

# Spiritual Assessment for Early-Stage Dementia Patients (July 2, 2014)

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Early-Stage Dementia is defined as "Stage 4: Moderate Cognitive Decline" on the Reisberg Scale (also known as the Global Deterioration Scale for Assessment of Primary Degenerative Dementia). Early-Stage, or Stage 4, is characterized by the following symptoms:

*This stage includes difficulty concentrating, decreased memory of recent events, and difficulties managing finances or traveling alone to new locations. People have trouble completing complex tasks efficiently or accurately and may be in denial about their symptoms. They may also start withdrawing from family or friends because socialization becomes difficult. At this stage, a physician can detect clear cognitive problems during a patient interview and exam.*[\[11\]](#)

The aim of this paper is to address a component of the emotional and spiritual state of someone with Early-Stage Dementia that goes unaddressed in the above definition: Awareness. Though subtly implied in statements such as "*may be in denial about their symptoms*" and "*They may also start withdrawing from family or friends because socialization becomes difficult*," what makes this population so important is that they have awareness over the way their lives are in transition. As spiritual caregivers, our job is to notice the level of awareness an Early-Stage Dementia patient possesses and use it to delve deeper into issues such as grief, social and familial judgments, and isolation while the patient still has the capacity to reflect upon these abstract concepts.

In 2012 the Alzheimer's Association reported that there were 5 million individuals living with Alzheimer's disease and related dementias in the United States. According to this estimate, by 2050 the number is expected to rise to between 11 and 15 million.[\[2\]](#) In their new report released this year

they reveal that 1 in 9 people age 65 and older has Alzheimer's disease.<sup>[3]</sup> Taking into consideration the sheer number of people suffering from some form of dementia in the U.S., it is logical to infer that a large number of said people would fall into the "Early-Stage" category. In fact, the Alzheimer's Association reports that nearly half are. Keast's research of spirituality among dementia patients poses that "*preserving a sense of purpose, fostering meaningful connections with the surrounding world, and retaining a relationship with God*"<sup>[4]</sup> are paramount to those living with dementia. Similarly, Koenig concluded that there are "twenty-five major psychological and spiritual needs of older adults"<sup>[5]</sup> with 'meaning and purpose' and 'support in coping with loss and change' in the top five. Given these findings, the need for spiritual care for this increasingly expanding population is imperative. It is compelling to note that because diagnosing criteria can be nebulous Alzheimer's and other types of dementia often go undiagnosed. Because of this, half of the estimated 5 million Americans with Alzheimer's may not know they have it.<sup>[6]</sup>

Returning now to the issue of 'awareness', a functioning understanding of what it means to have awareness is necessary. It is my estimation that awareness requires something to be aware *of*. In other words, awareness (as an abstract concept) can only exist if there is a thing or an entity that is the object of attention. In the case of someone with dementia, the object can be previous cognitive abilities. For instance, someone who has always been able to balance a checkbook may no longer be able to do so, and becomes aware of that change. Balancing a checkbook is something that required little effort in the past, but because of the onset of dementia, it has now become nearly impossible. A key component of awareness is the ability to compare current functioning against some criterion such as one's own previous functioning.<sup>[7]</sup>

## **Awareness and Grief**

By making the assumption that awareness is present for Early-Stage Dementia patients, one can also assume that said awareness triggers various difficult emotions, one of which being grief. In becoming aware that

cognitive abilities have deteriorated, a patient might find themselves grieving for their prior life. As spiritual caregivers, a question that often opens the door to greater reflection in this situation is "What was your life like before?" This simple inquiry invites the patient to reflect on those things they used to enjoy (hobbies, relationships, work life, etc.). Delving further into this exploration of grief, a follow up question could be "What do you think you'll miss most?" This query does two things: (1) it allows them to single out something that is foremost important to them, and thereby gives us greater insight into what is meaningful and what might be worth following up on and (2) it suggests to the patient that they are on a continuum and that there will be a time when they may not be able to remember the thing that is so important for them to remember at this moment.

Grieving over loss of their prior life however, is not the only kind of grief that someone in the Early-Stage may experience. Anticipatory grief is another kind of grieving which takes place. Anticipatory grief refers to losses not yet realized but expected by the patient. Examples may be relationships and how they will change and evolve as the patient's disease changes and evolves. A wife diagnosed as being in the Early-Stage of dementia may grieve over the anticipated loss of the relationship with her husband. Will she remember him? Will she remember the many years of their love and what will happen when she no longer does?

Finally, there may be present losses perceived by the patient. Western society places a high value on cognitive skill and on the ability to function independently.<sup>[81]</sup> Patients with Early-Stage Dementia may see their diagnosis as a direct challenge to these values. If the culture values cognitive function, how then are those with dysfunction treated? How does the patient in turn believe they will be treated if they have dementia? Exploration of this kind of grief can often reveal what might be a perceived loss by the patient and may also reveal what they perceive their self-worth as being. Loss and grief are ever present for those with dementia and may encompass loss of identity (present loss), loss of a life once lived (past loss), and what their lives will look like as their disease progresses (future loss).

## **Social Context**

People develop dementia in the context of a social network composed of family, friends, and the wider cultural backdrop. Each element of the social context can have an impact on the way the patient understands and makes sense of what is happening.

## **Family**

In the context of a familial unit, there will inevitably be a shared perception of what it means to have dementia. Often this is based on an older family member who was once diagnosed with dementia. This point of reference can sometimes be detrimental to the newly diagnosed patient. A patient will frequently hear things about how the earlier family member "lost their mind" or became "difficult." The patient may internalize this during the early part of their disease and choose not to tell family for fear that they too will be seen as a burden or treated as a pariah. However, as spiritual caregivers we know that support from family can make a world of difference in how a patient processes their new state. Questions one can ask to draw out more information would be "How is your family dealing with your diagnosis?" or "Are you finding that you can talk with your family about what you're experiencing?"

## **Friends**

Frequently those suffering from Early-Stage Dementia will recount that friends had at one point been supportive but they are no longer part of their support system. This is a curious dilemma and one that needs to be explored more at length particularly around whom it is that is initiating the isolation. Are friends uncomfortable with the way their friend has changed or is it the patient who is initiating the withdraw of friendship? Social networks over time will often dwindle resulting in fewer chances for interaction and this in turn can lead to issues of depression and anger. Friends who are reassuring can sometimes reinforce defensive or minimizing responses from those recently diagnosed. This defensive stance can often lead to patients purposefully creating distance between themselves and their friends.

## **Cultural Backdrop**

In 2008 the Alzheimer's Association put together a series of town hall meetings to "give voice to people with Early-Stage Alzheimer's."<sup>[9]</sup> Hundreds who attended stated that the stigma associated with the disease was one of their top concerns. The overriding theme influencing much of the discussion was that people in the early stage of Alzheimer's are misunderstood because of myths and misconceptions about the disease and that this misunderstanding leads to a dominant negative stigma associated with having the condition. Given this cultural backdrop, a person with early dementia may go to great lengths to hide their diagnosis.

## **Conclusion**

So where is God in all of this? Where is the presence of the Divine? And how is this state of awareness helping or hindering the patient's connection to the sacred? Holding the following as a definition of spirituality, what then is our role as caregivers to those who suffer from Early-Stage Dementia?

*Spirituality: That which lies at the core of each person's being, an essential dimension which brings meaning to life. Constituted not only by religious practices, but understood more broadly, as relationship with God, however God or ultimate meaning is perceived by the person, and in relationship with other people.*<sup>[10]</sup>

As spiritual caregivers, we are aware that there are those for whom religion is an important part of life. We also acknowledge that there are some who would consider themselves spiritual but not religious. The above definition is also broad enough to work for those who have a more humanistic point of view, recognizing that all humans have a spiritual component.

If we truly hold that spirituality encompasses not only the presence of Spirit, but that it includes our relationships 'with other people' then we cannot ignore the importance of helping those with Early-Stage Dementia foster connections with family and friends, and with the Divine in whatever way they view it. It is our duty and our charge as spiritual caregivers to walk alongside and to explore with those who are suffering. Writer Christine Bryden, diagnosed with dementia writes:

*As I travel towards the dissolution of my self, my personality, my very 'essence', my relationship with God needs increasing support from you, my other in the body of Christ. Don't abandon me at any stage, for the Holy Spirit connects us. It links our souls, our spirits -- not our minds or brains. I need you to minister to me, to sing with me, pray with me, to be my memory for me.* [\[11\]](#)

## Notes

[\[1\]](#) Reisberg, et al., 1982; DeLeon and Reisberg, 1999

[\[2\]](#) Alzheimer's Association, 2012 Alzheimer's Disease Facts and Figures, [http://www.alz.org/downloads/facts\\_figures\\_2012.pdf](http://www.alz.org/downloads/facts_figures_2012.pdf)

[\[3\]](#) Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures, [http://www.alz.org/downloads/Facts\\_Figures\\_2014.pdf](http://www.alz.org/downloads/Facts_Figures_2014.pdf)

[\[4\]](#) Keast, et al., A Systematic Review of Spirituality and Dementia in Long Term Care, 2010

[\[5\]](#) Koenig, Harold G. Counseling Troubled Older Adults, (Abingdon Press, 1997) p.231

[\[6\]](#) Alzheimer's Association, 2014 Alzheimer's Disease Facts and Figures, [http://www.alz.org/downloads/Facts\\_Figures\\_2014.pdf](http://www.alz.org/downloads/Facts_Figures_2014.pdf)

[\[7\]](#) Clare, Developing Awareness about Awareness in Early-Stage Dementia, 2002

[\[8\]](#) Clare, Developing Awareness about Awareness in Early-Stage Dementia, 2002

[\[9\]](#) Alzheimer's Association, [http://www.alz.org/national/documents/report\\_townhall.pdf](http://www.alz.org/national/documents/report_townhall.pdf)

[\[10\]](#) MacKinlay, Spiritual Care: Recognizing Spiritual Needs of Older Adults, 2006

[\[11\]](#) Bryden and MacKinley, 2002

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