown can be a significant barrier. If a person with dementia is struggling to place her order with a waiter who does not know she has dementia or does not understand what dementia is, he may be frightened. What is wrong with this person? Is she suffering a stroke or heart attack? What about the people at my other tables, waiting for their meals? An educated waiter will be able to pick up cues that point to the person’s condition, or receive a discreet word from her dining companion. Rather than responding with anxiety or annoyance, he may say “let me give you a little more time” or make helpful suggestions: “The chicken is very good; would you like to have that?” We are fearful of or annoyed by persons living with dementia because we lack direct experience of sharing public space with them. The more persons with dementia venture out into community, the easier it will be for the community to learn how to welcome and include them.

Particularly in need of education are those who work on the “front line” of organizations that regularly serve older persons: hair stylists, bank tellers, retail clerks, etc. Likewise those who work in museums, YMCAs, public parks and a host of other settings must learn how to extend hospitality to those with dementia, their caregivers and friends.

Advocacy and education must also be extended into the workplace. Many persons with early-stage AD are fully capable of continuing employment, whether financially compensated or in a volunteer capacity. Not only will the workplace benefit from their continuing abilities, but the social interaction of the workplace will improve the quality of life for the worker.

The American Alzheimer’s Association’s store sells small cards that read: “The person I am with has Alzheimer’s. Please be patient. Thank you.” Friends and care partners report that discreetly displaying that card is often transformative; a sales clerk who had been anxious, even frightened before seeing it is able to focus on being present in kindness and patience. As more and more persons with AD or other dementias share in our common life, we can look to a day when such cards are no longer necessary.

## MISSION AND SERVICE

Our society is prone to privatize and medicalize a wide range of experiences, including our suffering, looking to physicians rather than to the community for healing and wholeness. This is certainly true of dementia, widely regarded as a personal tragedy to be addressed only by the immediate family and health care professionals. This is not true in all societies. A physician who grew up in Taiwan noted that she never realized that her grandfather had AD until she attended medical school in the US and took her first class in geriatric medicine. “He changed as he got older, but to us he was just “grandfather.”

In many European nations, a variety of community-based programs serve those journeying into dementia and their care partners in ways that make life richer and more joyous, and help maintain their integration with the community. These programs are inexpensive and do not require complex organization or special expertise to organize or maintain; they are well within the ability of most congregations. Several are described here (references and resources are included at the end of this pamphlet).

**Memory Cafes**—Memory Cafes were first established in Holland more than a decade ago, and now proliferate throughout Europe, particularly in the U.K. They are just beginning to become established in the US. While there are many variations, they share core themes in common. They are typically offered every other week in the afternoon. The setting may be a church or community center. Persons with mild to moderate dementia attend with a family member or friend to share two hours of creative, joyous social time in a setting free from stigma and anxiety. The program almost always includes refreshments (in England this means tea with biscuits or cake), group singing, games (sometimes designed to recall happy memories), and perhaps an art project or other creative activity. Raffles in which small prizes are given are quite popular. Inevitably, the joyous atmosphere leads to a “softening of the categories;” at times it is hard to know for certain which participants have dementia and which do not. Trained volunteers guide the activities and make themselves present to participants. There is usually a nurse or social worker available to answer questions and provide information about other resources. It would be hard to overstate the difference Memory Cafes make in the lives of those who participate. As one woman expressed it, “I arrive with a stranger and leave with my husband!” There is never a charge for participation, but most attendees choose to make a direct donation

or purchase raffle tickets, making the program self-sustaining. Hosting a Memory Café is perhaps the single most effective outreach program a congregation could develop to begin building a dementia-friendly community.

**Singing for the Brain**—This can be an independent program, or it can be incorporated into a Memory Café. Since musical memory resides in a different area of the brain than language, often persons who struggle with speech can still find great pleasure in singing. Generally participants (again including both persons with dementia and their care partners or friends) are seated in a circle. A trained facilitator opens the gathering by helping all those present to greet one another by name in song, then they sing a variety of familiar songs as a group. Like a Memory Café, Singing for the Brain creates a setting where categories soften and joy abounds, lifting spirits in a manner that can persist long after the gathering ends. One woman who brings her largely aphasic husband to the gatherings reports that he is most likely to initiate conversation with her after attending. For churches with a music program, this would be another simple and low-cost form of community outreach.

**Organized outings and creative engagement**—Too often dementia causes the world to become smaller for both the person diagnosed and his or her care partners. Organizing outings to museums, gardens and other interesting settings opens that world up and provides wonderful stimulation. Engagement with the arts can be particularly meaningful, for the arts speak to us on many levels, emotional as well as cognitive. The Museum of Modern Art in New York City has sponsored the program “Meet me at MOMA,” for a number of years, inspiring similar programs like the Spark! Alliance (cultural programming for people with memory loss) that includes 10 museums

in Wisconsin and Minnesota. Trained guides help their visitors with memory loss to engage with a work of art, culture or history, and sometimes to participate in an art project themselves. Most communities feature a history or art museum, or perhaps a botanical garden, suitable for such outings. Typically these programs are offered on a day where the institution is closed to the general public, sheltering participants from overstimulation and allowing staff to focus on this special opportunity.

**Respite Care**—Too often the primary family care partner of a person with dementia is overstressed and unsupported in this challenging role. Sometimes the most significant way we can help persons with dementia is to provide support for those who care for them, enabling them to continue caring for them in their own home and community when they might otherwise need to cede that role to a skilled-care facility. Setting up a full program of respite care (perhaps for three hours each week) in a church is certainly possible, but the program would need to be carefully designed and well-staffed to make certain that it is safe for those who attend. Another option would be to train volunteers to provide respite care in the home so that the primary care partner can run errands, attend to personal needs, or simply have lunch with a friend. One more possibility would be to train volunteers to respond to crisis situations that develop in the home setting, stepping in on short notice when the primary caregiver becomes overwhelmed.

A congregation considering undertaking such ministries should consult with local agencies (governmental and not-for-profit) serving older adults and persons with dementia (including the local chapter of the Alzheimer's Association) about pressing local needs and resources for training volunteers. These organizations will also serve as invaluable referral resources, directing people to

the programs you initiate. A Memory Café is perhaps the easiest program to create, and once its impact and importance is recognized it is likely to spark others to develop related programs, weaving the fabric of dementia-friendly community.

Ours is an aging society, and as the number of older adults in our congregations and communities increases, the church will be called to new practices and new ministries, particularly with the growing numbers of persons living with dementia. We are called to counter the narrative that insists that dementia is a kind of living death with a narrative consistent with the good news our Lord proclaimed to persons of all ages and in all of life's circumstances: "I am come that they might have life, and have it more abundantly!"

### FOR FURTHER READING

- Growing Old in Christ** (Hauerwas, Stoneking, Meador and Cloutier, editors. Eerdmans, Grand Rapids, MI, 2003). *A wide range of theological reflections on the meaning of aging as a Christian.*
- Spirituality and Personhood in Dementia** (Jewell, editor. Jessica Kingsley, London, 2011). *Albert Jewell is a British gerontologist and Methodist minister who has here assembled essays on spirituality and dementia, with guidance on how we can be present to our friends living with dementia.*
- Aging Together: Dementia, Friendship and Flourishing Communities** (McFadden and McFadden, Johns Hopkins University Press, Baltimore, 2011) *Blatant plug: this is the book in which Susan and I explore more fully the themes raised in this pamphlet.*
- A Guide to the Spiritual Dimension of Care for People with Alzheimer's Disease and Related Dementia** (Shamy, Jessica Kingsley, London, 2003) *The author, a teacher and clergywoman, offers practical help in designing worship services, supporting caregivers, etc.*
- No Act of Love is Ever Wasted: The Spirituality of Caring for Persons with Dementia** (Thibault and Morgan, Upper Room Books, Nashville, 2009) *This very accessible book is particularly valuable in a congregational setting.*

## WEB RESOURCES: MEMORY CAFÉS

On our blog ([agingtogether.blogspot.com](http://agingtogether.blogspot.com)) we describe several of the Memory Cafés we visited in the U.K. A description of one in Falmouth can be found here: <http://agingtogether.blogspot.com/2011/07/memory-cafe-meets-here-today.html>

The U.K. Rotary Club has made dementia their mission and service priority. They have published this helpful guide to setting up a Memory Café: <http://www.repod.org.uk/downloads/REPoD%20guide%20to%20setting%20up%20a%20Memory%20Cafe.pdf>

Memory Cafés are particularly well established in Cornwall. Here you can read a brief description and see several pictures: [http://www.cornwallrcc.org.uk/downloads/crcc\\_embracing\\_memory\\_loss.pdf](http://www.cornwallrcc.org.uk/downloads/crcc_embracing_memory_loss.pdf)

Memory Cafés (called Alzheimer Cafés) began in The Netherlands in 1997. This document from the Dutch Alzheimer Society has much detail about organizing them: [http://www.alzheimercafe.co.uk/Acrobat/HOW\\_TO.pdf](http://www.alzheimercafe.co.uk/Acrobat/HOW_TO.pdf)

## WEB RESOURCES: SINGING FOR THE BRAIN

Here you can watch a delightful video which describes the program and its benefits, including part of a session: [http://alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=760](http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=760)

This site also has information about Singing for the Brain: <http://www.nhs.uk/Video/Pages/singing-for-the-brain.aspx>

## WEB RESOURCES: OUTINGS AND CREATIVE ENGAGEMENT

Read about the much-acclaimed “Meet me at MOMA” program here: <http://www.moma.org/meetme/index>

Here is the Wisconsin SPARK Alliance site:

[http://www.alz.org/sewi/in\\_my\\_community\\_19695.asp](http://www.alz.org/sewi/in_my_community_19695.asp)

Many kinds of outings are possible. Here is the site of a British organization that offers various types of adventures to persons living with dementia: <http://dementiaadventure.wordpress.com/>