Mental Disorders and Their Impact on Home Care

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ALZHEIMER’S CARE:
A Primer for In-Home Care

By Merrily Orsini
According to the Alzheimer's Association, as many as five million Americans have the disease – over 10 percent of people over the age of 65 have Alzheimer’s, and the percentages correspondingly go up with increasing age. The direct and indirect costs of Alzheimer’s, dementia, and other related cognitive impairments are estimated at over $148 billion dollars annually, and that figure continues to rise as the percentage of those reaching older ages increases and as people continue to live longer.

What exactly is Alzheimer’s? The simple answer is that it is a progressive degenerative brain disorder. The effects on the brain are relentless as the memory is progressively destroyed and the capability to learn, make judgments, communicate, and carry out normal daily tasks is greatly diminished in the last stages of the disease to the point where there is total dependency.

Diagnosis for Alzheimer’s is currently based on symptoms, a patient’s medical history, and neurological examination. Unfortunately, to date, Alzheimer’s cannot be 100 percent accurately diagnosed until death. The brain has to be examined for the tell-tale sign of Alzheimer’s disease, neurofibrillary tangles, and this examination cannot be done during life. Early intervention does seem to help, however, and there are new drugs on the market to help keep the effects of the disease at bay, if started early. These drugs don’t work on everyone, but when they do work, they can be very effective in delaying onset of the symptoms. Also, recent studies suggest that lifestyle plays a role, and that better eating habits and exercise can help delay the onset of the disease. At the first signs of forgetfulness, playing mind games or learning new activities that require using different parts of the brain are also thought to assist in keeping the symptoms delayed. “Use it or lose it” really counts in this situation.

Living with Alzheimer’s can be an oppressive experience for both the person with the disease and the family or any caregivers who are involved. There are many moments of misunderstanding or confusion, and the behaviors and symptoms can become frustrating and feel insuperable for both the patient and anyone involved in the care. The loss of memory and other disturbing behaviors can often cause immense separation in families, and can create an unnecessary nervous tension all relationships.

It is often painfully difficult for family members to watch their loved one seemingly “waste away” in his or her own mind; the struggle to maintain a form of sanity is often too much for many relatives, and oftentimes results in distancing themselves from the loved one with the disease.

As a home care agency, you will likely see more than your fair share of dementia and Alzheimer’s cases. Understanding the disease and its progressions, how to assess someone to determine cognitive functioning level, and how to train caregivers to work with a cognitively impaired person are essential for anyone working in home care.

**Personal Experiences with Alzheimer’s as an Agency Owner**

In the 17 years during which I owned a home care business, I had multiple personal experiences with cases of Alzheimer’s disease and dementia. However, none were as impactful as my very first.

In 1983, my agency was hired to provide service a few hours per day, a couple of days per week to a woman with mid-stage Alzheimer’s who was being cared for by her husband. This was a very supportive family situation with grandchildren who were present, supportive, and attentive, but the extended family simply did not have the time to provide the necessary ongoing assistance that their grandmother needed as the disease progressed. The husband unexpectedly died two weeks later. The care became 24/7 at that time, and we took care of this client until her death 11 years later. During those 11 years, I visited the client at least once per week for the first couple of years, and then at least monthly after that. Since there was very little written about Alzheimer’s at that time, there were no guidelines on home care for someone with the disease. The quest for education and guidance on the progression of the disease and how it related to home care became a passion. This woman was entrusted to my care, and it became a mission to learn how to care for her in the best way possible so she could retain as much dignity as possible and be safe, secure, and cared for lovingly until her death.

In those 11 years, my caregiver team and I watched the ravages of Alzheimer’s on this woman, from being mildly confused and disoriented to being unable to walk or eat, completely bedbound with no voluntary movements at that stage. It was an incredible learning experience, and one that my agency embarked on and embraced as an opportunity to understand how to care for a person with Alzheimer’s. Thus started a long and rewarding journey of compiling resources, setting standards for care, understanding the best ways to screen for cognitive...
impairments, creating relevant activities, and communicating to families and others how best to provide home care to a person with Alzheimer's disease. The intent of this article is to educate home care agencies interested in improving or embarking upon the specialty assessment, care, and training needed when adding Alzheimer's care to the range of home care services.

How Can In-Home Caregivers Help a Patient with Alzheimer's?

The famous Nun Study started in 1986 revealed many things about Alzheimer's previously unknown. The most startling finding was that many of the nuns, even though they were in their 80s and 90s, were functioning on a very normal scale despite the fact that many had the signs of Alzheimer's disease in their brains that showed up after their death. Why? It was found that it was the type and amount of mental activity the nuns were exposed to that made a huge difference. Plus, the more complex their early writings, and the more emotionally positive they were in life, the lower the risk of mental dysfunction and even disease or death among the sisters in the study.

This study led to the anecdotal observation from my 17 years caring for those with Alzheimer's that retirement and inactivity cause symptoms of cognitive impairment to present sooner. When we received a case where a very active man had gone from using his brain in a variety of ways at work to total retirement and a focus on more trivial activities such as fishing, playing golf, or working in the yard, we saw mental decline set in. Recent studies have reinforced the fact that mental stimulation can help slow down the progression of the disease. This is one area where in-home caregivers can really excel. As a home care agency, providing staff education on meaningful activities, mind exercising products, and targeted tactics to add to the Alzheimer's care routine can make a marked difference in the quality of life for the client as well as improve the quality of care.

The key to keeping the disease at bay in its early stages is mental and physical stimulation. When working with a client who has Alzheimer's, it is important to first work with families and the client to learn what the client's previous interests and activities were. Those interests and activities can then be integrated into day-to-day caregiving activities for some mental and physical stimulation that is familiar. Typically, the motor memory is not lost with Alzheimer's, so activities from childhood and young adulthood will be remembered most vividly. Activities from the past like dancing, playing music, knitting, or playing golf might work, depending on the patient's past activities. However, to stimulate the brain, it is also important in the early stages of Alzheimer's to use the brain in ways that are outside of the individual's normal brain exercises. If the person does crossword puzzles, help him or her learn a new language. Listen to music. Explore art. Read aloud to each other. Visit a new place. Play one of the many online mind stimulation games now available, or participate in mind stimulation workbook activity borrowed from the brain injury industry. Make the day interesting and fun, and have learning new things as a component in as many activities as possible.

Preparing to Offer Specialty Care for Alzheimer's

Where does home care fall into taking care of someone with Alzheimer's? In chronic care situations where someone chooses assistance to remain at home, it is estimated that over 50 percent have some type of dementia or Alzheimer's disease. Chances are that as an in-home care provider, you are going to have to tackle the complexities of Alzheimer's head on, so why not be proactive and learn how to assess and provide this specialty service? There are definitely many things to consider and to learn about to care for the client, dealing with the family and support system, and training and support for your caregiving team.

Arranging for someone else to provide care is an emotionally laden situation for families, and understanding the disease and how it affects behavior is imperative for those providing
care, both for the agency personnel and the direct care staff. That understanding will be beneficial in appreciating what the patient and the families are going through. Generally, the person suffering from Alzheimer’s is not the same person the family once knew; it’s a very difficult long-term situation. The Alzheimer’s patient may be asking for the loved one constantly, and the loved one is reticent to leave because of that. However, in order to remain calm and loving, the family caregiver must be encouraged to obtain some care relief.

First is the assessment process. Many family members “cover” for the cognitively impaired person by ending his or her sentences and answering questions for the person. Also keep in mind that in familiar conversation, a cognitively impaired person may seem to be functioning normally. Thus testing for cognitive impairments should be a step that is done 100 percent of the time when completing an in-home assessment for care. The Mini-Mental State Exam (MMSE) is a simple test that has traditionally been used to screen for dementia. There is now also a simple but effective test just released in the United Kingdom called Test Your Memory (TYM) that has recently shown to be even more accurate than the MMSE at identifying early memory problems.

One caregiving situation specifically comes to mind. We were caring for an elderly man who had incredible rages. However, the family neglected to inform us of this. They were probably afraid that we would not take the case had we known. One night when his caregiver was in the house alone with him, he became afraid, thinking she was a stranger. He hid behind a door and when the caregiver walked by, he struck her and injured her. We then knew firsthand the dangers of some of the mental changes in the disease: how the brain reacts and how the person really becomes someone other than the person they once were. This also gave me a deeper understanding of the stress that families are under when they come to the home care agency for help. Plus, we added some pertinent questions to the in-home assessment that actively questioned some of the behavior, helping to identify up front the issues that might arise, and to then adequately prepare for them.

Taking care of someone who has a cognitive deficit is a completely different type of care than taking care of someone with a physical challenge. With a physical challenge, the caregiving duties are focused on completing tasks and assisting with the activities of daily living, from transferring to toileting, ambulating to dressing, companionship to housework, and meal preparation to transportation. When providing care for someone with a dementia, the care demand is constant. It is important to note that it takes a specific personality to provide the ongoing care. Someone with patience, a kind and gentle personality, and a calm demeanor will make the best caregiver. The caregiver also has to be comfortable with a situation that is less physically demanding and more mentally demanding.

The patient with Alzheimer’s employs constant repetitive demands and questions due to his or her confusion, which adds to the stress on the care provider. Oftentimes the client also cannot be trusted to know safety from danger. In the kitchen, for instance, there is the constant threat of leaving cooking food unattended, or turning on the stove and putting a flammable object on the open flame or the hot surface. The confusion and disorientation from dementia could cause a person to go outside, unaware of night/day, where they live, etc. and get in harm’s way, or worse, escape to some unknown location. Alzheimer’s is a progressive disease, so it will always get worse. Someone may be a little disoriented or confused when care first begins, but over months and years, the behaviors and symptoms will exacerbate.

There also comes a point in Alzheimer’s progression where familiar surroundings become a moot point. At some point in the disease, it is imperative for the Alzheimer’s patient to be in an environment designed for the behaviors associated with the disease. Wandering and sundowning are specific problems that can be addressed by some simple environmental changes. Agencies can work with families to prepare the home environment, designing it for the symptoms of the disease. For example, creating an area to wander where clients won’t hurt themselves, and creating repetitive activities to keep them busy during the day, which are geared specifically to what the client is comfortable doing — stack, sort, garden, whatever their
particular interests were earlier. Most importantly, ways must be created to prevent the client from leaving the home unattended, and to allow space to wander without danger areas.

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Training to Work Effectively with Alzheimer's

The most important task an agency servicing Alzheimer's clients can undertake is caregiver training. Your caregivers are on the front lines with the Alzheimer's patients, and they will need to be equipped with the proper tools and understanding of what they will be facing. Here are some lessons I learned hard way, over my years of providing in-home care that are supported by the current literature and industry organizations' Web sites.

Old habits, familiar activities. The biggest lesson I learned very early on is that anyone passed the early stages of the disease needs to be recognized and worked with in relation to his or her former life as much as possible. In other words, take the time to understand who this person was in his or her pre-Alzheimer's life and go with that. If the client was a businessman who was used to going to work every day with a briefcase, sitting at a desk and telling others what to do, simulate that with a desk, papers, a briefcase, and let him move files around and complete tasks that feel familiar. For someone who was a homemaker, who took care of children and grandchildren, give her a real-looking baby doll. People who maintained households may have done a lot of folding and sorting, so use a basket of laundry and let them sort and fold. An outdoors person may want to take long walks. It may seem odd to caregivers, but recurring habits are comforting.

Respect is key. All too often, we forget that Alzheimer's patients are still people with periods of lucidity. Another vivid learning moment was with a client who had a very severe dementia. She was disoriented as to time and place, and was unaware of things going on around her. I was speaking to her caregiver in the third person and suddenly she looked at me with clear vision and memory and said, "I think it's disrespectful for you to talk about me in my presence like that." That was the only moment of clarity she had for months, but she did have it, and it taught me a lesson on how to discuss patients even if they seem totally demented; continue to treat them with respect and dignity and not talk about them in their presence.

Exercise the brain. Alzheimer's symptoms such as forgetfulness, confusion, and disorientation are not a normal part of aging. It is true statistically that the older people get, the more likely they are to get Alzheimer's. But there is also an equal amount of research that shows there are ways to exercise the brain to keep the symptoms of the disease from manifesting, if caught and worked with early as soon as symptoms are presenting. Caregivers can play a key role in cases where Alzheimer's is in the early stages. Educating caregivers on brain stimulating activities is a proactive way in which home care can make a positive difference.

Going home again. When those with Alzheimer's want to go "home", they become agitated and upset; home to them may not be where they've lived the last 10 years, but could be the home they had as a child, or when they were first married. If a caregiver is outside taking a walk and tries to go back home, the Alzheimer's patient may refuse to go in because it's not "home". At that point, it is best for the caregiver to walk the client around the block again and say that they're going to go see what's here, and go into the house as if visiting someone else without insisting it's the client's home. Working with the current mental state without tipping the emotional scale is very important. Remember, this is reality for the client and feels very, very real to him or her.

Proving thorough documentation. Another common problem caregivers will experience is the Alzheimer's client calling the police and insisting the caregiver has broken into the house, and is robbing or harming them somehow. This happens frequently. To alleviate and address this, make sure there is a care plan book and legitimate documentation of the caregiver/agency in the home.
Setting up Caregiver Training

One of the best ways to ease the pain of the isolation of Alzheimer’s is to educate caregivers about the disease, and encourage them to learn more and ask questions. It is important to understand some basic fundamentals about this disease so that compassionate, relevant care and treatment can be properly administered without making the client feel inept or provoking anger.

Remember that many times caregivers have never had experience with Alzheimer’s, nor do they understand the symptoms, behaviors, and progression of the disease. It is also important to realize that while Alzheimer’s might be frightening or confusing to some, it is not contagious or particularly dangerous if proper care is given. While there are no cures for this disease, effective care and moral support are often the best tools with which to manage the care. When setting up caregiver training on Alzheimer’s care services, I recommend including the following areas in an agency training program.

Early Signs. It is vitally important to understand some of the early signs of Alzheimer’s, and as mentioned previously, important to test so the mental status is clear. Caregivers can and should play a vital role in interacting with the family and having the knowledge of how to work with someone in the early stages of Alzheimer’s or a related dementia. While some memory loss is reasonable and expected as we age, the signs of Alzheimer’s are significantly greater, and are often accompanied by other symptoms. People suffering from this disorder often have difficulty with general communication, thinking, reasoning, comparing, and learning new skills or possibly even re-learning old skills. Again, testing is key. And after testing, seek advice and counsel from appropriate medical personnel.

The symptoms below are basic warning signs for Alzheimer’s:

1. Memory loss;
2. Difficulty performing familiar tasks;
3. Language problems;
4. Becoming disoriented;
5. Poor judgment;
6. Problems with complex mental tasks;
7. Misperceiving items;
8. Mood or behavior changes;
9. Confusion, fear, suspicion; and
10. Loss of initiative.

As we age, our bodies change and oftentimes we lose some of the capabilities that we once had. With Alzheimer’s, however, it is more serious. Many feel that they are losing more than just abilities, but rather that they are losing their minds.

Communication. Trying to communicate with clients who have Alzheimer’s can be a challenge. Both understanding and being understood may be difficult. Caregivers need to be provided with ways to communicate simply and effectively with clients. These include:

- Choosing simple words and short sentences combined with the use of a gentle, calm tone of voice.
- Avoiding talking to the client like a baby or talking about the person as if he or she weren’t there (in the third person).
- Minimizing distractions and noise — such as the television or radio — to help the person focus on what you are saying.
• Calling the person by name, making sure you have his or her attention before speaking.
• Allowing enough time for a response. Be careful not to interrupt.
• Trying gently to provide a word if a client is obviously struggling to communicate a thought.
• Trying to frame questions and instructions in a positive way.

Bathing. While some people with Alzheimer’s don’t mind bathing, for others it is a frightening, confusing experience. Caregiving activities often include bathing, but extra care and considerations are needed for those with Alzheimer’s.
• Plan the bath or shower for the time of day when the person is most calm and agreeable. Be consistent. Try to develop a routine.
• Tell the client what you are going to do, step by step, and allow him or her to do as much as possible.
• Prepare in advance. Make sure you have everything you need ready in the bathroom before beginning. Draw the bath ahead of time.
• Minimize safety risks by using a handheld showerhead, a shower bench, grab bars, and nonskid bath mats. Never leave the client alone in the bath or shower.
• Try a sponge bath. Bathing may not be necessary every day. A sponge bath can be effective between showers or baths, and can be less traumatic if the client is in a state of confusion.

Dressing. For someone who has Alzheimer’s, getting dressed presents a series of decisions, and can be very overwhelming. Choices such as what to wear, getting some clothes off and other clothes on, and struggling with buttons and zippers present challenges. As a caregiver, stepping in with extra care can alleviate the stress for an Alzheimer’s client.
• Try to have the client get dressed at the same time each day so he or she will come to expect it as part of the daily routine.
• Encourage the client to dress himself or herself to whatever degree possible. Plan to allow extra time so there is no pressure or rush.
• Allow the client to choose from a limited selection of outfits. Fewer choices will be less overwhelming.
• Arrange the clothes in the order they are to be put on to help the client move through the process.
• Choose clothing that is comfortable, easy to get on and off, and easy to care for. Elastic waists and Velcro enclosures minimize struggles with buttons and zippers.

Eating. Eating can be a challenge because some people with Alzheimer’s want to eat all the time, while others have to be encouraged to maintain a good diet. Many times it is the slip of the memory that makes a client forget whether he or she ate or not. A caregiver, once again, has a great deal of influence on the day-to-day quality of life in an Alzheimer’s case.
• Ensure a quiet, calm atmosphere for eating. Limiting noise and other distractions may help the client focus on the meal.
• Provide a limited number of choices of food and serve small portions. You may want to offer several small meals throughout the day in place of three larger ones.
• Substitute finger foods if the client struggles with utensils. Using a bowl instead of a plate also may help.
• Have healthy snacks on hand. To encourage eating, keep the snacks where they can be seen.

Activities. Practicing brain stimulation is the best method in fighting Alzheimer’s progression when the signs first appear. In later stages, however, trying to use the brain becomes impossible and can cause anger or frustration. Finding activities that the client can do and is interested in can be a challenge. Building on current skills generally works better. Teaching something new will not work.
• Don’t expect too much. Simple activities often are best, especially when they use current abilities.
• Help the person get started on an activity. Break the activity down into small steps and praise the client for each step completed.
• Watch for signs of agitation or frustration with an activity. Gently help or distract the client to something
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else should that occur.

- Incorporate activities the person seems to enjoy into his or her daily routine, and try to do them at a similar time each day.

*Exercise.* Incorporating exercise into the daily routine has great benefits for Alzheimer’s clients. Think about what kind of physical activities they enjoy; perhaps walking, swimming, dancing, or gardening. Determine the time of day and place where this type of activity would work best.

- Allow as much independence as possible, even if it means a less-than-perfect garden.
- Encourage physical activities. Spend time outside when the weather permits. Exercise often helps the client sleep better.

*Sleep Problems.* For many people with Alzheimer’s, nighttime is often a difficult time. Getting the client to go to bed and stay there may require some advance planning. Sometimes it simply is not possible, as days and nights are confused.

- Set a quiet, peaceful tone in the evening to encourage sleep. Keep the lights dim, eliminate loud noises, and even play soothing music if the client seems to enjoy it.
- Try to keep bedtime at a similar time each evening. Developing a bedtime routine may help.
- Encourage exercise during the day and limit daytime napping.
- Restrict access to caffeine late in the day.
- Use night lights in the bedroom, hall, and bathroom if the darkness is frightening or disorienting.
- If the sleep is completely reversed, then make certain the area for wandering is well lit and safe. Use a baby monitor to listen for unforeseen problems.

*Hallucinations and Delusions.* As the disease progresses, Alzheimer’s clients may experience hallucinations and/or delusions. Hallucinations are when the person sees, hears, smells, tastes, or feels something that is not there. Delusions are false beliefs from which the person cannot be dissuaded. Tactics for dealing with these include:

- Avoid arguing with the client about what he or she sees or hears or believes to be true. Try to respond to the feelings he or she is expressing, and provide reassurance and comfort. Do not try to correct mistaken ideas or identities. Just go with it.
- Try to distract the person to another topic or activity. Sometimes moving to another room or going outside for a walk may help.
- Turn off the television set when violent or disturbing programs are on. The client may not be able to distinguish television programming from reality.
- Make sure the client is safe and does not have access to anything he or she could use to harm anyone.

*Wandering.* Keeping the client safe is one of the most important aspects of caregiving. Many Alzheimer’s sufferers have a tendency to wander away from their home or their caregiver, even when the home is considered escape proof.

- Make sure that the client is wearing or carrying some kind of identification at all times even while the caregiver is in the home.
- Keep doors locked. Consider advising the client’s family to install a keyed deadbolt or an additional lock up high or down low on the door. If the client can open a lock because it is familiar, a new type of latch or lock may help.
- If for some reason the client wanders away while the caregiver is on duty, educate on contingency plans and what should be done to locate the client.
- Register with the Alzheimer’s Association Safe Return Program, or the Silver Alert programs set up through each State Unit on Aging.
- Make use of activity sensor technology that is Web based and remotely monitored.

*Home Safety.* Caregivers can play an important role in helping safety-proof their clients’ homes. Creating a safe environment can prevent many stressful and dangerous situations. Recommendations by caregivers to families can really help.

- Install secure locks on all outside windows and doors, especially if the client is prone to wandering. Remove the locks on bathroom doors to prevent the client from accidentally locking himself or herself in.
- Use childproof latches on kitchen cabinets and any place where cleaning supplies or other chemicals are kept.
• Label medications and keep them locked up. Also make sure knives, lighters, matches, and guns are secured and out of reach.

• Keep the house free from clutter. Remove scatter rugs and anything else that might contribute to a fall. Make sure lighting is good both inside and out.

• Consider installing an automatic shut-off switch on the stove to prevent burns or fire; or disconnect the stove entirely and just use the microwave.

Looking to the Future

There are currently many studies and active research projects going on around the country to find cures, look for ways to prevent the disease, and create products that will assist in caring for the person who has Alzheimer’s disease. To date, some successes have been found in monitoring activity to establish baseline and then using those baselines to determine safety in the home for the Alzheimer’s patient. Other monitoring using Web cams and sensors on doors, stoves, etc. has been found useful in remotely tracking someone alone in a home and keeping him or her out of harm’s way. The stumbling block in using technology is how the affected person reacts to new processes. However, the usefulness to the caregiver has proven immense, both in training to handle difficult situations, and in allowing some respite away from the patient. There is much hope that the future will bring a cure, ways to prevent onset, and assistive technologies to make living with and caring for someone the disease far easier than it is today.

It is reported that every 72 seconds, someone develops Alzheimer’s disease. Whether you embark on Alzheimer’s by accident or purposefully, as a home care agency, you are almost guaranteed to have to deal with this disease at some point and need to understand how to provide the best care. It remains imperative to educate yourself and your staff about the disease in order to successfully manage the caregiving situations that will arise. Your clients and their families will be grateful for your knowledge.

The Alzheimer’s Association Safe Return Program is an easy-to-use program that really works — to date it has close to a 99 percent success rate. It comes as a bracelet or necklace with an emergency phone number and a unique ID number, so if a person gets lost, separated, or wanders, anyone can find them (law enforcement, a good Samaritan, etc.) and call 800-625-3780 to be connected with MedicAlert’s emergency response personnel.

Resources
http://www.alz.org/index.asp
http://www.nia.nih.gov/Alzheimers
http://www.mayoclinic.com/health/alzheimers-disease/D800161
http://www.neuroanatomywisc.edu/selfhears/Nuns&alzheimers.htm
http://www.athought.com/consumer/disorders/alscareguide.html
http://alzheimers.about.com/od/caregiving/a/communication.htm
http://www.ashbymemorymethod.com/Welcome.php
http://retassuredsystem.com/
http://www.quietcayre.com/
To sign up for this program, call 1.888.572.8566 or visit www.alz.org/we-can-help-medicalert_safereurn.asp.

Testing for Cognitive Functioning:
Access the Mini-Mental Status Exam here:
http://www.bani.us/MiniMental.htm
Access the Test Your Memory Exam here:
http://www.bmj.com/cgi/data/bmj.b2030/DCI/1TYM
Access the Test Your Memory Exam Scoring here:
http://www.bmj.com/cgi/data/bmj.b2030/DCI/2TYM scoring

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