Praying With Those Who Might Forget: Pastoral Considerations with Memory Impairment

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This article gives an account of a person who had memory impairment and received pastoral care, with an emphasis on pastoral needs and prayer. The author provides a first-hand account addressing both sides of the pastoral care interaction. She experienced years of memory impairment comparable to mild to moderate Alzheimer's Disease. Now, however, she is a seminarian. She provides a detailed account of pastoral care received during the time of memory impairment and considers both the visiting pastor's intent and the author's recollection of the prayer and pastoral care received. Part of the uniqueness of this account is that persons with memory impairment do not usually regain their cognitive functioning and then also obtain pastoral education from which to provide the guidance gained as both patient and pastor.

Despite an extensive quest for pertinent literature, I have uncovered none that specifically address prayer in pastoral care with those who have dementia or other progressive memory impairments. It is common for pastor or chaplain to visit such persons, and to the extent that prayer is an essential ingredient to pastoral care, I hope that an account focusing on praying with those who might forget would be a useful resource. I am able to approach this account with a unique perspective. I have a medical condition that, when untreated, presents as symptoms of dementia. The medications I currently take address the memory impairment while impairing my cognitive functioning in other ways. I therefore offer this account with the best quality I can provide. My goal is to give the reader a glimpse into one person's experience with memory impairment, to offer some guidance for pastoral visitors praying with those who might forget.

Living with Chronic Memory Impairment

I was eventually diagnosed with temporal lobe epilepsy, now well managed with medication. In my case seizures were complex partial seizures, meaning that the body movements many associate with seizures were not present; instead, the seizures impaired internal, cognitive functioning. The symptoms I lived with, I argue, can be generalized to persons with more common diagnoses related to memory impairment, such as dementia and Alzheimer's disease. Particular to my seizures were memory lapses or amnesic "blackouts," which happened several times a day. I would sometimes be found by loved ones (thank God!) wandering out in public, utterly disoriented, and with no sense of purpose. In addition to this I had frequent word-finding difficulties, occasional inappropriate emotional responses to normal stimuli that didn't warrant them, a frequent experience of having been misunderstood, and a pervasive state of mental confusion and sometimes suspicion. Regarding the latter, if I had no memory
of something having happened, and bystanders insisted that it did happen, I was inevitably prone to being suspicious. It’s tough to accept being repeatedly ignorant of one’s own experiences. Between these episodes I was lucid and seemed quite normal, being able to carry on conversations in a customary manner, as well as recall recent events, the ones that took place between seizures. Because the seizures increased in frequency over the years, the condition was progressive.

A powerful metaphor for me is a page in a connect-the-dots book for children. My memories are the dots. The pictures are based largely on what others told me, how they said the dots were connected, which left me little choice but to accept their images of my own life.

Connecting the dots of my memory to form a continuous picture of my personal experience meant a lot to me. Gestalt psychologists will confirm that the process I naturally employed as a result of my illness is integral to human nature and the way we make sense of the world. We perceive the blinking lights on a marquee sign to be moving when there is no motion, because our minds desire continuity. Whatever the raw materials of stimulation, we tend to construct a perceptual whole by grouping isolated dots into meaningful percepts—by filling in the blanks, and grouping things in ways that make sense to us. We all do this.

What happens with chronic memory impairment is that we may construct the big picture by connecting a supply of too few dots, because we could not remember some of the important ones. Still, it is our nature to form that whole and continuous perception—our understanding of a person, a situation, the world, society, and ourselves. With insufficient data, we might have to revert to accepting the perceptual wholes given to us by others, leaving gross uncertainty in terms of what our life is really like. In other words, this speaks to issues of identity. I suggest that pastoral care with those who might forget must revolve around this ultimate issue of identity, and that prayer is perhaps the ideal discourse for the healing transformation that is needed, addressing two core issues I detail later in this article. The following is a description of two specific instances of pastoral care I received. The accounts are from both my recollections and the pastoral care provider’s, as shared during the interviews for the preparation of this account.

Visit #1

The first visit occurred when I was in the hospital due to complications from a spinal tap. The pastor, Linda, was aware of my general medical health because she kept in frequent touch with me and I speak openly. Just before she arrived at the hospital she called me and asked if I would like her to bring me anything. Her aim with this phone call was to ascertain my level of alertness as well as my current mood. These go together, as she believed that when I am alert I could accurately report my mood. She generally would call just a few minutes before visiting.

When she came into the room she noticed that I was unusually upset by something. I described to her in detail what had just happened. I reported several difficult interactions that had just occurred with one nurse. Apparently I had requested pain medication, which was on order from my doctor, and I could take it more frequently than I had been. The nurse said he did not believe I needed it and refused to give it. He then called the neurologist and told him that I was drug-seeking. As a result, I wasn’t allowed to take the prescribed medication.
After hearing this account, Linda is rather assertive and quite persuasive, she was able to get the nurse to realize I was actually in pain, and that I should be allowed to take the prescribed medication. She tells me today that she believed this sort of “social work” sometimes has to happen first, before the more spiritual aspects of pastoral care can happen. She spent time assuring me that in this instance I was having a normal response to an abnormal situation. I always liked to hear this, having had too many instances of the converse.

Then, noting that I was still upset, she wanted to pray with me at that moment. Her prayer would be based on knowledge she had obtained from me a few months earlier, on “a good day.” Back then she had asked me to describe where I was when I was sure that God’s presence was with me, and she wrote these and other things down for herself. When she asked for this, she had directly and honestly told me that she inquired so she could remind me of important things if I were to forget them later.

I appreciated her candor—when people speak directly we convey that there is nothing to be embarrassed about. I had told her that when I was in the Coast Guard, I found the most holy place I’ve ever been: the middle of the ocean, with no lights for hundreds of miles, and our own deck lights off as well. When I was not on watch I would lie down in the small boat that sat on the deck towards the back of the ship. I could hear the water, feel the stillness of slow and slight sea swells, and see stars I’d only read about, because the sky was as clear and undisturbed as it was created to be. In the utter absence of all distraction and injustice, I was most certain that God was with me.

And so she prayed, “O God of starry skies and still oceans, so far from land that nothing distracts from your presence, we come to you in prayer asking that you might make yourself known to Erika even as she is in this cold place, reassuring her of your presence and love, Amen.” She wrote this down on a piece of paper that she left on the wheeled hospital table; she hoped that as I later discovered the paper I would know that I was loved by God who was present with me, and also loved by the congregation of the church.

**My Response to Visit #1**

I don’t recall the pre-visit phone call. In fact I later found it humorous in discussing this later as I told her I really wanted her to bring me some salad, which I actually dislike. Sometimes I didn’t make sense. In visiting persons with dementia, O’Connor was sometimes overwhelmed “by their despair and melancholy.” He would ask a question like, “How are you today?” and get a response like, “I am looking for my mother.” Dementia makes interpersonal conversation inherently something different from what we might expect. Communication with God, we might assume, exists beyond the more concrete conversational capacities we are accustomed to in visitation.

I did, however, find the paper she left me with the prayer about God and the starry skies and still oceans, and I felt totally embraced by God’s love. Actually, I could have encountered the written prayer, been touched by it, and then forgotten that I’d done so, only to go through the whole process again and again later, repeatedly embraced by the love. But so what? It was good that she left that written prayer.

I absolutely do not recall this visit having taken place at all. But I did
remember telling Linda my Coast Guard story in a prior month, and this prayer’s language matched with my own wording. That caring prayer, even though I have no factual memory of my own wording. I don’t recall her verbal affirmation of my distress either—I don’t remember the argument with the nurse, I don’t remember my upset response to it, and I don’t remember her visit. But I remember later that night encountering that piece of paper. So the visit had served to bring peace to my spirit, and as we prayed together the prayer most likely calmed me as well, but in addition the residual effects of the written prayer as I later stumbled upon it were very powerful.

I frequently felt alone in this particular, cold and unfriendly hospital. The prayer brought me to a place where I knew God was present, and so even in the midst of a trying situation—and especially in the midst of a trying situation—I felt assured of God’s loving presence. “By putting some of the patient’s feelings into the prayer, the chaplain has said that all the patient’s experience is worthy of God’s attention.” I think this prayer was an amazing illustration of this sort of care.

I assume that when praying with someone who has normal memory, a pastor could accomplish this by asking, “What would you like us to pray about?” But had she used words I shared in that visit, and written them down, I could again be left later on questioning why I had shared what I did, or what on earth I was thinking expressing this or that. I’m not sure how a positive outcome she could have effected without using words that I would distinctly remember having shared. I would typically find it very disturbing to be told that I had said things I didn’t remember saying, as it happened all the time. Blackouts take so much away.

So this prayer carried me to that place on the ocean that I remember so vividly! My memory impairment affected recent years—this prayer brought me back more to the good ol’ days, to when I was living stories I could tell by heart and feel like they were still real today, with the smell of the ocean and my greatest struggle being how to clean the perpetual salt specks off my eyeglasses. This prayer served to remind me that I wasn’t always in a cold and lonely physical setting, and it worked with a particular memory I held dear—rather than demanding I recall something more recent or related to my day, something that may not have been possible.

The “old knowledge,” as I call it, is treasured by many with chronic memory impairments. Ask what I did yesterday and I might not know. Ask me about my childhood, or former professions, and I’ll be glad you brought it up because then I can connect and feel like a social being. It renews a sense of worth, that I have something to contribute interpersonally, that I’m worth listening to, and that I am still shaped by the memories I’ve held onto. On top of all that I am reminded of God’s presence—an ideal assurance when my feeling is that I am alone. What better way is there to pray?

Visit #2

The second visit occurred about a year later, at the same chilly hospital. My cognitive functioning was slightly worse. At this point I was very concerned with assessing my current situation in relation to God. Linda reported that I insisted that most of our conversation be about issues of identity, which I expressed as a need to reconcile “Who I am” with “Who I was.” This was central. I remember being almost consumed with this. I
picked this visit as my second illustration because it is another specific visit that I don’t recall, that Linda does recall, and it makes a very different point from the first illustration as I reflect on it today.

Upon entering the hospital room, Linda noted that I was wearing an eye patch due to a sudden onset of double vision. She knew that my primary coping mechanism is humor, a ritual exchange in its own right, and that I tend to be put as ease with witty retort. She and I apparently bantered a bit about the eye patch. Her intent was to acknowledge that this was an unpleasant situation, that it was reasonable for me to be frustrated and to desire to cope, and she conveyed that through a familiar and effortless exchange of humor.

I really wanted to talk about identity, so she listened. My main issue had to do with intelligence. Before this illness my considerable intellectual skills were central to my sense of who I was. We all have our gifts and mine was intelligence. This was what I thanked God for my whole life, for this great gift of the brain I was given. So after the eye patch humor passed I talked about my broken brain and how I felt. I expressed my fears because it was becoming apparent that I was no longer the person I knew myself to be.

It’s not that I lost ability like a pianist who develops arthritis. It’s hard to “think differently” about things when it’s the brain itself that is not working right. I literally was unsure who I was, as the central notion of my identity was my intelligence—my awareness, and my abilities to think critically, creatively solve problems, and communicate effectively with others. And the location of our knowledge of self is, after all, in our memories. So I wondered if I could modify that which was becoming increasingly inaccessible. What do I pray for then?

The memories of what we think, feel, and do—in large part—are the constituents of who we are. And as we encounter new situations, new learning takes the form of new memories. What’s left without these things? The pianist still hears the melody though he or she can’t play it.

Linda’s response to this was to emphatically declare that even with my broken brain I was the smartest person she has ever known. In addition to this she hoped to convey to me that I am a person of sacred worth, and that my church family would treat me as such regardless of changes in mental ability. She viewed her role as primarily one of presence, something constant and familiar even if the visit is forgotten afterwards. She tells me today that she wanted to “give me a break,” bringing humor and a familiar face into an unpleasant context, rightly assuming that I would appreciate both. Her visit was representative of God’s constant presence, which she modeled with her physical presence of the visit and prayed with her prayer. In prayer she prayed something close to the following: “Holy One, Erika is feeling very frustrated right now, and we pray that your presence may be a continual reminder to her that she is deeply loved.” Thus she emphasized continuity. She rightly perceived my need as having to do with dealing with change and believed that her response in prayer would remind me that in the midst of changes, God’s presence does not change.

My Response to Visit #2

I remember nothing from this visit. When interviewing Linda for this account, she said, “Looking back, my response wasn’t very pastoral. I just couldn’t get over how bothered you were about your brain when you were still the smartest person I’ve ever known.” Her insistence that I was still the
smartest person she knew did have some weight because I consider her to be quite intelligent; so whenever she’d say this to me, which was often, I’d reflect on why she kept emphasizing that.

I need to say that I am unusual in my compensatory ability, and so it cannot be easy to see how to pray with me, if I cannot verbalize my precise need. I tend to create strain on a pastor’s intuition. For example, when I was most cognitively ill and my neurologist had the talk with me about it no longer being safe for me to live alone, and when I needed reminders to eat and to bathe, I was in graduate school and got my first master’s degree with the only 4.0 grade point average in my program, while I was virtually unable to learn anything new. I mention this to illustrate my state of being at the time—my spiritual needs that I wanted to bring to God in prayer were likely difficult to ascertain (or even believe!) from looking at me. Incidentally, I hope my ability to share them in this paper may amplify a perspective not heard from otherwise.

I wouldn’t go so far as to say her visit and her prayer were not pastoral and caring, but one key element was misaligned, and I’ve been reflecting on it ever since my thinking has been improved.

I knew myself to be Erika. And I believed Erika was a person of sacred worth. But with such extreme changes that I no longer felt like I was Erika then first of all, who am I? That’s the question she spoke to—I was still the smartest person she knew. But more importantly I wondered, on a level below spoken language, is this new person also a beloved child of God? What can I base that on if not my experience? The memories of God’s presence are what form my faith! Since my memory was impaired, I really couldn’t form new memories of God’s presence in this new and different version of my life either. God certainly loved the former me. See, I needed a new basis of faith, one that could carry me through the ups and downs of cognitive functioning each day, from the times of alertness and anguish as I’m speaking of here through the times of disorientation and blackouts.

We look to history to see evidence of God’s faithfulness. My story had fast become an old edition, from back when I could remember things I’d said, done, and felt. I noticed people’s faces change as I told the same story multiple times, indicating that I had apparently shared it before. But the more recent years were largely fuzzy and I wanted to interact. And when I was aware enough to process this it scared me a lot. Who is God if not the God to whom I prayed when I was a child? That’s the God I knew and still remembered. Like all relationships this one too has a memory. If my memory failed, not only was I not sure whom I was becoming (as new learning was extremely sparse), but I was also unsure if God had two different seats at God’s table—one for the former me and one for this new aloof version.

Ultimately, being told I was still mostly brilliant didn’t address these things. And her prayer, although not by any means harmful, didn’t give me the voice I needed to put this together and bring it to God, the God I hoped would know what I was trying to say. The pastor who prays has to keep all of this in mind. It’s no wonder some try to avoid visiting people like me!

Being so frequently misunderstood led me to conclude that it was not possible to understand me, and this prayer would have confirmed that. I don’t remember this visit but I remember my state of mind. My frequent states of confusion made it hard for me to articulate and thoughtfully communicate in the ways I once did. I wanted to believe that God could know my heart and hear my prayers, but I had a true need for a pastor to demon-
strate that. This prayer was like a really nice sermon that just isn’t a good fit for a particular Sunday. The lesson here is that persons with memory impairment are routinely misunderstood, at least as much as they misunderstand others. Inasmuch as prayer is communication and understanding with God, I really do feel it is imperative for a pastor to either “get it right” or admit the momentary inability, lest he or she contribute to the spiritual crisis still not addressed.

Prayer, more than perhaps anything else, can serve to connect us to a greater understanding of self that allows God’s love to come in. Behold, God stands at the door and knocks. If anyone hears God’s voice and opens the door, God will come in and eat with her and she with God (adapted from Revelation 3:20). Prayer helps us hear God’s knocking, reminds us when we forget that we can open the door, and assures us that God will be intimately with us, no matter how crazy we think we look as we open the door. All of this is potentially accomplished through prayer—but the prayer absolutely must align with the careseeker’s feelings. To misrepresent her or him, in a relationship trying to be discovered anew, can make the very idea of the relationship seem out of reach.

Integration

“Reason is the way we communicate, and learn, both individually and as a society. But the rational part of the brain is not the whole brain. There is an area within the non-rational part of the brain, call it the unconscious, which is still functioning.” That is the place where one makes meaning, forms percepts, and feels emotion. How the pastor works with that is particular to the careseeker’s meaning, perceptions, and emotions—which are not necessarily related to physical reality or context—because that’s what the pastor has to work with.

Without an appreciation of the reality of the careseeker, however distorted it may seem, the pastor is operating at a level of theories of personhood, for example, rather than at a level of human experience of the other. Pastoral care must go beyond the skillful actions of social work.

Writing to address the theological issues raised by Alzheimer’s disease, David Keck says, “This disease does differ from other examples of disease, anguish, and death.... [because] we can no longer presume the existence of the cognitive subject when we are thinking theologically. The loss of memory entails a loss of self...” How we think of a human being is challenged with Alzheimer’s Disease, and it is similarly challenged by other illnesses of progressive memory impairment. When praying with someone who might forget, we might need new skills. Most ministry has something to do with engaging the cognitive functioning of the person before us. “Our skills for listening, for helping a person gain insight into his or her life’s experiences, our basic ability to understand the faith of the [careseeker] are all based on cognitive abilities that are weakened...” Notice that these are the things pastors typically mine to inform empathic prayer. As we go about meeting the memory-impaired careseeker we must be mindful of these atypical challenges.

As pastors we are called to meet a careseeker in at least two ways, both having to do with identity. The first relational obligation is that we acknowledge and interact with the careseeker’s identity—that is, who she knows herself to be, coupled with her perception of the present moment. This
involves not only recognizing overarching themes of identity, but also carefully listening for details of the particular context of the encounter. The second relational obligation is that we acknowledge and interact with the careseeker based on who we know him or her to be as a beloved child of God, and therefore of sacred worth, made in God’s image.

I believe that persons with memory impairment have an acute need to align their evolving personal identity with the divine truth of God’s consistent love. In my experience I found it most valuable to conclude that my identity was rightfully a beloved child of God. From interviewing seven people who had a diagnosis of dementia, Karen MacKinlay concluded that some persons with dementia do not feel human, “a profoundly sad comment on the way one who has dementia may feel.” I had another way of addressing the feelings. Rather than trying to connect the “me” I didn’t understand anymore with the more communal identity of being a beloved child of God, I tried to embrace the former with the latter corporate identity of what it means to be a person. Many whom I’ve spoken to about this find it novel, but I’m hoping it makes sense at this point, as prayers can facilitate such revelation when one becomes uncertain who one is, or fears whom one will soon be.

Prayer offers one powerful way to simultaneously affirm a careseeker’s sense of self and affirm that he is a beloved child of God. Some (including this author) would say that is the central role of pastoral care with persons who might forget—to bring a careseeker’s identity into the broader, nurturing identity of being a beloved child of God, with a fundamental responsibility of never denying who the careseeker knows herself to be independent of our interactions. The central thread is a mixture of identity and communication. Chronic memory impairment threatens both of these. Both of these are involved in prayer. There should be a caution label on this: “Prayer can really be life changing—Please use generously and with caution.”

Some pastors provide pastoral care to persons with dementia in part through ritual action (the literature is specific to the diagnosis of dementia). I think I would have valued that. The only ritual I was engaged in as a careseeker was routine prayer, but I certainly used ritual in daily life—elevating constancy as a means for survival. I habituated everything I could when I was lucid, because then when my brain was not working right I might be able to do what I was supposed to do “without thinking.” I imagine this would be wonderful in prayer and pastoral care—any ritual action that has symbolic meaning for my faith and with which I could participate without thinking.

Describing non-verbal forms of communication particularly in the care of persons with dementia, Goldsmith writes, “It’s not surprising that religious ritual can be extremely important when working with people with dementia because it can ‘carry the person along’...Ritual can help a person to have meaning and self-identity.” Because ritual is communication it could definitely be integrated into or even used wholly as prayer, meeting the needs of someone who might forget by involving more parts of the person’s being than just the thinking aspects. After all, we don’t “think” God nearly as much as we feel, experience, work for, and find hope with God.

There is a practical meaning in my connect-the-dots metaphor. In communicating with persons who have dementia or any chronic memory impairment, we should employ “personhood affirming strategies” when providing care. The idea is to be able to communicate with persons who
have dementia in ways that may enable their spirit. An interpersonal type of strategy comes in the form of the directive to “facilitate accomplishments, by providing the missing steps between intention and completion.”11 This makes me smile every time I read it. This can be adapted for prayer. And what a wonderful and genuinely positive approach to prayer this is: to facilitate accomplishments.

I am drawn to this idea for many reasons. Facilitation does not take away ownership; the one who intends something and also completes it has done something that is his very own. Providing the requisite “missing steps” in prayer sums up the pastor’s active role in terms of praying. We must not take the completion/ending away from someone unintentionally. The pastor can make this error by asking, “What would you like us to pray about?” and then speaking the whole prayer himself. But let us consider this routine scenario for a moment: here the pastor invites the prayer, asks the careseeker for input, and then completes the prayer. This does not accomplish the directive that has to do with providing the missing steps between intention and completion. In this typical way of doing prayer in a visit, the careseeker facilitates the pastor. I would urge the pastors reading this to reflect and find the flawed logic in this common practice, particularly when praying with someone who might forget.

I can’t provide particular instruction on how to go about doing such a facilitation in prayer. By definition, it has to be both initiated and completed by the careseeker. The onus of the pastor then becomes hearing that initiation, being an agent of God’s grace in providing the missing steps in the middle, and then accompanying the person through completion, without taking control of the endpoints that signify both ownership and dignity.

I stand by my assertion that praying with those who might forget requires the dual considerations of identity and communication. If we view prayer from the perspective of our relationship with God, memory impairment actually is less important. “Theologically, the nature of the person is less dependent on human memory than we might think. The nature of the person as created by God is in relationship with God...Human memory plays a part in this relationship for human beings, but not necessarily for God.”12 This speaks to my own conclusion that my identity as a beloved child of God had to engulf, rather than sit beside, my whole personal identity up to that point. The emphasis in prayer must have something to do with helping someone get to that point, if prayer is to be about the business of connecting people with God, because people with memory impairment cannot always get there themselves.

Conclusion

Leaving a written prayer, and using the careseeker’s own words whenever possible, ideally words she will remember having spoken, is a wonderful pastoral act. In fact, such a prayer might bring more comfort than regular prayers with regular people, by its very nature. The process of repeatedly discovering something that is nurturing might allow for a cumulative effect that makes it more meaningful, to the soul, than just getting the chance to appreciate it once.

Looking back from the health of my life today, if I could have conveyed one spiritual need, it would have been a plea for help in reconciling personal identity (my understanding of self in relation to my present context)
with an understanding that I am a beloved child of God. That was my prayer and I wasn’t able to communicate it—neither to the pastor nor to God. I would have been spared at least a couple years of anguish had someone identified this. Though they are right in the middle of our faces, we can’t see what color our own eyes are.

Prayer through pastoral care would have best served my needs by addressing these two complementary uproars in my heart. First, please affirm that my perception is okay, that how I connect the dots is real for me and therefore right for me. If I’ve made a grossly incorrect picture, especially of someone’s personal actions in my life, then show me your more objective picture while acknowledging that my picture is reasonable given the dots I have. Second, show that God knows my heart, and hears my prayers, and is lovingly present in my attempts to perceive the world. That even as my sense of who I am is drastically challenged and mutated, God is with me in the changes and I’m still consistently loved. In other words, the ultimate perceptual whole is the personal identity of being a beloved child of God. Prayer is the ultimate way to affirm who someone is in this way, by bringing him and whatever his perceptions of the moment may be, to the God who loves him as much as always.

It is important to note that persons with chronic memory impairment will likely recall emotional aspects of events. Our brains store and recall declarative/factual memories differently from affective/emotional memories. And perception, or how we make meaning of things, is a different process that integrates the others. Another ability to keep in mind is that spoken language is processed differently from, say, the translation of meaning conveyed by a smile. Speaking only for myself, my emotional memory was always intact. I would routinely “know” that an experience was good, bad, happy, unfair, scary, etc., even though I had no recollection of the event. This is important for pastoral caregivers to be aware of—your time is well spent, and we don’t forget the spirit of the interaction, the actual venue for God’s elegance, just perhaps the description of it.

Endnotes
2. The practice of asking for such information from a person when she is alert and oriented is a topic for another paper. From my experience, soliciting specific illustrations from someone’s personal life, of examples that can affirm God’s active presence, can be immeasurably useful when acute crisis keeps one from accessing those thoughts for oneself. The goal is to allow one to pray without thinking.
7. Donald McKim (Ed.), God Never Forgets: Faith, Hope, and Alzheimer’s Disease


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