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Editor's Message Jennifer Pilcher-Warren, PhD, CMC

Greetings! I am very excited to present this latest issue of the Journal of Aging Life Care which explores the unique challenges for Aging Life Care Managers who are serving younger clients with atypical dementias. Having grown up in a family where both my maternal grandmother and aunt were diagnosed with Young-Onset Alzheimer's disease, this is a topic near and dear to my own heart. However, for many of us in the care management field who have traditionally worked with geriatric clients, this is a new and often challenging population to work with.

Whether because of improved detection, increased awareness among medical providers or the fact that incidences are more frequent due to early baby boomers, the reality is we are seeing an ever-increasing number of younger clients with dementia in our practices. There is a high likelihood that these clients will have a less common type of dementia. For example, in 75% of FTD cases, onset occurs before the age of 65 (Onyike, CU; Dhiel-Scmid, J: The epidemiology of frontotemporal dementia, *International Review of Psychiatry*, 2013: 25: 130-137).

These clients may have recently



retired or even forced to leave work, often not on good terms and thus may be experiencing devastating financial consequences. Frequently, these clients have grade school or teenage children living at home, further complicating the

situation. Caregivers for clients with young-onset dementias experience levels of stress, burden, and depression that some studies suggest are even higher than for caregivers of clients with late-onset (van Vliet, D., de Vugt, M. E., Bakker, C., Koopmans, R. T. C. M. and Verhey, F. R. J. (2010), Impact of early onset dementia on caregivers: a review. *Int. J. Geriatr. Psychiatry*, 25: 1091-1100. doi:10.1002/gps.2439). As a result, these clients, and their families, deserve a different care management approach.

Resources for this population are scarce. We, as Aging Life Care Managers, are often placing these younger clients in facilities where they have no peer group, where programming is often inappropriate, and direct care strategies are either unclear or insufficient. Moreover, in addition to age, facilities are often resistant or simply unwilling to accepting clients with atypical dementias such as FTD

or Lewy Body Dementia due to stigma about associated behavioral issues. In fact, according to the Cognitive Neurology and Alzheimer's Disease Center at the Northwestern University Feinberg School of Medicine, most adult day programs and residential care facilities are not prepared to address the special needs of a younger patient, especially if their behavioral symptoms are difficult to manage. It is understandable why facilities would worry about the safety of their other residents who are not as healthy, mobile, and functionally capable as this younger population. However, as very few placement options exist for these clients, it can leave the Aging Life Care Manager perplexed and in a very difficult position.

This issue is designed to highlight the particular struggles of this type of client and increase awareness of their unique challenges. We hope the authors' expertise provided in this issue will serve to educate and/or reinforce each reader's understanding of the different types of atypical dementias, present real life situations where Aging Life Care Management has been effective in working with these clients, provide some strategies and techniques for working with these clients, and inform you about new, innovative, and practical ideas being used to care for this population. On behalf of the entire board and my fellow Guest Editor, Ted Aransky, MEd, LSW, CMC, we hope you enjoy this latest issue and find it beneficial.

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Frontotemporal Degeneration: Explaining the Importance of Differential Diagnosis

Brad Dickerson, MD, Jennifer Pilcher-Warren, PhD, CMC, and Katie Brandt, MS

Frontotemporal Dementia (FTD) is the name given to a number of brain disorders that primarily affect the frontal and temporal lobes of the brain. They are usually slowly progressive and may affect various aspects of a person’s cognitive function, behavior, language, emotions or personality, and/or movement. FTD is estimated to affect 50,000 – 60,000 Americans and is the 3rd most common neurodegenerative dementia after Alzheimer’s disease and Dementia with Lewy Bodies. The onset for FTD is typically between the ages of 40-70, but onset as early as age 20 has been reported. FTD is the most common type of young onset dementia and is diagnosed most frequently in people between 50-60 years of age. Median life expectancy for people with FTD is 7-8 years, however, the rate of progression varies significantly among patients. Today it is estimated that in approximately 15-40% of all FTD cases, a genetic cause can be identified. Researchers are working in partnership with patients and families to learn more about the connections between family history, genetic mutations, and disease presentation.

The pathology of FTD is much more complex than that of Alzheimer’s disease. With FTD, the damage to the brain begins in the frontal and/or temporal lobe. The initial presentation of the disease can vary depending on whether the frontal or temporal lobe is affected first. When the initial pathology affects the frontal lobes, the main changes are in personality and behavior, known as Behavioral Variant FTD. Alternatively, when the temporal lobe is involved, patients present with loss of language skills, and may be diagnosed with the language variant,

Primary Progressive Aphasia (PPA). Further, there are still other variants of FTD that involve movement disorders as well. To learn more about all variants of FTD, go to www.theaftd.org.

At the Massachusetts General Hospital Frontotemporal Disorders Unit, the staff there see many patients with atypical or early-onset cases of dementia with many patients having been diagnosed with either Behavioral Variant FTD (bvFTD), or Progressive Aphasia (PPA). The variants of FTD that involve movement disorders can be even more rare than either bvFTD or PPA. For that reason, this discussion will focus on those two diagnostic categories. For clarity, see the visual below that illustrates how we will divide these categories for the purpose of this discussion.

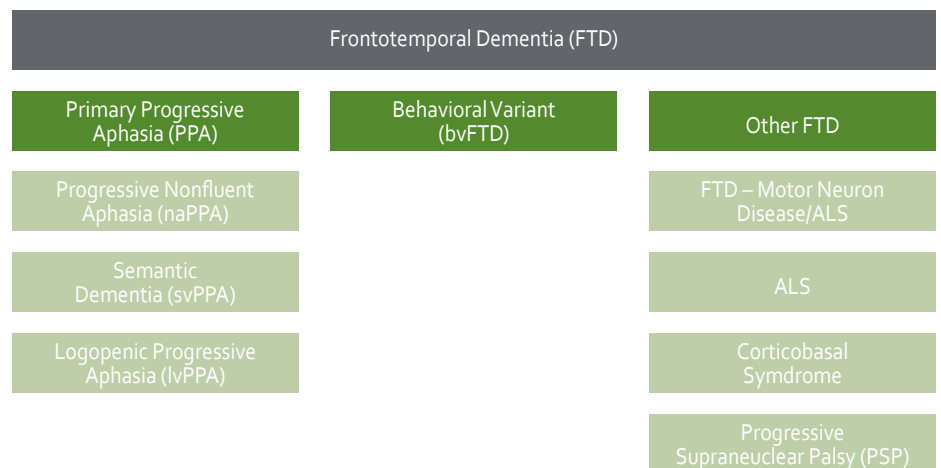
Behavioral Variant FTD (bvFTD)

Rather than changes in memory, as with Alzheimer’s disease, in the early stages of bvFTD patients typically present with changes in personality, ability

to concentrate, social skills, motivation and reasoning. Identifying bvFTD can be challenging because symptoms can be subtle in early stages, and may combine features that are traditionally in the realm of psychiatry (e.g., personality changes, lack of empathy, compulsions). Patients are often first evaluated in general psychiatric settings and about 50% are initially diagnosed with a primary psychiatric illness. Families of those with bvFTD have often been noticing gradual changes in their loved one’s way of behaving and responding emotionally to other people. Memory, language, and visual perception are not usually impaired in the early stages, but will be as the disease progresses.

Behavioral Variant FTD affects “comportment”, i.e., the ability to recognize what behavior is appropriate in a certain social situation and adapt his/her behavior to the situation. However, patients with bvFTD have often lost the ability to see themselves as others see them. For this reason, they are often unable to recognize if they are acting

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in a socially unacceptable or unreasonable manner. Many patients with bvFTD also lack the ability to recognize their deficits or illness. These changes are often what is recognized early in the disease as “personality changes” by family members.

The most common features of bvFTD are as follows:

Disinhibition

- Socially inappropriate behavior and/or impulsivity. For example, talking to strangers or displaying embarrassing behavior in public.

Apathy

- Loss of interest, drive and/or motivation, which can lead to abandoning activities that were enjoyed previously and avoiding social contact.

Loss of sympathy/empathy

- Diminished response to other’s feelings, diminished personal warmth/social connection, making patients appear selfish and unfeeling.

Repetitive/compulsive/ritualistic behavior

- Often with no particular purpose, such as repeating patterns of movement, and behaviors like hand wringing, tapping or pacing.

Change in eating/drinking behavior

- Changes in food preferences, often with a preference for sweet food, excessive intake, or restriction in food choices.

Decline in self care

- Issues with hygiene or inability to perform ADLs.

Difficulty with reasoning, judgment, organization, and planning

- Mental activities that promote decision making, being able to categorize information, and move from one perspective of a problem to another -- such as managing financial or medical decisions.

Primary Progressive Aphasia (PPA)

PPA is a form of FTD that involves a progressive loss of language function. The deterioration of the brain begins primarily in the temporal lobe, the part of the brain that is responsible for speech and language. Many patients initially experience difficulty thinking of common words while speaking or writing. PPA will worsen as the disease progresses to the point where verbal communication is very difficult. In the early stages of PPA, memory, reasoning, and visual perception are not affected, so many patients with this form of the disease are able to function reasonably well in routine daily activities despite their language difficulties. Adults of any age can develop this disease, but it is more common under the age of 65. In many cases, the person with PPA is the first to notice something is wrong and their complaints may be blamed on stress or anxiety.

People with PPA tend to have similar clusters of symptoms. Currently, researchers recognize three sub-types:

Semantic Variant (svPPA) – Word Understanding

- Characterized by reduced ability to understand language
- Difficulty understanding single words
- Loss of word meaning

Non-fluent/Agrammatic Variant (naPPA) – Word Order and Word Production

- Difficulty with word order and word production
- Reduced ability to produce speech/language, slow and labored production of words, distortion of speech
- Tendency to produce the wrong words
- Grammatical errors
- Apraxia of Speech –difficulty saying sounds, syllables and words due to inability of brain to control body parts needed for speech such as lips, jaw, and tongue.
- Stammering or stuttering

Logopenic Variant (lvPPA) – Word Finding

- Halting speech, difficulty repeating
- Spelling errors common, naming of objects is impaired
- Variable speech ability. Speech may be fluent during casual small talk but more challenging when a difficult or precise word needs to be used.
- More apt to use fillers such as “the thing you use for it”, “you know what I mean” or “whatchamacallit”.

Patients with any of these variants experience difficulty with communication including:

- Knowing what they want to say but the words won’t come out
- Adjusting to a new communication style
- Feeling rushed to get their thoughts out
- Loss of previously enjoyed activities
- Decreased comprehension of complex language
- Feeling self-conscious and less useful
- Use of vague/general words
- Paraphasic substitutions of words or phonemes

In addition to a decline in language abilities, some non-language abilities such as memory, attention, judgment, or changes in behavior and personality can be affected. Disinhibited or inappropriate behaviors are more common in Semantic PPA while difficulty with problem solving, multi-tasking movement, and mobility is more common in naPPA.

Other Variants of FTD

There are also 4 other variants of FTD that involve issues with motor skills and movement. However, these diseases are very rare and diagnosed infrequently.

Corticobasal Syndrome

- Cognitive and memory loss
- Asymmetric rigidity
- Apraxia (clumsiness of hand use)

Progressive Supranuclear Palsy (PSP)

- Behavioral and cognitive loss
- Parkinsonism
- Eye movement disturbance

FTD-Motor Neuron Disease/ALS

- Cognitive loss
- Behavior impairment
- Motor symptoms

ALS

- Motor symptoms
- Upper and/or lower motoneuron pathways

For all patients with FTD, the disease starts out distinctly as one of these variants, but will progress to involve other domains over time. Depending on the type and location of change in the brain, changes in movement may also occur for all variants of FTD, including: incoordination, slowing or stiffness, changes in walking or an increase in falls, changes in eye movements, and impaired swallowing. Survival for FTD patients is variable and can be anywhere from 2-20 years after the onset of symptoms. Average survival is between 7-8 years for most diagnosis, depending on how early the diagnosis was made.

Care Management & Differential Diagnosis

It is extremely important for Aging Life Care Managers to have as much information about the specific diagnosis of their clients and its symptomology in order to appropriately advise and guide their clients. If you have a client that has received a diagnosis of dementia, but the particular variation has not been identified, there are several reasons why doing so is important.

Practical

There are practical reasons that having a specific diagnosis can help your clients. FTD is a qualifying diagnosis for the “Compassionate Care Allowance” through social security. If a patient has this diagnosis, not only are they entitled to SSDI for income replacement, but they are fast tracked and can start receiving benefits in as little as 4 weeks. This is significant as

It is extremely important for Aging Life Care Managers to have as much information about the specific diagnosis of their clients and its symptomology in order to appropriately advise and guide their clients.

compared to other, less conclusive illnesses, such as Fibromyalgia, where approval may take many months or even years (<https://www.ssa.gov/compassionateallowances/>).

Treatment

A differential diagnosis is important as it will inform treatment, both pharmaceutical and non-pharmacological. For example, for Logopenic PPA, a rare variant of FTD, drugs typically used for Alzheimer’s disease might be helpful. However, these same drugs would not be effective for someone with Behavioral Variant FTD. Non-pharmacologic interventions would also be different. For instance, if a patient with PPA was working with a Speech Therapist, the therapeutic approach and goals could be very different than they would be for treating

other illnesses such as stroke or Alzheimer’s disease.

As demonstrated in the box below, the approach to Speech Therapy for a patient with PPA is vastly different than the approach that would be used with other diagnoses. If a differential diagnosis had not been made, it is likely the family would not know to seek out a therapist with specific knowledge of PPA. As a result, the patient and family could become increasingly frustrated and hopeless and feel as if the speech therapy was not effective. On the other hand, a Speech Therapist that was specifically trained in PPA, would know that the goals for working with a PPA patient would be very different. The therapist might work with the PPA patient and their caregiver to improve ways to express his/her needs when the patient could not find the right word. The therapist might teach the patient to describe the object that was desired. For example, the patient might describe wanting something “cold...white...I’m thirsty” and the caregiver would work on the skill of identifying that the patient was asking for milk.

Engagement Strategies

Different engagement strategies are needed for patients with FTD than those with Alzheimer’s disease or dementia. You can often engage a patient with Alzheimer’s disease by reminiscing over old family photos or listening to music they used to enjoy. *(continued on page 6)*

DIFFERENCES IN SPEECH THERAPY APPROACH

PATIENT: JIM, AGE 89, STROKE VICTIM
GOAL: improvement in speech and ability to speak
METHODS:

- Work alone, 1:1 with speech therapist
- Practice re-learning vocabulary words
- Practice getting stronger in ability to speak for longer periods of time

PATIENT: SARAH, AGE 59, PPA
GOAL: improving communication
METHODS:

- Work together with speech therapist and caregiver
- Focus on compensatory strategies and “work arounds”
- Improve functional communication

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other words, you can rely on your past knowledge of the patient in order to engage them. With patients with FTD, on the other hand, because there are such strong personality and behavior changes, it is likely that the bvFTD patient will not enjoy the same things that they used to and engagement strategies will have to rely on engaging the patient in the current moment.

As you can see in the example below, the way we engage with patients with FTD must be distinctly different than the strategies we use to engage patients with other kinds of dementia. For many families of FTD patients, they feel as if the person sitting in front of them looks like the person they knew, but doesn't act or feel at all like he/she once did. The daughter in the first example can revisit her relationship with her father and can refer to things they have had in common in the past. The wife in the second example, however, will have to totally redesign her relationship with her husband in order to engage him. (As it turns out, the wife and staff discovered later that Mike really enjoys musicals such as Annie and Grease and found many wonderful ways to engage him in that activity).

Behavioral Strategies

Differential diagnoses are vitally important for informing the strategies we will use to redirect and address difficult behavior. When memory loss is the primary symptom a patient is experiencing, utilizing "therapeutic fiblets" can often be effective. (A therapeutic fiblet is a term that refers to telling a version of the truth in order to avoid upsetting a person with cognitive impairment or to help him/her make a decision in their best interest). In working with a patient with FTD, however, this approach would only be effective if the patient had compromised executive function. Here is an example; we have an FTD patient at MGH who lives in an Assisted Living Community. His wife visits each week and each week she tells him he needs to stay as she is traveling for work. Because this patient is not good at as-

sessing time, this approach works and allows the patient to happily live in the Assisted Living Community. However, if he did have a sense of time and a strong memory, this approach would not work.

Additionally, strategies for addressing risky behavior in FTD patients are different as well. Due to disinhibition, problems with executive function and compulsiveness, patients with FTD put themselves in danger more often than those with Alzheimer's disease or memory loss. People with FTD may be more apt to make choices that are not good for their health, such as having multiple sexual partners or eating sugary foods even though they are diabetic. An FTD patient can be functional with finances, speech is intact, and they can get themselves to the bank. However, they are so impulsive they can ruin their finances by investing in risky

situations or spending all their money.

Conversations about potential risks must be had earlier with patients and their families in order to avoid potential dangers. For example, while an FTD patient can often drive safely and functionally and will not get lost in the car, he/she may blow through a stop sign because they are so inner focused and have less impulse control. A person with PPA might have the memory to get where they are going, but if they get pulled over because a head light is out, the police might think their speech impairment is due to being intoxicated or high and will arrest them for driving under the influence. For these reasons, a patient with FTD may need to cease driving at an earlier time than a person with Alzheimer's disease.

Caregiver Support

The Care Manager should also be aware of the additional strain these

DIFFERENT ENGAGEMENT STRATEGIES

PATIENT: TOM, AGE 67, ALZHEIMER'S DISEASE

BACKGROUND: Tom lives at home with daughter who is a full-time caregiver. Tom always loved the singers Michael Bolton and Celine Dion. He has always loved meatloaf and still does.

ENGAGEMENT STRATEGY: Tom's daughter knows that a good way to fill a long afternoon stretch is to play Tom's favorite Michael Bolton CD and make a meatloaf and mashed potato dinner. Tom enjoys sitting in the kitchen and singing to the CD while his daughter cooks the meal.

OUTCOME: Tom and his daughter are able to spend stress-free time together. Tom enjoys the music and his daughter completes the task of preparing dinner and feels good because she was successful in improving mood and engaging Dad. Because her dad is happy and engaged, they have a pleasant mealtime which leads to a calm bedtime and evening routine. Dad is much more compliant with personal care because of positive mood.

PATIENT: MIKE, AGE 32, BEHAVIORAL VARIANT FTD (bvFTD)

BACKGROUND: Mike lives in a care facility because he can no longer live at home. Mike used to love alternative rock and wife remembers going to concerts with him. Wife also remembers happily playing alternative rock while drinking a glass of wine and preparing dinner together.

ENGAGEMENT STRATEGY: Wife brings old pictures of concerts they attended and CDs of alternative rock music to listen to with Mike.

OUTCOME: Mike is not interested in old photos and is even agitated by them. Wife tries turning on alternative music and Mike does not like it. Wife feels discouraged and unable to connect to Mike. Wife feels inadequate, depressed, grief stricken. Mike is not engaged.

patient's caregivers are experiencing. Burden and stress is higher among FTD caregivers than among caregivers of patients with Alzheimer's disease or other dementias. This is most likely due to the fact that it is so much more difficult for caregivers of FTD patients to connect with their loved ones because of changes in personality and preferences. The young age of these patients is also very challenging for their caregivers, who are frequently spouses. Caregivers of these patients have often experienced major financial difficulties due to their spouse leaving the work force. Many of them are forced to continue working and leave their spouse at home. In addition, many of them are caring for the FTD patient as well as young children at the same time.

Moreover, there is a scarcity of resources for these caregivers. Many of the interventions for caregivers, such as support groups and educational programs, are typically tailored for patients with Alzheimer's disease and are not suitable for FTD caregivers. If the caregiver is forced to place their loved one with FTD in a facility, they are faced with the reality that most nursing homes, assisted living facilities, and day centers are tailored to older clients. As a result, even when placement is achieved, staff at these facilities are frequently unable to cope with the symptoms of FTD. For all of these reasons, the support and guidance of an Aging Life Care Manager is essential for these caregivers to sustain and care for themselves as they continue to care for their loved one with FTD.

Resources for FTD

- The Association for Frontotemporal Degeneration: www.theaftd.org
- MGH Frontotemporal Disorders Unit: www.FTD-Boston.org
- Cure PSP www.psp.org
- ALS Association: www.alsa.org
- Alzheimer's Association: www.alz.org

*Remind your families that the Alzheimer's Association can support

families with all kinds of dementia. Some helpline staff have even received specialized training in the rare dementias.

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Brad Dickerson, MD is Associate Professor of Neurology at Harvard Medical School and Director of the Frontotemporal Disorders Unit at the Massachusetts General Hospital, an integrated multidisciplinary unit dedicated to the highest level of care of patients with these conditions. Dr. Dickerson is also on staff as a behavioral neurologist in the MGH Memory Disorders Unit. Dr. Dickerson is an active clinical consultant in many aspects of cognitive and behavioral neurology of neurodegenerative and related disorders, including frontotemporal dementia, primary progressive aphasia, Alzheimer's, mild cognitive impairment, posterior cortical atrophy, and related conditions, and the use of neuroimaging and other diagnostic markers in neurodegenerative diseases.

Dr. Dickerson has published extensively in the field of neurodegenerative disease, neuroimaging, aging, and cognitive neuroscience. He is on the advisory board of the Massachusetts Alzheimer's Association and the national Association for FTD. He is active in teaching, leading an annual course on Cognitive Neurology at the American Academy of Neurology and co-directing the annual Harvard Dementia Course. He is also an active mentor of trainees in neurology, psychiatry, and psychology, and of graduate and medical students, as well as undergraduate and high school students interested in this field.

Dr. Dickerson has published more than 70 manuscripts and book chapters and is in the process of editing 2 textbooks in the field of cognitive neurology and dementia, and runs a brain imaging laboratory affiliated with the Martinos Center for Biomedical Imaging.

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Katie a caregiver who knows firsthand how essential the support of community is for those affected by rare disease and dementia. Katie lost her husband Mike to the rare disease, Frontotemporal Degeneration (FTD), when he was 33 years old. Shortly thereafter, her father was diagnosed with Alzheimer's at the age of 59. Today, Katie is an advocate, an educator, and a volunteer in the rare disease and dementia community. Katie's story of love, loss, and resiliency is unique, but it has universal truths.

Katie has started a new campaign, Love Is Out There, to raise awareness for FTD, caregiving, and empowering families to take the power back from rare diseases. Through social media, community events, and educational forums, Katie and her network will raise awareness for families struggling with FTD and let them know that resources and support are out there. She has spoken at colleges, conferences, hospitals, the Massachusetts State House, and on Capitol Hill to share her experiences.

In the summer of 2012, she contacted The Association for Frontotemporal Degeneration and offered herself as an advocate and a volunteer. It was the beginning of a great relationship and a new career for Katie. Currently she serves as the Caregiver Support Services Director for the Frontotemporal Disorders Unit at Massachusetts General Hospital in Boston.

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Ms. Pilcher Warren was awarded her doctoral degree in Gerontology from the University of Massachusetts in Boston. Her professional experience has focused primarily on care and housing arrangements for elders with Alzheimer's disease and related dementias, including policy and fundraising work for the Alzheimer's Association of Eastern Massachusetts, the Alzheimer's Association of Utah, and the Massachusetts Association of Older Americans. She has held several positions on the board of the New England Chapter of the Aging Life Care Association and is currently the Editor in Chief for the Journal of Aging Life Care. For seven years, Ms. Pilcher Warren was affiliated with Hearthstone Alzheimer Care Assisted Living programs in Massachusetts and New York, where she held a number of management positions. For 8 years, Ms. Pilcher Warren worked both as a Geriatric Care Manager and as the Director of Operations for AZA Care Management of Boston. She currently holds the position of Senior Executive Director of Care Management for Overlook C.A.R.E., a non-profit Life Care Management practice with offices located in Hingham, Dedham, Plymouth, and Charlton, MA.



Younger-Onset Alzheimer's Disease: Key Legal and Financial Issues for the Aging Life Care Manager™

Donald M. Freedman, Esq.

While Alzheimer's disease (AD) is primarily a disease of old age, for about 5%, or about 200,000 people in the US, the disease has an onset prior to age 65, and includes people in their 40's and 50's and sometimes even younger. Young-onset Alzheimer's disease is defined by the Alzheimer's Association as Alzheimer's disease arising prior to age 65. For care planning purposes, however, age 65 should be seen more as a red flag than a bright-line criterion. While the clinical presentation of early stage disease may be similar regardless of age of onset, the family, work, legal, and financial context of the disease may be very different in the younger cohort. People affected by this disease may well be working, and are likely in mid-career. They may well still have dependent children, and may have caregiver responsibilities for aging parents.

While the need for personal care and other support services may be demonstrated within the young-onset population, eligibility for government care assistance is often limited to people who have reached age 50, 55, 59½, 62, 65 or "normal retirement age" (between 66 and 67 depending on year of birth).

For long-term disability insurance benefits, age 65 may signify the end of benefits, or a significant reduction in benefit levels. Tax considerations in planning for care can be very important in stretching family resources, and in this context as well, age plays a significant, although often seemingly arbitrary role. For example, ages 55, 59½, 65 and 70½, among others, signal either the availability or loss of potentially advantageous tax rules.

While this article focuses on what

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is special in care planning for the younger cohort, we must not lose sight of key protective strategies that are important regardless of age of onset. Key among these are durable powers of attorney, health care proxies, and wills.

Important Advanced Planning Considerations

Given the foreseeability of a progressive loss of capacity to make decisions about legal, financial, medical and other matters, the Aging Life Care Manager should give priority attention at the earliest possible time to counseling protective steps needed to provide for substitute decision-making upon later incapacity. Pertinent instruments include a durable power of attorney, for legal and financial decisions; a health care proxy, for medical decisions once the individual is no longer able to make them on his own; a medical directive or "living will" to express preferences about care at end-of-life; and

"HIPAA" medical information releases, to give persons you wish access to otherwise private medical information, even prior to incapacity.

In the presence of a diagnosis of dementia, one should appropriately ask whether the individual has the capacity to execute such an instrument. While legal standards vary among the states, and while some cases may warrant formal assessment, it is certainly the case that many people with dementia that has progressed enough to interfere with work and life activities may nonetheless still have the capacity to execute such documents. A diagnosis should not in itself be considered determinative. Generally, an individual has the capacity to sign if able to understand the general purpose and use of the instrument and to appreciate his relationship with the persons named.

Having a durable power of attorney and health care proxy makes guardianship unnecessary in most cases. However, if the individual lacks the capacity to execute a durable power of attorney or health care proxy, a court-appointed guardian (for personal and medical decision-making), conservator (for financial decision-making), or both, may be needed.

Employment Issues and Income Protection

If the individual is working at the time of onset, counseling must be directed to helping the individual think through continuing or terminating work on appropriate terms. Aside from personal preferences about work and concerns about lost income, the individual must be helped to consider the nature and extent of risk to himself,
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his employer, his co-workers, and those served by the work.

If the individual remains otherwise able to work, the Americans with Disabilities Act (ADA) and many state laws require most employers to make reasonable accommodations to the known physical or mental limitations of otherwise qualified individuals.

The Family and Medical Leave Act (FMLA) is a federal law requiring most employers to provide unpaid, but job-protected, leave for employees to deal with a serious medical problem of their own or of a spouse or parent. The Act allows eligible employees to take up to 12 work weeks of unpaid leave (continuous or intermittent) during any 12-month period. Covered employees are also entitled to continuation of the same group health insurance benefits, including employer contributions to premiums that would exist if the employee were not on leave.

Concern about loss of income is, of course, a crucial consideration in deciding whether and when to stop work. Therefore, consideration must be given to alternative vehicles to provide at least a measure of income maintenance.

If the individual is unable to perform the duties of his current position, he may be entitled to short-term disability insurance benefits as an employment fringe benefit or under an individual insurance contract. Stricter standards typically apply to long-term disability benefits. If the individual is terminated from his job or forced to resign because he is no longer able to perform required duties, he may nonetheless be eligible for state unemployment compensation benefits if he remains ready, able, and willing to work elsewhere in some other capacity.

If the individual is no longer able to engage in any significant productive work activity, the individual may consider applying for Social Security Disability benefits. To be eligible, the individual must meet certain "insured status" as well as "severe impairment" tests. In most cases pertinent to this topic, insured status requires that the individual have at least 40 quarters of coverage under Social Security by hav-

ing worked in "covered employment" and having paid FICA as an employee or self-employed person. The worker must also have earned at least 20 quarters of coverage during the 40 quarters immediately preceding the onset of disability. (The most commonly encountered workers who are not covered are employees of many state and local governments. These employees may (or may not) be eligible for benefits under other state and local governmental programs.) To meet the "severe impairment" criteria, the worker must be "unable to engage in any substantial gainful activity by reason of a severe physical or mental impairment or combination of impairments which has lasted or is expected to last for more than 12 consecutive months."

Ordinarily, a person should consider applying as soon as possible after onset of disability, in light of the required five-month waiting period for benefits after onset, the 24-month wait for Medicare and the limitation to 12 months of retroactive coverage. It is important to note that the onset of disability usually means when you actually stop work due to your condition, and not the earlier date when you may have received your diagnosis, or the later date at which your compensation stops; for example, if you are receiving continuing pay for accumulated vacation time or under a severance agreement.

Note that diagnosis of "young-onset Alzheimer's" results in an expedited medical evaluation as the result of Social Security's "Compassionate Allowance" initiative relating to certain medical conditions generally found to be disabling.

Monthly cash benefits are payable to the worker and also to the spouse age 62 or older, or of any age if providing care to a minor or disabled child. Lastly, they are payable to a child of the worker who is unmarried, younger than 18, or age 18 or 19 but still in high school as full-time students, or 18 and older and severely disabled (the disability having started before age 22).

An often underutilized cash benefit is the Veteran's Administra-

tion special monthly pension: Aid and Attendance. Monetary support of up to \$1,788 per month to a veteran, \$1,196 per month to a surviving spouse, or \$2,120 per month to a couple for certain veterans and surviving spouses who cannot function completely on their own and require the regular attendance of another person to assist in eating, cooking, bathing, dressing, leaving home, etc. Also potentially qualifying are individuals who are blind, patients in a nursing home because of mental or physical incapacity, and residents in assisted living facilities who require assistance on a regular basis to protect themselves from daily environmental hazards. Often overlooked is the potential eligibility of a healthy veteran caring for a sick spouse, who may qualify for up to \$1,406 per month.

A veteran under 65 must be disabled and ordinarily must have had at least 90 days of active military service, with at least one day during a period of war. Eligibility is limited to veterans who lack "sufficient means" to provide for their own care. The VA applies asset and income measures depending on age and other circumstances. \$80,000 in assets (aside from the residence) is a commonly understood measure of sufficient means.

Health Insurance, Income and Asset Protection

Concern about the loss of health insurance is often a critical factor in deciding how and when to stop work. In some cases, it may be possible for the individual to insure under a spouse's employment plan. Where such coverage is not available, Federal "COBRA" law provides for the temporary continuation of employer group coverage lost due to separation or reduction of hours, for the disabled worker, spouse, and dependent children for up to 29 months. Many states expand coverage to smaller employers. Coverage is expensive, as the employer need not subsidize the group rate, and can under certain circumstances even charge a premium. Nonetheless, COBRA may be critical in providing continuing health insurance coverage given the uncertain future of the Affordable Care Act.

Medicare is available to the individual in younger-onset cases only where the individual has been awarded Social Security Disability benefits and has been entitled to benefits for at least 24 months. The individual's spouse, whether or not she has worked and paid Medicare taxes, will not be eligible for Medicare until age 65. Medicare provides no coverage for children except in the case of an unmarried child with a severe disability arising prior to age 22. In any case, Medicare is geared and limited to acute care rather than to the long-term services and supports that are typically the focus of care-planning in the younger-onset context.

Medicaid is the state-administered, federally regulated program under which states receive federal financial assistance for providing certain health and rehabilitation related services, including long-term services and supports, to people meeting certain personal and financial requirements. Long-term services and supports include assistance with activities of daily living (such as eating, bathing, and dressing) and instrumental activities of daily living (such as preparing meals, managing medication, and housekeeping). Also funded by Medicaid is nursing facility care, adult daycare, home health aide services, personal care services, transportation, and supported employment, as well as assistance provided by a family caregiver, together with care planning and care coordination services.

Eligibility and services vary depending on age, marital status, composition of the household, and the kind of service required. While all fifty states participate in Medicaid in some manner, the extent to which states choose to provide optional services or to participate in many waiver programs differs widely, as does eligibility criteria. Given the stated intention of the current administration to revamp the program, endeavoring to provide specific guidance here would be problematical. That said, we may at least point out certain aspects of Medicaid law that have historically

been fruitful for planning.

The transfer of assets as a strategy to facilitate Medicaid eligibility has generally been discouraged by the law over the years, through longer look-back periods (now five years) and more punitive formulas for determining the duration of transfer penalties. However, exceptions that have persisted over the decades reflect countervailing policies that the government has also found to be important, despite a liberalizing effect on eligibility. Since 1985, the law has sanctioned a number of

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strategies to protect a spouse at home from impoverishment where the other is institutionalized. This policy mandate finds manifestation in rules allowing transfer of assets to the community spouse; the deduction from the income of the institutionalized spouse to support a minimum maintenance needs allowance for the community spouse; in provisions allowing the set-aside of marital assets for the support of the community spouse; and an exception to generally restrictive trust provisions carving out an exception for trusts for the surviving spouse established and funded by a will. Also over this

time, the law has authorized certain transfers to or in trust for the benefit of minor and disabled children. In identifying at least these vulnerable populations – spouses separated by institutionalization and the minor or disabled children of parents requiring long-term care – public policy has reflected important concerns beyond cost containment that, it is hoped, may continue to be a focus in some form in future iterations of the Medicaid program.

The income position of couples in the younger-onset circumstance is undercut by the loss of employment income to both the individual with the condition as well as the spouse who is now at least partially committed to caregiving. At the same time, while care expenses are expanding, there is no abatement in other budgetary demands, particularly in the presence of minor or dependent children. With the bulk of family resources typically locked up in retirement accounts and the equity value of the residence, how are such resources to be accessed?

Funds withdrawn from IRAs, 401k's, and other retirement accounts are taxable, regardless of age at the time of withdrawal. However, the extent of the impact can be moderated at least to a degree by planning withdrawals in conjunction with medical and care expenses, which can partially offset one another.

Funds withdrawn from an IRA prior to age 59½, and funds withdrawn from a 401k with a former employer prior to age 55, are subject to a penalty unless an exception applies. Exceptions most pertinent to this context involve withdrawals by an individual who is disabled; withdrawals to pay certain educational expenses; and withdrawals paid in substantially equal periodic amounts based on actuarial life expectancy.

To access home equity, consider financing or refinancing for a larger loan amount, either from a bank or, circumstances allowing, from a family member. Consider applying for a home equity line of credit, a second

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mortgage, or home equity loan, from a bank or family member. Consider applying for a reverse mortgage, although evaluate this option with particular care as special risks, limitations and high expenses are involved.

If the individual has long-term care insurance, counseling should be directed to determining whether the individual currently meets the medical qualifications for payment of benefits, often expressed in terms of need for assistance with a specified number of activities of daily living. Also, the question arises as to whether the claim should be made as soon as the need for services arises, or to defer the claim and conserve benefits for nursing home placement. We ordinarily recommend claiming as soon as you qualify. Many people underutilize benefits. However, many states provide a measure of protection from Medicaid estate recovery for the estates of individuals who have received Medicaid support and have had long-term care insurance meeting certain criteria. Families should be counseled to ensure that use of their insurance benefits, where applicable, is in accordance with these requirements.

Before arranging for services for which insurance reimbursement is expected, confirm with the insurer that the particular agency you have in mind qualifies under the policy.

Home Health Service Considerations

Many people arrange for home health services through private "home health" or "home care" agencies. Of course reputation for quality must be foremost among selection criteria, but home health agencies may be organized in fundamentally different ways, with very different legal and financial implications for the consumer. The most important legal distinction is between agencies that directly employ their workers, and a home care placement agency.

In the former case, the agency withholds and pays state and federal income taxes, Social Security and Medicare taxes; pays federal and state unemployment taxes; and provides worker's compensation insurance (to compensate the worker for injuries arising in the course of the employment).

In the latter case of workers placed by the agency, responsibility for taxes and insurance, and the family's potential liability in the event of worker illness or injury, is a matter of federal and state tax law, employment, insurance, and personal injury law. As an Aging Life Care Manager, make certain that your client is fully informed of the legal and financial ramifications of the arrangements you are recommending, or at least as to what questions to ask.

Concluding Note

Individuals and families finding themselves suddenly and unexpectedly having to deal with the impact of Alzheimer's disease or related disorders, especially when in the prime of life, are faced with challenges on so many levels. The issues involved in the legal and financial domains are complex and unfamiliar. Dealing with them in a comprehensive and ongoing way and starting as soon as possible after onset, is essential for the effective protection of the individual and family. To be effective, care planning by an Aging Life Care Professional® must be coordinated with legal and financial planning. The case for a team approach to planning, centered on the needs of the individual and his/her family, could not be plainer.

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Think of Aphasia

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Introduction

Aphasia, the loss of ability to use language, is a common manifestation of many medical conditions found in patients for whom Aging Life Care / care management services are sought. A patient with aphasia might present as having problems using language to express themselves (expressive aphasia), as problems using language in understanding others (receptive aphasia), or both. Aphasia can range in severity from mild to severe, with corresponding degrees of impairment as a result. In a full assessment of a patient's needs, it is important to identify and describe any aphasia and how it impacts meeting the demands of everyday life. Many times, aphasia can be harder to recognize if what brought the person to attention are the more dramatic consequences of losing social cognition such as executive dysfunction, especially impulsivity.

Aphasia can be a result of many intracranial pathologies. The most commonly recognized cause is stroke, after which aphasia manifests as much as 40% of the time. Aphasia can also be seen after traumatic brain injuries, intracranial bleeding (e.g. subdural or subarachnoid hemorrhages), infections (e.g. encephalitis, meningitis), brain tumors, or other intracranial pathologies. In cases where the onset of the underlying problem is acute and discrete, the aphasia appears just as acutely and tends to be more responsive to speech therapies, with a greater prospect for recovery or stabilization.

Aphasia can also be a result of neurodegenerative processes, ones that are more gradual and insidious in onset and progression. This includes the aphasias seen with the Dementia

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of Alzheimer's Disease and its variants, Parkinsonian/Lewy Body Dementias, or Fronto-Temporal Lobar Dementias. The diagnostic criteria for a major neurocognitive disorder (colloquially, a dementia) described in DSM 5, as well as diagnostic guidelines from other sources, specifically names language impairment as a primary deficit sufficient for offering a diagnosis of a major neurocognitive disorder. It is often harder to recognize in the short term because the loss of language skills is slower and more gradual, paralleling the progression of the condition itself. In these cases the aphasia tends to respond in a more limited way to speech therapies, in part because of the general cognitive decline and in part from the inexorable progression of the underlying illness.

Although aphasia is common among patients with these conditions, it is not always recognized explicitly. Often well before Aging Life Care / care management services are sought, regular caregivers have developed routines taking care of such people, unconsciously having taken into account the loss of language skills.

In the absence of language, people use behavior as a primary method of communication and regular caregivers become adept at recognizing nonverbal cues that might signal, for example, if someone is hungry or needs to use the bathroom. Recognizing these cues obviates the need for the patient to use language in asking for something they want. Similarly, caregivers often build a familiar routine around daily care such as changing clothes or bathing. Remaining within an established routine reduces the need for caregivers to explain, using language, what is taking place, or for patients to understand the language about what caregivers may be asking them to do. For this reason, establishing routine is essential for any client experiencing aphasia.

When these routines happen smoothly, and the caregiver is "filling in the blank" correctly, everything usually proceeds okay. However, there are many circumstances where it does go wrong and what could follow is an exponential increase in caregiving effort. For example, if the patient does not ask to use the bathroom and nonverbal

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cues are misinterpreted, it could lead to impulsive incontinence and to caregiver stress, social censure, client discomfort, extra housekeeping burdens, and the additional ADL care that follows. Another example, if the patient does not understand what the caregiver is asking them about changing clothes before bed, it could lead to an impulsive resistance of care, with combativeness and the possibility of inadvertent injury to the patient or caregiver. In cases like these, the consequence of impulsivity and aphasia together is likely to be more substantial than the consequence of impulsivity alone. When an impulsive behavior appears dangerous, it can result in interventions to try to address the behavior, such as hospitalization or medication. Such interventions do not help in addressing the underlying deficit in communication itself.

Although there are specific disciplines trained to recognize and treat aphasia, any professional, including Aging Life Care Managers, can develop basic skills to identify which of their clients might be affected. With that recognition, patients and their families can be offered interventions specifically directed at aphasia and its consequences as part of their care plans. Consciously identifying and addressing the consequences of aphasia in all Aging Life Care / care management evaluations can make a meaningful impact in care overall.

Recognition

Consciously looking for language problems can be part of any professional interaction. This might include:

- direct observation of language deficits
- awareness of one's professional experience and behavior during the clinical encounter, and
- collateral history from caregivers about events taking place in the patient's environment

These caregivers (including nurses, aides, and social workers) are likely to pick up subtle signs of communication problems. Speech-language pathologists and other medical professionals

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typically combine their clinical examinations with such reports from a patient's caregiver in their assessments.

Aphasia can present as both verbal and written impairments. With auditory comprehension impairment, a patient may have difficulty understanding verbally presented directions, manifesting most with multi-step commands and long sentences. With comprehension impairment of written language (e.g. agrammatism, alexia), a patient may have difficulty reading, manifesting as difficulty with books, menus, and calendars. With expressive impairment of written language, a patient may have difficulty with writing, manifesting as difficulty signing their name or writing personal information (e.g. completing medical forms/documents). With expressive language impairment of spoken language, a patient may have difficulty:

- naming objects or coming up with the word they want to use
- pronouncing words clearly, resulting in word or sound substitutions (e.g. "chair" for "table" or "might" for "fight")
- offering independent ideas spontaneously, as opposed to repeating what they hear or using rote phrases (e.g. "I love you", "Get away!")
- answering open ended questions
- making and expressing choices
- constructing their wants or ideas in an organized way.

More subtle signs and symptoms of aphasia may include frustration with communication attempts, withdrawal from communicative situations, social isolation, and appearing to have a depression.

A professional can also use an awareness of their own experience during a professional encounter as clues to a possible aphasia. In social interactions with inherent difficulty in communication, for example a language barrier, people often change the way they speak. This typically includes some combination of speaking more slowly, more loudly, more simply with vocabulary and syntax, and using accompanying gestures. A professional, noticing they are doing so during a clinical encounter, should be cued to suspect that the patient may have an aphasia. Similarly with older patients who may be hard of hearing, a professional should not automatically attribute difficulty in communication to the hearing problem, rather allow for the possibility of a co-morbid aphasia.

Collateral history from caregivers is invaluable in identifying language problems. Patients with aphasia learn to accommodate for their impairments, developing strategies for minimizing everyday communication burdens. They might participate only passively in whatever discussion is taking place. They might try to avoid interaction with others, especially where conversation is taking place. They might be overly affectionate and reliant on gesture to maintain attention of the people they want. They might always defer to a default option, for example when presented with a dinner choice of several options, a response of "I'll take the chicken" or "I'll have the special" takes the pressure off generating language. Asking caregivers about such events might lead to clues about a possible aphasia.

Intervention

If a professional identifies a patient with language impairment, a referral to a speech-language pathologist for a comprehensive communication evaluation can be sought.

A patient can gain the most benefit from language treatment when their other cognitive skills remain functional enough to demonstrate insight into the communication deficit, to maintain a motivation to participate in therapy, and to utilize compensatory techniques during communication interactions. Circumstances when speech language pathology services can markedly beneficial include recovery after an acute neurological event such as a stroke or traumatic/non traumatic brain injury. Speech language pathology services may not be as beneficial if the language disorder is part of an ongoing neurodegenerative process. Additionally, individual goals of care should be

treatment plan to address the language goals important to that patient. Common treatment goals include remediation of specific language domains, teaching compensatory techniques to maximize communication skills, and teaching strategies to the patient and their care team ways to communicate more effectively. Overall, the primary goal is to help the person with aphasia communicate using language over behavior.

Communication Strategies

There are two primary types of communication strategies: internal communication strategies and

- using multi-modal communication (i.e. using gesture, pointing, drawings, and facial expressions to supplement verbal expression).

A patient with aphasia may also be a candidate for an augmentative or alternative communication (AAC) device, which can be low tech or high tech. A low tech AAC device may be a picture board. The patient can express basic wants and needs by selecting a word or picture. There are also high tech AAC devices, like a computer based speech generating device, where a patient may select target icons to generate words, phrases, and sentences to express wants, needs, and ideas.

Environmental Strategies

Environmental/adaptive strategies may also help facilitate communication and focus on what can be done around the patient. Examples of environmental/adaptive strategies a caregiver can utilize include:

- reducing environmental distractions while speaking, making sure the surroundings are quiet
- looking directly at your communication partner face to face to pick up on non-verbal cues like facial expressions, gestures, and body language
- speaking at a normal volume; being louder will not help
- speaking slowly and with simple language, using phrases and short sentences when possible, one statement at a time
- allowing time to respond, giving the patient the longer time they need to generate their thoughts and ideas
- asking yes/no questions or choice questions versus open ended questions (i.e. "Do you want cereal or eggs for breakfast?" versus "What do you want for breakfast?")
- encouraging participation in social activities when appropriate
- not pretending to understand what the patient has said when you do not. Instead, repeat back

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taken into consideration. If those goals of care are focused on maintenance or palliation, as opposed to intensive therapy, a limited approach can be used, for example emphasizing only environmental or adaptive modifications.

If a full comprehensive speech language pathology assessment is indicated, such an evaluation will include assessment of all domains of language (receptive, expressive, reading, and writing), speech production, and cognitive/social features of communication. Based on this assessment, a speech-language pathologist can identify the type and severity of aphasia, communication strengths and weaknesses, and the impact on the patient (e.g. quality of life, daily activities and care, social situations).

Once a patient is identified with aphasia, a speech-language pathologist can develop an individualized

environmental/adaptive strategies. Internal communication strategies focus on what the patient can do themselves in using language. A patient with aphasia may be able to use internal communication strategies in different combinations, with variable levels of support. Examples of internal communication strategies include:

- thinking/generating ideas before speaking
- using circumlocution (describing a word or situation that a person may have difficulty generating)
- word finding strategies (using a description or synonym to replace the word the patient is having difficulty generating)
- setting the topic to make sure the listener knows the context of your message

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what you did understand and/or ask for clarification and repetition.

Teaching and reinforcing communication strategies with a patient's caregivers is essential in maintaining the consistency of a communication approach. It is helpful to have and display a written reference of communication techniques and environmental strategies where the patient happens to be (e.g. at home, during hospitalizations). Learning these communication tools should be part of any caregiver's introduction to the patient and encouraging caregivers to review these tools should be part of the supervision of caregivers. Where caregivers regularly change, this can be a challenge to delivering consistency of a communication approach. In such cases, someone from the team, such as a regular nurse or care manager, should be more proactive about offering education regarding the personalized strategies. Developing these written references for personalized strategies can be part of the services of a speech language pathologist. Additionally, the American Speech-Language and Hearing Association (ASHA) is an excellent resource of information about aphasia for caregivers and families.

Conclusion

Conducting any kind of professional assessment starts with discovering what the problem is which led to the referral. A professional assessment does not simply end with a superficial solution to the presenting problem, rather it includes identifying the underlying causes. Addressing these causes can provide a more stable and durable solution for the presenting problem itself. Many of the dramatic causes that lead to care management referrals, such as being unsafe at home or

being aggressive with caregivers, have language impairment as a proximate cause. A more sophisticated assessment would take that possibility into account, starting with careful attention to how a patient uses language during the assessment.

Language in its complexity is among the most powerful achievements of humanity. Using it allows the communication of ideas. It allows people to share with one another ideas about internal states (like how someone is feeling or felt), ideas through time (like a recipe for beer among hieroglyphs in a pharaoh's tomb from 5000 years ago), or ideas across space (like how aphasia might be impacting patients' daily needs in 2017). When illness robs people of the ability to use language is it among the most tragic losses. Finding a way to intervene in the hope of stabilizing such losses might be an invaluable part of a care plan. It starts with recognizing that someone may have an aphasia. It continues with studying and describing the impact on their life. It leads to developing communication strategies to compensate and teaching them to the patient's caregiving system. Care Managers that understand how to recognize, intervene and reinforce care plan strategies over time, can potentially make significant improvements to both client and caregivers' quality of life.

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“Be Unique, Live Unique”

A New Approach to Behavioral Cognitive Programming for Residents with Atypical Dementias

Lisa Jacobs, RN, and Jennifer Pilcher-Warren, PhD, CMC

In the western suburbs of Boston, Golden Pond, a stand-alone assisted living community, has designed a groundbreaking approach to serving residents with atypical dementias and other progressive neurological disorders. This program addresses the unique needs of these clients who most often suffer from Frontal Temporal Lobe Dementia (FTD), Parkinson’s disease, Multiple Sclerosis, Traumatic Brain Injury, and/or Chronic Concussion Syndrome. The program has adopted the tag line: “Be Unique, Live Unique” to emphasize their dedication to providing customized, person centered care as well as accentuate their distinctive clinical assessment and behavioral management approaches.

Lisa Jacobs, the program’s founder and a psychiatric nurse by training, initiated this program after identifying a need in her own community. After becoming Executive Director in 2015, Jacobs observed that her current residents fell into two distinctive classes: 1) Traditional memory care residents, average age 84, with moderate to end stage dementia and 2) A smaller subcategory of younger residents who presented with atypical dementias. These residents each had a presentation that did not fit the mold of the typical Alzheimer’s resident. They were

younger, more mobile, and appeared to have more cognition and ability to engage than their counterparts.

What Jacobs quickly assessed was that these residents were not benefiting from the current programming as it was geared toward those with moderate to severe cognitive impairment. In researching these atypical dementias as well as other neurological disorders, Jacobs discovered that while these diagnoses were distinctly different, she found some common

threads regarding intellect and ability that were less common in typical dementia residents. A pattern began to emerge illustrating the need for different programming for these younger, more mobile and differently abled residents.

From there, Jacobs reached out to community

partners, who she then asked to educate her on the specific needs of these potential residents and their families. What she learned was that specific programming and resources for these populations were seriously lacking. Jacobs learned that these families experienced grief, loss, and profound hopelessness while trying to care for their loved ones at home. She uncovered some realities the Aging Life Care Management industry has been aware of for some time.

First, families of people with atypical dementias had extreme difficulty in finding appropriate placement. Second, when placement was found, often their loved ones were bounced from placement to placement because their behavior was labeled as “problematic” or “aggressive”. Third, if a new resident could not adjust to the facility, they were seen as failing and were hospitalized and, most often, over medicated. Fourth, these residents often ended up with multiple hospitalizations and were then rejected by even more facilities. These realities often meant that a family was faced with placing their loved one in their 40’s or 50’s in a skilled nursing home facility.

Armed with this information, Jacobs and her team went to work on designing a program that could meet the specific needs of younger people with atypical dementias and neurological disorders. What they created is a therapeutic community that offers 3 types of engagement: meaningful, purposeful and passive engagement. For each resident, an individualized program is created that specifically targets how the staff will engage the residents in these three different ways.

Meaningful Engagement

The team focuses on person-centered engagement, i.e. evaluating what kind of activity is meaningful to the individual person. For example, one of the residents that lives at Golden Pond is a former CIA agent who loves to ride motorcycles. His meaningful engagement plan is to work with the

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A pattern began to emerge illustrating the need for different programming for these younger, more mobile and differently abled residents.

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maintenance team on engine repair or to sit on a motorcycle that is brought in by one of the staff. Another resident is a former professor who can quote Shakespeare and loves the Rocky Horror Picture Show. His program is based on encouraging these interests and finding ways for him to continue to engage in those activities.

Purposeful Engagement

The program's success is credited to the collaborative team of clinicians and therapists, including Speech and Language therapists, to design individual plans. One resident might be working on executive function, while another may be experiencing aphasia and is working on best communication strategies. Each resident works weekly with the Speech Therapist 1:1 to evaluate functioning and practice skills. One resident at Golden Pond worked with the therapist on communication strategies. The resident wrote a poignant piece about who he was and what he needed from others in order to communicate more effectively with them (see sidebar). His writing is an example of how the program helps these residents engage in a different kind of discussion about their impairments.

Passive Engagement

Like for typical dementia residents, passive experience is yet another way for these atypical residents to engage with the program. Simply sitting in the kitchen while staff is preparing food, experiencing aromas and finding successful connection with others by sharing a meal is extremely important for combating the anxiety and isolation these residents have often experienced in the larger community.

The BCAT (Brief Cognitive Assessment Tool) Approach

The team at Golden Pond have collaborated with Dr. Mansbach at the BCAT Institute and has become a premier provider of the principles of the BCAT approach. The BCAT Approach

GERALD'S STORY

My name is Gerald and I have a brain injury. I was riding my motorcycle and I crashed. It was terrible. Before my accident I was running a company. I worked and had lots of friends. I have done more in my life than most people.

After the accident, I thought I was okay. I thought I could do everything I used to do, except for my memory. I put on my clothes and I double check what I do. I don't always get everything right. I do everything I can possibly do to get myself better. Twenty times at a time, I get frustrated. If I can help myself, why not?

Today, I like to help people in Golden Pond. I love talking about cars and motorcycles. Sometimes, I have trouble thinking of a word. I just need extra time to come up with it. If you do not clearly understand a story I am telling you, please ask questions to clarify. I hope my story can help others.

is an applied concept for assessing and working with people who have memory and other cognitive impairments. It is designed for clinical and residential settings where cognitive functioning and impairment are central issues.

The BCAT Test System is comprised of five unique assessment tools that are used to assess current cognitive and mood functioning. The primary test, the Brief Cognitive Assessment Tool (BCAT), can be administered in 10-15 minutes or less. The BCAT was designed to assess orientation, verbal recall, visual recognition, visual recall, attention, abstraction, language, executive functions, and visuospatial reasoning. The test is sensitive to the full spectrum of cognitive functioning (i.e. can determine normal, MCI, or dementia) and provides separate Memory Factor and Executive Functions Factor scores. The BCAT has been proven to help predict the need for basic and instrumental activities of daily living, determine service needs, aid in fall prevention, and lower risk of hospitalization and utilization of pharmacological interventions.

Additional tests include the Brief Anxiety and Depression Scale (BADs) for evaluating mood impairment and the Kitchen Picture Test of Judgment (KPT) as a visually presented test of practical judgment. BADs is a screening mechanism that rapidly assesses and provides separate scores on anxiety and depression. BADs is ideal for providers that want to track mood status over time. KPT includes an illustration of a kitchen scene in which three potentially dangerous situations are shown. Residents are asked to describe the scene, identify the three problem situations, rank the order of importance of each situation, and offer solutions that would resolve the three problems.

Lastly, the Brief Cognitive Impairment Scale (BCIS), is used to assess cognitive functioning. The BCIS is an 11-item, 14-point scale. It was developed not only to track cognitive changes, but also to provide information to better manage behavior problems. These other screening instruments take less than 3 minutes each to complete. All BCAT Test System tools are designed for rapid

administration and should be repeated to track progress over time.

Using these tools, the staff can quickly and easily track the functional ability as well as changes in mood or emotional status. Most importantly for the population they are serving, the BCAT approach provides information that helps the team manage behavior problems – the primary issue that is expressed by families of these atypical residents.

Golden Pond is a Gold Level BCAT Certified community and it is the only assisted living facility in New England to carry this distinguished certification. Their unique cognitive behavioral programming is based on the necessity for meaningful engagement, effective communication skills, and proven best practices for behavioral management. Success in the program is defined minute to minute, allowing the residents and their caregiver's infinite opportunity to adjust and adapt.

The Clinical Team

Jacobs' team includes two full-time nurses, two full-time activities staff, and a 1:6 direct care staff to resident ratio. Her clinical team also includes a Neuropsychologist who does 1:1 therapy with the residents, a rehab team that includes Physical Therapy, Occupational Therapy, and Speech/Language Therapy, and a Psychiatrist and Nurse Practitioner who work hand in hand with the staff. The teams meet once a week to share results of the BCAT screenings and to brainstorm around individual care plans for their residents. In these meetings, they are looking not only at cognitive health, but also at physical, behavioral, psychosocial, medication, and other health issues that might impact the residents' behavior and success in their program. The team reviews whether med changes are working, if there are behaviors to address, and how the family is doing with the adjustment to the program.

In addition to using the BCAT Approach, Jacobs admits that running a program like this requires being committed, intentional and proactive in de-escalating behaviors or issues before they become large issues.

Moreover, the interdisciplinary clinical team is able to make rapid med changes and implement effective behavior plans on site, reducing the need for in-patient psychiatric placements. In her program, the aides are trained to become the "change agents" – changing their approach and the environment rather than expecting the resident to change his/her behavior.

Lessons for Care Management

What can the success of this program teach us as Aging Life Care Professionals? First, that it is possible to do this kind of unique programming for this underserved population in the private pay environment. Often Aging Life Care Managers hear from providers that there just isn't enough volume of potential residents that are able to pay privately for this kind of program. However, by combining those with atypical dementias with people with other neurological diseases, it is possible and can be both successful and profitable. In Golden Pond's case, the demand has only increased. The original program included 21 beds and is now being expanded to add on four more.

Second, in order to be successful at running a program like this, a provider has to be organized, creative, educated, and well-staffed with psychiatric support. As Aging Life Care Managers know well, it is one thing to say you will accept these residents; it is another to truly care for them.

Third, Aging Life Care Managers should investigate how the BCAT Approach could be used in their daily work, with clients in their homes or in communities. Even if a community was not utilizing the approach, Aging Life Care Managers could utilize these instruments to help work with the staff at a facility to inform their approach to dealing with difficult behavior.

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Ms. Jacobs has been a nurse for nearly 30 years. She received her nursing degree at Boston College and went on to obtain her Master's degree shortly thereafter. Ms. Jacobs is also a legal nurse consultant and works closely with other medical professionals to assure best practices and regulations to meet the ongoing and ever-changing needs of special populations, including seniors and those with traumatic brain injuries. Over the past three decades, Ms. Jacobs has utilized her specialty in neurobehavioral programming and as a nursing executive across many different settings including hospitals, skilled nursing facilities and assisted living communities. She originally worked at Golden Pond as the Wellness Nurse from 1996-2000. While there, she opened the first behavioral health program within an assisted living facility in New England. She has currently returned to Golden Pond as the Executive Director where she has had the opportunity to develop and implement unique programs for residents who live with atypical dementias.

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Ms. Pilcher Warren was awarded her doctoral degree in Gerontology from the University of Massachusetts in Boston. Her professional experience has focused primarily on care and housing arrangements for elders with Alzheimer's disease and related dementias, including policy and fundraising work for the Alzheimer's Association of Eastern Massachusetts, the Alzheimer's Association of Utah and the Massachusetts Association of Older Americans. She has held several positions on the board of the New England Chapter of the Aging Life Care Association and is currently the Editor in Chief for the Journal of Aging Life Care. For seven years, Ms. Pilcher Warren was affiliated with Hearthstone Alzheimer Care Assisted Living programs in Massachusetts and New York, where she held a number of management positions. For 8 years, Ms. Pilcher Warren worked both as a Geriatric Care Manager and as the Director of Operations for AZA Care Management of Boston. She currently holds the position of Senior Executive Director of Care Management for Overlook C.A.R.E., a non-profit Life Care Management practice with offices located in Hingham, Dedham, Plymouth, and Charlton, MA.

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Young Onset Frontotemporal Degeneration: A Family Story

Katie Brandt, MS

On my ninth wedding anniversary, I received a bouquet of two dozen roses. Fuchsia pink, ruby red, and vibrant orange, as bright as the sunshine outside on that warm August day in 2011. Our three-year-old son, Noah, loved pushing his face into the blooms, breathing in and out to inhale the strong scent. My father remarked at their beauty each time he meandered into the kitchen for a new cup of coffee. The thing is, the roses were not from my husband; they were a gift from a close friend. My husband, Mike, couldn't buy me flowers. He didn't know it was our anniversary. He didn't even know it was summer.

In 2009, Mike had been diagnosed with behavioral-variant Frontotemporal Degeneration (FTD). FTD is a rare progressive neurological disorder that causes damage to the frontal and temporal lobes of the brain. Unlike Alzheimer's disease, where loss of memory is often the first troubling symptom, individuals with FTD may experience difficulties communicating and making decisions. They may also behave in socially inappropriate ways. In the end, FTD causes dementia and makes it impossible for the person to function independently, including being unable to speak, walk, or swallow. Currently, there is no treatment to slow or stop the progression, a patient's prognosis is terminal. Typical age of onset is between 45 and 65. At the time of diagnosis, Mike was 29. By 2011, he required the type of 24/7 care that only a skilled nursing facility could provide. The kind gesture of the roses reminded me of another thing he could not do.

There was another person at



home with me when the flowers arrived; an Aging Life Care Manager, attempting to perform an intake for care management services amidst hugs, tears, and a basement search for a vase worthy of their beauty. It makes sense that a 31-year-old woman caring for a three-year-old at home and a husband nine miles away in a nursing home would need support. But, as my Aging Life Care Manager realized, my primary need was not centered around my husband -- it was with my Dad.

In 2008, my father had displayed a concerning level of forgetfulness and agitation. Cognitive issues were impacting his ability to function at work and at home. Over the next year, Dad

Looking back, I can point to that first phone call with my Aging Life Care Manager as a turning point in my role as a full-time caregiver.

had many medical appointments and scans. He completed rigorous neuropsychological evaluations and we nervously awaited a follow-up appointment set to determine a diagnosis. Seventeen days before that appointment our family was blindsided by a devastating loss. My mother died unexpectedly at the age of 58. Then came Dad's diagnosis of Alzheimer's. He was 59. Barely able to keep my head above water as I treaded the new roles of caregiver and single parent, I felt myself drowning after my father crashed his Jeep into the back of a truck, totaling the vehicle and having no recollection of the event. How would I take away the keys and keep him active each day? Who could watch him while

I was at the nursing home with Mike? How could I afford this new expense? My head swam with questions and no answers.

As a new mother, I attended baby yoga classes and the free story hour at the library to meet other moms. Our shared experiences of toddler tantrums, preschool sign ups, and sibling rivalry provided a great space to brainstorm solutions together. So, when I became a caregiver, I joined a support group. It was here that I heard about the services that an Aging Life Care Manager could offer. To me, it sounded as though they could be a guide through this new community of Elder Care and dementia support services. I was desperate to talk to someone who would understand my experience. I didn't have a single friend who was touring adult day care centers, and I needed to feel like I wasn't the only one living as a dual caregiver and parent.

At medical appointments for my Dad, we talked about medications, sleep habits, and the value of exercise. But, the doctors couldn't tell me about community-based programs or ways to get financial support for services and I didn't know where to begin. I didn't know if Dad should go to daycare or have a caregiver at home. I wondered if hiring a person to watch my Dad was the same as hiring a sitter to watch my son. I had devoured books on child development, but not read up on a single book about dementia. I felt unprepared to be his caregiver.

Looking back, I can point to that first phone call with my Aging Life Care Manager as a turning point in my role as a full-time caregiver. The care manager provided me with a patient and caregiver-centered evaluation that took a holistic look at our entire family. This evaluation validated that I needed extra help for my father and led to the formation of a plan targeted at meeting his cognitive needs and offering me respite. My care manager helped me hire my first companion for Dad, coordinating interviews, and attending as my support. I was able to go back to them at my own pace, reaching out as we experienced new transitions and new care needs.

After my husband passed away in 2012, I began working professionally

with caregivers and today I am the Director of Caregiver Support Services in the Massachusetts General Hospital Frontotemporal Disorders Unit. My personal experience as an FTD and Alzheimer's caregiver connects me with the caregivers I work with each day. Our Boston-based clinical research program draws families from all over New England, and even across the country. I am not able to work with each family individually in their home community, but I am able to educate them about the general benefits of services available, including Aging Life Care Management Services.

In my approach to working with families, I focus on three main areas; emotional support, connections with community resources, and strategies for behavior management. When I think about my interactions with my own care manager, I know that I received support in all three areas with the added tangible benefit of a written plan to move forward. I educate my caregivers today about the benefits of having an expert lead them through the new territories of diagnosis, care management at home and in the community. I encourage them to lean on professionals who are trained in best practices and remain on the cutting edge of care and rights for individuals with cognitive impairment. I let them know that the plans they put in place may improve health outcomes not only for their loved ones, but also for themselves.

When I think of August 10th, I think of all the anniversaries we shared together; special dinners at home, day trips to the beach, and little gifts we gave to one another. Our ninth wedding anniversary was our last. We didn't share a glass of wine or watch the sunset over the ocean together, but I would like to think of my meeting with my Aging Life Care Manager as an act of love for Mike. The care plan we wrote that day was a new set of vows, a testament to stand by him in sickness, and protect his health to the best of my ability. When I think of my wedding day, sometimes I laugh and sometimes I cry. When I think of our ninth anniversary, I feel proud to have lived my vows and hope Mike would feel that way, too.

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Katie is a caregiver who knows firsthand how essential the support of community is for those affected by rare disease and dementia. Katie lost her husband Mike to the rare disease, Frontotemporal Degeneration (FTD), when he was 33 years old. Shortly thereafter, her father was diagnosed with Alzheimer's at the age of 59. Today, Katie is an advocate, an educator, and a volunteer in the rare disease and dementia community. Katie's story of love, loss, and resiliency is unique, but it has universal truths.

Katie has started a new campaign, Love Is Out There, to raise awareness for FTD, caregiving, and empowering families to take the power back from rare diseases. Through social media, community events, and educational forums, Katie and her network will raise awareness for families struggling with FTD and let them know that resources, and support are out there. She has spoken at colleges, conferences, hospitals, the Massachusetts State House, and on Capitol Hill to share her experiences.

In the summer of 2012, she contacted The Association for Frontotemporal Degeneration and offered herself as an advocate and a volunteer. It was the beginning of a great relationship and a new career for Katie. Currently she serves as the Caregiver Support Services Director for the Frontotemporal Disorders Unit at Massachusetts General Hospital in Boston.

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